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Unpicking The Threads: How specialist and generalist nurses work with patients, carers, other professionals and each other to support cancer and long-term condition patients in the community

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# Unpicking The Threads:

How specialist and generalist nurses work with patients, carers, other professionals and each other to support cancer and long-term condition patients in the community

End of Project Report  
March 2013

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## EXECUTIVE SUMMARY

This report presents the findings of a study carried out between January 2009 and December 2012 in one metropolitan borough in the north of England. The central focus of the research was specialist and generalist nurses' experiences of collaborative working in relation to the support of cancer and long-term condition patients. To explore this topic we used an innovative interview tool – the Pictor technique – to gather visual representations of people's networks of roles and relationships involved in specific instances of the provision of patient care and support. We define collaborative working as occurring *when two or more professionals from different professional groups are required to interact to ensure that appropriate care is delivered to a service user.*

The overall aim of the study was:

*To examine how generalist and specialist nurses work with each other, with other professionals and with patients and carers to support cancer and long-term condition patients.*

Specific objectives were:

- 1. To examine what helps and hinders effective collaborative working for generalist and specialist nurses;*
- 2. To compare experiences of collaborative working in relation to cancer patients with those relating to LTC patients;*
- 3. To consider the implications of these findings for the development of services to support cancer survivors.*

The emphasis on cancer patients in objective 3 reflects the focus of Macmillan as a charity concerned with supporting people with cancer.

## INTRODUCTION

For many years, successive UK Governments have produced policy documents that stress the importance of good collaborative working within and across community and hospital-based services, between health and social services, and between public, private and voluntary sectors. Nevertheless, for health and social care as a whole, effective collaboration remains a challenge. This is, perhaps, not surprising, given the complex nature of collaborative working that

is revealed in the academic literature, with factors including interpersonal relationships, role definitions, organisational structures and cultures and political contexts all seen as shaping the way collaboration occurs. However, we argue that it is vital to look at collaboration from the perspective of those directly involved in its practice, so the present research takes a largely 'bottom-up' approach to the phenomenon. Our principle focus on generalist and specialist nurses is for two reasons. First, our own and others' previous research shows the importance of effective collaboration between different types of nurses in palliative care and it is therefore useful to broaden the examination to services before end-of-life. Secondly, the proliferation of nursing roles in recent years creates significant challenges for collaborative working.

Looking specifically at collaborative working in relation to cancer care, research tends to concentrate on teamwork in and around treatment, or on palliative care. However, whilst the importance of effective collaboration has been recognised in the survivorship literature, there has been far less research undertaken specifically in relation to the support of people living with and beyond cancer. There is a substantial body of research examining how professionals work together to support people living with long-term conditions (LTCs), often with an emphasis on collaboration across health and social care. In this study, a specific research objective was thus the direct comparison of experiences of collaborative working in cancer and LTCs.

## METHOD

### **The research setting**

This research took place in a metropolitan borough in northern England, centred on a large former industrial town, surrounded by other smaller towns and with a semi-rural area on one side. It shares borders with several other mainly urban areas. Life expectancy is lower than the national average, and there are marked differences between the most and least deprived areas. There are high morbidity and mortality rates for a range of chronic illnesses. Most of the borough is served by a single Acute Trust, and a single Community Trust, though a minority of patients access services in neighbouring areas. The Local Authority that provides social care is effectively co-terminous with the Health Trusts.

### **Design**

We employed a semi-structured interview design, incorporating as a central element the "Pictor" technique, which we explain further below. Wherever appropriate we asked interview participants to provide and discuss two examples of collaborative working, one focused on a cancer patient and one on a LTC patient. The core participant groups were generalist and specialist nurses

who worked with cancer and/or LTC patients. We also recruited a substantial number of participants from other groups whose perspectives helped set the context for the nurses' experiences of collaborative working.

### Sampling and recruitment

Recruitment of generalist and specialist nurses is shown in Table (i), below. For the community generalist nurses we recruited from teams based across different locations within the borough. We accessed these groups initially via their line managers; once their permission was obtained we sent recruitment packs to individual nurses, seeking where possible to obtain variety in terms of tenure and location. For the specialist nurses, we sought to recruit from a range of different teams, and from cancer and long-term condition specialisms. Patients and carers were recruited via local support groups. The one group from which we were not able to recruit was the community palliative care specialist nurses (PCSNs) whose manager declined to allow us access to them.

Table (i): Nurse participants

<b>Nursing group</b>	<b>Target recruitment</b>	<b>Actual recruitment</b>
Generalist	N = 30 (community matrons = 10, district nurses = 20)	N = 28 11 community matrons 15 district nurses 2 ward nurses
Specialist	N = 20	N = 17 7 community-based LTC specialist nurses 4 acute-based LTC specialist nurses 4 acute-based cancer specialist nurses 2 acute-based PCSNs

In addition to these participants we recruited the following: 11 Community Trust managers, 4 Acute Trust managers, 1 cross-sector manager, 2 general practitioners (GPs), 3 social services staff, 6 patients (3 cancer and 3 LTC) and 6 carers (3 cancer and 3 LTC). This amounts to a total of 78 participants.

## **Interview procedure**

All interviews with professionals were held in private and quiet settings within participants' workplaces, as chosen by the participants themselves. Interviews with patients and carers were held in their own homes at their request. The great majority of interviews were between 50 minutes and 75 minutes in duration. Interviews were digitally recorded with participants' consent, and transcribed in full.

Interviews with professionals were in three main parts:

- (1) We asked them to describe their own role and provide some background information about their professional experience and career history.
- (2) We used the Pictor technique to explore a particular case (or cases) of collaborative working.
- (3) We discussed with participants their hopes, fears and expectations for the future of their service in relation to the care provided for cancer and/or LTC patients.

## **The Pictor technique**

Pictor is a visual method that we have developed for exploring experiences of collaborative working. It requires the participant to select a case of collaborative working that is fresh in their mind. They are asked to think about all the people involved in the case – professionals and lay people – and write the name, role or other identifier for each on a separate arrow-shaped 'Post-it' note. They then lay the arrows out on a large sheet of paper in a pattern that helps them explain what happened in the case and their own and others' roles in it. The 'chart' thus produced serves as a focus for discussion of the case between the interviewer and participant.

For professionals whose work included a substantial element of direct patient contact, we asked them to choose where possible two cases: one based on a cancer patient and one on a long-term condition patient. In a minority of cases participants were only able to provide one type of case due to the nature of their work.<sup>1</sup> Those who did not have clinical roles provided examples of specific collaborative projects on which to base the Pictor section of the interview.

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<sup>1</sup> Note that three of the acute-based managers were able to provide patient-based cases due to their regular involvement in clinical work with patients and families. One community-based manager had very recently worked as a community nurse specialist and also provided a patient-based case.

In the interviews with patients and carers, the focus was on their own case. We started with a discussion of the course of their illness and the services they accessed, and then asked the participant to produce a Pictor chart based on their own experience. After discussion of this, we concluded with questions about how they would like to see services develop in future.

### **Analysis**

In our analysis we drew on both types of data generated in this study: the interview transcripts and the Pictor charts. Transcripts were analysed thematically following the template analysis style and utilising the NVivo software package. Pictor charts were examined for features of their construction that pointed to important issues regarding collaborative working – especially for the core nursing participant groups.

## **FINDINGS**

Our findings are organised in relation to three main areas: *the importance of personal relationships between professionals, understanding and enacting roles and identities* and *“survivorship” in concept and practice*. Throughout we will highlight, wherever relevant, differences and similarities in perspectives on cancer and long-term conditions.

### **The importance of personal relationships between professionals**

Good relationships between professionals did not simply oil the wheels of interactions. In many cases they also played a crucial role in enabling professionals to access support for patients and their families, and to overcome barriers to the effective coordination of care. Conversely, poor relationships could make the task of helping patients significantly more onerous than it otherwise might be. Perceived threats to good networks of relationships were an important aspect of the fears many participants had about current and impending NHS changes. There were no major systematic differences in what mattered in interprofessional relationships according to whether people were discussing cancer or LTC cases, nor between types of nurses. Below we summarise findings in relation to aspects of inter-professional relationships that emerged as important for collaborative working.

*Accessibility and availability:* This was the most commonly-mentioned aspect of interprofessional relationships. Participants wanted to be sure they could contact other professionals as and when they needed to. Physical proximity helped, and many participants stated their preference for face-to-face interaction. Good telephone and/or electronic communication was valued too,

particularly by specialist and ward-based nurses discussing relationships with doctors. Gold Standards Framework (GSF) meetings were especially valued by district nurses and community matrons.

*Longevity of relationships and shared job history:* Long-standing relationships with other professionals often facilitated mutual understanding and trust. Where these did not exist, a shared job history could also be helpful in aiding collaborative interaction – that is, where a participant had previously worked in the same job role as the person with whom they were collaborating.

*“Stepping on toes”:* In complex cases involving many services, some overlap of roles is inevitable. Past research suggests that this is most likely to be experienced negatively by those who feel that valued aspects of their role are threatened. It was notable that in this study a high proportion of such instances were reported by district nurses.

*Respect:* Many participants referred to the importance of personal and professional respect in relationships. This had real practical consequences for professionals; if others you worked with respected you as a professional they would be more likely to trust your clinical judgement and allow you to act on it, or to follow your advice. Discussion of respect most commonly related to relationships between nurses and doctors, with participants frequently describing it as something that had to be earned over a length of time.

*Making an effort:* Linked to the notion that respect needs to be earned was a more general recognition that sometimes relationship-building took a considerable effort. Participants felt this was worth doing, however, because the good collaboration it facilitated had direct benefits for patients.

## **Understanding and enacting roles and identities**

*Patterns of collaborative working:* Data from the Pictor charts provide insights into who participants worked with in the cases they chose to discuss. Note that that these cases are not necessarily representative of all cases, but looking across groups of participants they can reveal important ways in which patterns of collaborative working differ.

Overall, all the nurse participant groups appear to have worked with a large number of different professionals and lay people in their chosen cases – the least was 10 and the most 18. In keeping with our previous research, community matrons had the highest number of individuals and/or agencies included on their charts, reflecting their case management role. There was no consistent



difference in the number of arrows placed on the charts between cancer and LTC cases, suggesting neither type was intrinsically more complex than the other.

Looking at who the different nurse participant groups included on their charts, it was evident that acute-based specialist nurses tended to include relatively large numbers of other professionals in the acute sector, and relatively few in the community sector. On no occasion did an acute-based specialist nurse include a community matron on her or his chart. In contrast, community-based nurses included acute specialist nurses quite frequently, though more often in LTC than cancer cases.

When we examined how people chose to represent the cases they were discussing, the acute specialist nurses again stood out. They were much more likely than other groups to organise their Pictor charts as a “timeline”, depicting key events in the patient’s journey in temporal order, showing the services involved at each stage. From our analysis we concluded that this was a reflection of the way in which condition-specific specialist nurses work in the acute sector. Their involvement with patients tends to be episodic; for check-ups or assessments and otherwise when there is a crisis or exacerbation in the condition. Also, much of their collaboration is with other specialist nurses and/or with Consultants and their teams, and involves referring the patient on for a particular intervention, or seeking advice and information. In contrast, community-based nurses tended to present Pictor charts as a “network” of roles and relationships. They describe a wider range of types of interaction with other agents, reflecting we conclude the more diverse types of collaboration necessitated in community settings, and the fact that these are not necessarily linked to where the patient is on their illness trajectory.

*Role understanding:* Overall, participants reported that other professionals they worked with had a good understanding of their roles (and vice versa). There were, however, some exceptions to this. Historically, the introduction of the community matron role had created difficulties – there had been uncertainty on all sides about how their role fitted in with others, and district nurses in particular had been worried about overlap. These problems appeared to have diminished considerably, in part through the efforts of the community matrons themselves to get to know colleagues in other services. It should be noted that we have seen similar issues relating to the introduction of the community matron role in previous studies – in some cases markedly more severe.

The other area where role misunderstanding was evident was between the nurses in the acute and community sectors. This was far from universal, but there were several cases where acute-based nurses appeared to have a rather limited grasp on how community-based nurses worked; equally, some acute

specialist nurses reported that community nurses did not always understand the nature of *their* role. In some specialties where there were both acute and community-based specialist nurses, participants reported that occasionally other professionals did not understand who offered which services.

*Co-ordinating care:* An important focus of our analysis was on the perceived roles of different staff groups in coordinating patient care, and how this may have differed between cancer and LTC patients. As would be expected, community matrons had a clear role in case managing LTC patients, which despite initial difficulties (as discussed above) was now generally recognised by others. They did not view care coordination of cancer patients as central to their role in the same way, but most of those we interviewed did describe cases where they were closely involved with cancer patients. Most often this happened when a patient already on their caseload developed cancer, but on occasion a community matron was asked to help with a complex cancer case by a GP, because of her case management skills. District nurses strongly asserted their important role with cancer patients, especially at the end of life. They did see themselves as having care coordination responsibilities for these patients, although the increasingly task-focused nature of the contemporary district nurse role and their heavy workload limited their capacity to do this.

Specialist nurses generally did not engage in the kind of care coordination role described by community matrons (and to a lesser extent district nurses) – though they did interact extensively with other professionals for such tasks as negotiating referrals, seeking advice or passing on patients for particular interventions or support. The two exceptions to this were both cancer specialist nurses who described active coordination of services for their patients. In the Acute Trust, many routine aspects of coordination with the community sector were managed by the Community Liaison Service. Nevertheless, all the acute-based nurses we interviewed had some direct contact with colleagues in the community.

The prevalence of cancer/LTC co-morbidities is evident in the fact that most of our specialist nurses provided Pictor cases for the disease type that was *not* associated with their specialism (e.g. LTC specialist nurses describing cancer cases). In some areas there were well-established procedures for how services coordinated with each other - for instance between COPD and lung cancer services. Elsewhere, it appeared that patients could find themselves rather “parceled up” between different services, with no one having a full overview of their case.

Effective information systems were important to the way different professionals communicated and coordinated with each other. This study did not set out to

systematically evaluate such systems, but staff perceptions of them are important to understand as part of the context of collaborative working – especially as this was a time of considerable change and development both locally and nationally. As one would expect, individual and group views on particular systems were very varied, but a common thread in the experiences described by participants was that they were more likely to view developments optimistically where they had been consulted about them, and even more so where they had been involved in their design. It was important to participants that they could see the potential for benefit to their own clinical role in new or changed information systems. Developments that were seen as serving a remote bureaucratic role were viewed with cynicism.

Coordinating care across organisational and geographic boundaries can be particularly challenging. In our data what struck us most forcibly about cross-boundary collaborative working was that it very often took considerable time and effort to make it operate well. Processes and procedures in other organisations could be unfamiliar and sometimes perceived as unhelpful. Difficulties could be exacerbated where professionals did not have ongoing relationships with people in other organisations with whom they needed to collaborate. On occasion, the willingness of staff “on the ground” to collaborate was undermined by higher level politics between their respective organisations. Many staff, particularly in the Community Trust, were concerned that the forthcoming NHS changes (just announced at the start of our study) would create further problems by proliferating new organisational boundaries – for example through the creation of multiple GP Consortia within the area they served.

### **“Survivorship” in concept and practice.**

We will consider first our participants’ views on the notion of cancer as a chronic or long-term illness, before examining perceptions of professional roles in relation to cancer survivors.

The notion that cancer is becoming more like a long-term condition received varied responses from our participants. At one extreme some utterly rejected the idea, insisting that cancer and LTCs were intrinsically different. At the other, some were strongly committed to thinking about cancer and cancer services in this way. Many were ambivalent, accepting commonalities between cancer and LTCs at one point and emphasizing fundamental differences at another. Even if staff accepted that cancer had in some respects become more like a LTC than in the past, some made the point that patients and families did not think this way: they still tended to see cancer in “kill or cure” terms. Patient and carer interviews backed up this perception. Furthermore, there was a widespread belief that cancer patients were advantaged over LTC patients in the NHS; in their access to benefits, continuing care and palliative care, for example. This was linked to a

wider societal perception that cancer was more deserving of sympathy than other conditions and its services therefore had more “kudos”.

Our nurse participants were aware of “cancer survivorship” as a term, though their level of understanding of it varied. Managers were conscious that there were new challenges arising from survivorship, though admitted that as yet little had been done to address them. One initiative, driven by commissioners, that can be seen as linked to the survivorship agenda was the fairly recent requirement that all newly diagnosed cancer patients should be referred to district nursing services, and visited by a district nurse. Some of our district nurse participants complained that cancer patients were not consistently referred to them on discharge from the acute sector. In any case, many of the district nurses were unenthusiastic about this policy: they did not have a clear idea of what their role was with patients who were quite recently diagnosed, and felt many patients did not want district nurses to be involved. They were also concerned about the additional workload that could result from this policy.

There was no equivalent for people living with cancer to the case management role played by community matrons for LTC patients. This might explain why two of our four cancer specialist nurses took the initiative to try to coordinate services – including community and social services – for their patients, as noted above.

## DISCUSSION

In this final section, we will draw together the main lessons learned in relation to our three research questions.

### **What helps and hinders effective collaborative working for generalist and specialist nurses?**

Our findings highlight many factors that impact on the experience of collaborative working for generalist and specialist nurses. These principally include:

- Interpersonal and inter-team relationships
- Role understanding
- Professional identities
- Communication issues, including the effectiveness of information systems
- Organisational structures and processes within the NHS (locally and nationally)
- The political context of NHS changes

- Wider societal attitudes towards and understandings of cancer and LTCs

Such findings are in keeping with previous research, and illustrate the multi-level nature of the phenomenon. The distinctive point we would make, though, is with regard to the role of relational issues in collaborative working. Rather than seeing these as one among a number of important factors we would argue that relationships and relating are the core of collaborative working, and as such all those concerned with this phenomenon – researchers, practitioners and policy-makers - should view it through a *relational lens*. Whatever the level at which an intervention or change is made, its impact on relational issues must be taken into account. In particular, when changes to services and/or organisations are proposed, people should ask the question: “how is this likely to impact on relationships amongst the professionals involved in delivering services, and between professionals and patients and their families?” All too often in the NHS this question has not been considered, and changes have proved harmful to effective collaborative relationships.

### **How do experiences of collaborative working in relation to cancer patients compare with those relating to LTC patients?**

Our analysis suggests there are no real differences in what makes for good (or bad) collaborative working according to whether the focus is on cancer or LTC patients. However, the detail of who is involved and what they do for patients does differ in significant ways between condition types, and this has an effect on experiences of collaborative working. Perhaps the most striking difference between condition types is with regard to the nursing services available to patients in the community. LTC patients may have involvement with services such as community matrons, Community Specialist Nurses and district nurses throughout the course of their illness. In contrast, in most cases there is no specific community nursing support for cancer patients between initial diagnosis and end-of-life.

### **Developing services to support cancer survivors**

We have seen above that there is a gap in support for cancer survivors within community-based services. Our study cannot provide definitive answers to how this should be addressed, but viewed in combination with previous research it does help to inform the available options. One option is to extend existing roles: the likely pros and cons of extending nursing roles that were included in this study are summarised in Table (ii) below.

Table (ii): Pros and cons of extending specific roles to support cancer survivors

<b>Nursing role</b>	<b>Pros of extending</b>	<b>Cons of extending</b>
Community matrons	<ul style="list-style-type: none"> <li>• Case-management skills</li> <li>• Knowledge of LTC patients – useful for co-morbidities</li> </ul>	<ul style="list-style-type: none"> <li>• Often limited knowledge re cancer</li> <li>• Organisational arrangements may be unhelpful</li> </ul>
District nurses	<ul style="list-style-type: none"> <li>• Well-established service in community</li> <li>• Skills and knowledge re cancer patients</li> </ul>	<ul style="list-style-type: none"> <li>• Task-based nature of role</li> <li>• Cancer knowledge focused on end-of-life</li> <li>• DN services overstretched</li> </ul>
Cancer specialist nurses	<ul style="list-style-type: none"> <li>• Excellent knowledge of cancer patients</li> </ul>	<ul style="list-style-type: none"> <li>• Limited knowledge of community services and setting</li> </ul>

A further group that might be considered for an extended role in cancer survivorship is Practice Nurses. We did not interview members of this group in the present study, their involvement with LTC patients was mentioned by some of our participants. Recent and ongoing work to train Practice Nurses for a role with cancer patients, supported by Macmillan, appears to show promise.

Instead of – or as well as – extending existing roles, another option is to develop new dedicated nursing roles to work with cancer survivors. On the basis of this and previous research, key requirements for any such new role would include:

- Thorough knowledge of cancer and its effects (physical, psychological and social)
- Skills in liaising with other services
- Interpersonal skills for working closely with patients and families

The successful implementation of such new roles is likely to be strongly influenced by the way their integration with existing services is managed. Nurturing good relationships may be as important as more formal aspects of service coordination.

## CONCLUSION

### **Recommendations for practice and policy**

- When designing and implementing change in services, think carefully about the impact on relational aspects of collaborative working. Consider a “relationship audit”, mapping out existing networks of relationships that are significant in the way particular services function. Tools such as “Pictor” could be used for this.
- Recognise the value of face-to-face interaction in collaborative working.
- Find ways to facilitate sharing of knowledge between nurses who are mostly involved with cancer patients and those mostly involved with LTC patients.
- Provide education about cancer survivorship for all staff whose role might involve working with cancer survivors, so that they can understand the purpose of initiatives related to it.

### **Recommendations for future research**

- To build on this study, longitudinal research investigating relational networks amongst health professionals (and others) over time would be valuable. The impact of interprofessional relationships on patient care needs to be systematically assessed.
- Research needs to examine different health and social care staff groups’ understanding of cancer survivorship, especially with regard to how it relates to their everyday practice.
- We need to explore health professionals’ personal perceptions of cancer and long-term conditions – which may be distinct from “professional” knowledge - and how this relates to their understanding of their role.
- Where organisations are changing or introducing new nursing roles to address survivorship, these need to be evaluated in a rigorous and independent manner.

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# **1. INTRODUCTION**

This report presents the findings of a study carried out between January 2009 and December 2012 in one metropolitan borough in the north of England.

“Unpicking the Threads” is in terms of qualitative research a very large project, with 78 participants interviewed in depth and producing 114 visual representations of cases of collaborative working through the “Pictor” technique. It also addresses a complex intersection of issues: collaboration across acute and community, specialist and generalist boundaries, and comparisons of experiences in relation to cancer and long-term conditions (LTCs). Participants come from a wide range of professional groups – and especially nursing groups – as well as including cancer and LTC patients and carers.

In this introductory section we will summarise the policy and academic background to the study, and outline the interest and involvement of Macmillan Cancer Support in this area. We will follow this with a brief description of the setting, with particular reference to the organisation of health and social care provision at the time of the research. We will conclude by stating the aims and objectives of the study.

## **1.1 Collaborative working in the care of patients with cancer and long-term conditions**

### **1.1.1 The policy context**

It is recognised nationally and internationally that effective collaboration between professionals is essential to the provision of good quality care for patients with serious illnesses such as cancer and long-term conditions such as COPD, heart failure, diabetes, neurological conditions and so on. This includes collaboration between different health professions (e.g. Hughes, Hemingway, & Smith, 2005); across primary/community, acute and tertiary sectors (e.g. Moran, Poole, Bell et al, 2000); and between health and social care services (e.g. Rummery & Coleman, 2003).

Focusing on the UK context, successive Governments have produced a wide range of policy documents proclaiming the virtues of collaboration, partnership working and integration, within and across community and hospital-based services, and between public, private and voluntary sectors. (e.g. Our Health, Our Care, Our Say: A New Direction for Community Services – Department of Health, 2006; Creating an Interprofessional Workforce - Department of Health, 2007; The Public Health Responsibility Deal – Department of Health, 2011). Numerous local, regional and national initiatives have sought to make improvements in practice. Despite all this attention, and despite some examples of successful schemes, for health and social care as a whole, effective collaboration remains a challenge (Godlee, 2012).

#### 1.1.2 Academic literature on collaborative working: an overview

In terms of the academic literature, a significant barrier for anyone trying to draw lessons is the inconsistency in how the concept of collaborative working is defined, and how it is differentiated from related concepts, such as teamwork, inter- and multi-disciplinary working, and integrated care (Choi & Pak, 2006; Xyrichis & Ream, 2008). Literature on concepts such as integrated care (Gröne & Garcia-Barbero, 2001), partnership working (Gardiner, Gott & Ingleton, 2012) and shared decision-making (Gravel, Légaré & Graham, 2006) also overlaps significantly with that on collaborative working. Our focus on “collaboration” as the key concept reflects our conviction that what happens on the ground between professionals involved in a particular case is what really matters to patients and their families. The importance of personal and professional relationships amongst professionals is highlighted in our own previous research (e.g. King, Melvin, Ashby & Firth, 2010) and that of other scholars (e.g. D’Amour, Goulet, Labadie, San Martín-Rodriguez & Pineault, 2008). From our point of view, *collaborative working occurs when two or more professionals from different professional groups are required to interact to ensure that appropriate care is delivered to a service user*. The individuals concerned need not be members of a formally constituted team, and the level of collaboration can vary from the transient and superficial (such as a short phone call passing on a specific piece of information) to close, long-term working relationships. “Different professional

groups” may mean people with different roles and specialisms within a profession (e.g. generalist and specialist nurses), in different professions (e.g. doctors and physiotherapists) or in different sectors (e.g. health care and social care staff). We also include within the concept of collaboration interactions between health professionals and patients/carers, above and beyond the provision of treatment or the passing of treatment-related information. Finally, we recognise that some of the most important collaboration is not within teams but between teams and thus cannot be understood just in terms of the extensive literature on teamwork in healthcare.

While we argue that there are good grounds for seeing relationship issues as central to good collaborative working, they need to be set in the context of inter-group and organisational factors that have been shown to impact on the effectiveness of collaboration. Role understanding is one such factor: if professionals do not have a clear understanding of their own and others’ roles, negotiating effective collaboration may be difficult (Gardiner et al, 2012). Where roles potentially overlap, this may be seen as other professionals “stepping on toes” and give rise to territorialism (Street & Blackford, 2001), especially if valued aspects of professional identity are perceived to be threatened (Ross, King & Firth, 2005). Equally, wider structural and cultural aspects of organisations impact on collaborative working. D’Amour et al’s (2008) model of collaboration includes the organisational dimensions of “governance” and “formalization”, and their case studies show how factors such as leadership and support for innovation influence the success of collaborative working. In a study of collaboration in unscheduled emergency care, Cooper, O’Carroll, Jenkin and Badger (2007) found this was impeded by conflicting “blue collar” and “white collar” cultures within the service.

Turning to the literature on collaborative working in cancer and long-term conditions, we see a very different picture for each of the disease types. There is a considerable volume of published work on collaboration between specialist and generalist services in palliative care, as highlighted in a recent systematic review by Gardiner et al (2012). There is also a smaller literature on

collaborative working amongst generalist professionals, often linked to the operation of the Gold Standards Framework (GSF) (e.g. King et al, 2010; Mahmoud-Yousef, Munday, King & Dale, 2008; King, Thomas, Martin, Bell & Farrell, 2005). This work in the main does not deal exclusively with one type of condition, but given the historical tendency for palliative care services to focus on cancer it is safe to assume that the research mostly draws on experiences with cancer patients.

With regard to collaborative working outside of a palliative context, there is a substantial amount of literature looking at this topic in relation to developing and evaluating models of chronic illness care (e.g. Coleman, Austin, Brach & Wagner, 2009; Sutherland & Hayter, 2009). Collaboration is frequently just one aspect of the research in this area rather than the main focus, and often relates particularly to joint working between health and social care services (Davey, Levin, Iliffe & Kharicha, 2005; Leutz, 2005). Work on collaboration in cancer services prior to the palliative / end-of-life stage tends to focus on teamwork in and around treatment (e.g. Fennell, Prabhu Das, Clauser, Petrelli & Salner, 2010) although the importance of service integration and multi-disciplinary teamwork is recognised in the survivorship literature (Boyle, Robinson, Dunn & Heinrich, 2005; Surbone, Baider et al, 2010).

The research described in this report centres on collaboration between different groups of specialist and generalist nurses, though sets this in the context of wider perspectives on collaborative working from other professionals, managers, patients and carers. We argue that this focus on nursing is justified for two reasons. Firstly, our own and others' previous research shows the importance of effective collaboration between different types of nurses in palliative care (King, Melvin, Ashby & Firth, 2010; Gott, Seymour, Ingleton, Gardiner & Bellamy, 2012) and it is therefore useful to broaden the examination to services before end-of-life. Secondly, the proliferation of nursing roles in recent years creates significant challenges for collaborative working (McKenna, Keeney & Hasson, 2009).

The question of what counts as a “specialist” and a “generalist” in nursing is not a straightforward one, and there is disagreement in the literature as to how to make this distinction. We have taken the position that a specialist nurse has advanced training in a particular condition (or group of conditions) and a role that is defined in relation to that condition, with a high level of decision-making autonomy. In agreement with the definitions in the NHS Scotland Advanced Nursing Practice Toolkit (NHS Scotland, 2008) we do not see “specialist” and “advanced” as synonymous. While a specialist nurse by definition will have had advanced training in her or his area, some generalist nurses may also have a high level of post-registration training.

### 1.1.3 Collaborative working: a Macmillan perspective

In seeking to improve services for people with cancer, Macmillan Cancer Support have long recognised the importance of good collaboration amongst professionals. A key Macmillan publication was the report on out-of-hours palliative care (Thomas, 2001). This emphasised the importance of good communication and coordination between professionals in supporting palliative care patients in the community, and led directly to the development of the Gold Standards Framework (GSF) for community palliative care, which also stresses the crucial role of inter-professional collaboration (Thomas, 2003). Macmillan has funded several research studies relating to collaborative working in palliative and supportive care, including some by members of the present research team (e.g. King et al, 2010; Mahmoud-Yousef et al, 2008). Macmillan has also sought to apply principles of effective collaboration in its own research and development work, involving academics and practitioners from different professional and disciplinary backgrounds. The book *Communities of Influence* (Donaldson, Lank & Maher, 2011) provides an analysis of Macmillan’s experiences.

### 1.1.4 Theoretical position of the current research

On the basis of the literature, our approach to the current study needed to be one that facilitated close attention to issues of relationships and roles in collaborative working but also allowed us to explore wider organisational issues. We would

argue that to achieve this requires an orientation towards collaboration as experienced in everyday practice, rather than as conceptualised in more abstract terms of principles and policies (though how these are felt to impact on practice *is* relevant). We therefore draw on the constructivist tradition in psychology, as this has a strong concern with the way people understand themselves in relation to others (Butt, 1996; 2004). Our approach is also informed by interactionist views of professional identity (MacDonald, 1995), which (like constructivism) see identities as emerging from professionals' interactions with the world in which they live and work – especially with fellow professionals, patients and carers. The constructivist perspective recognises that the ways in which we make sense of our world often become taken-for-granted and treated as if simply “natural”. In studying the experience of collaborative working we therefore need methods that can help people think about aspects of daily practice that have become habitual and hard to reflect upon.

## **1.2 Aims and objectives**

The current project sought to build on our previous work, to focus on role understanding and inter-professional relationships between specialist and generalist nurses, across community and acute settings. We wanted to broaden our scope from exclusively end of life cases, and also to explore directly comparative working for cancer and LTC patients. Initially, we wanted to make cancer survivorship a main focus of the study; however, as we began data collection it quickly became apparent that many of the nursing groups we interviewed did not see themselves as significantly concerned with survivorship. This is, of course, an interesting issue in itself and one we return to later, where we consider the implications of our findings for cancer survivorship, but we felt it was a more accurate description of the content of our data to refer in the title of this report to “patients” in a wider sense. Our concern with services for patients across the whole illness trajectory rather than just at end of life remains.

The overall aim of this study is thus:

*To examine how generalist and specialist nurses work with each other, with other professionals and with patients and carers to support cancer and long-term condition patients.*

Specific objectives are:

- 1. To examine what helps and hinders effective collaborative working for generalist and specialist nurses.*
- 2. To compare experiences of collaborative working in relation to cancer patients with those relating to LTC patients.*
- 3. To consider the implications of these findings for the development of services to support cancer survivors.*

The emphasis on cancer patients in objective 3 reflects the focus of Macmillan as a charity concerned with supporting people with cancer.

## **2. METHODOLOGY**

Ethical approval for this study was obtained from the NRES Yorkshire – South Yorkshire and the Humber Ethics Committee in November 2009 (REC reference 09/H1310/76), and governance approval granted by the NHS Trusts directly involved in the research.

### **2.1 Methodological approach**

This study is concerned with how particular groups of nurses experience collaborative working in the course of providing care and support for cancer and LTC patients. As such, a qualitative interpretive approach is well-suited to meeting the aims and objectives of the research. As we have stated above, our



thinking about professional roles, relationships and identities is informed particularly by constructivist understandings of the person – especially Personal Construct Psychology (PCP: Kelly, 1955; Butt, 1996), and by interactionist views on the nature of professions and professional identities (Macdonald, 1995).

## **2.2 Method**

### 2.2.1 The research setting

To meet the aims of our study we wanted to examine collaboration within and between acute and community sectors in a single setting, rather than to compare experiences across areas. We felt that this would be facilitated by identifying an area where there was a high degree of co-terminosity in the populations served by local acute, community and social care services, but with other significant providers nearby to enable us to explore issues of cross-border collaboration. With these considerations in mind, the setting chosen for this research is a metropolitan borough in northern England, centred on a large former industrial town, surrounded by other smaller towns and with a semi-rural area on one side. It shares borders with several other mainly urban areas. Life expectancy is lower than the national average, and there are marked differences between the most and least deprived areas. There are high morbidity and mortality rates for a range of chronic illnesses. Most of the borough is served by a single Acute Trust, and a single Community Trust, though a minority of patients access services in neighbouring areas. The Local Authority that provides social care is effectively co-terminous with the health Trusts. At the time of our study the Community Trust was moving towards Foundation Trust status and seeking to expand through merger with a number of neighbouring community services.

### 2.2.2 Design

We employed a semi-structured interview design in this study, incorporating as a central element the “Pictor” technique, which we explain further below. Wherever appropriate we asked interview participants to provide and discuss two examples of collaborative working, one focused on a cancer patient and one on a LTC patient. The core participant groups were generalist and specialist nurses who worked with cancer and/or LTC patients. We also recruited a substantial number of participants from other groups whose perspectives would help set the context for the nurses’ experiences of collaborative working.

### 2.2.3 Sampling and recruitment

The generalist and specialist nurses we set out to recruit are listed in table 1, below, with target and actual numbers recruited. The main focus of the study was on district nurses (DNs) and community matrons (CMs) as community-based generalist nurses, community nurse specialists (CNSs) and acute nurse specialists (ANSs) – both for cancer and for LTCs. For the community generalist nurses we sought to recruit from teams based across different locations within the borough. We accessed these groups initially via their line managers; once their permission was obtained we sent recruitment packs to individual nurses, seeking where possible to obtain variety in terms of tenure and location. For the specialist nurses, we sought to recruit from a range of different teams, and cancer and long-term condition specialisms. Patients and carers were recruited via local support groups. Potential participants were asked to return a reply slip with contact details, which we then used to arrange an interview at a time and place of their convenience. Full written consent was taken at the start of the interview. The one group from which we were not able to recruit was the community Palliative Care Specialist Nurses (PCSNs) whose manager declined to allow us access to them.

Overall, we recruited to target for community matrons and added an extra interview with a trainee community matron. We stopped district nurse recruitment at 15 rather than 20 as we had achieved a good geographical spread across teams and a strong degree of consensus on main issues had clearly

emerged. We added the two Ward Nurses because other interviews suggested their perspective would add usefully to the data set. The slight under-recruitment of specialist nurses was due to our inability to recruit community-based PCSNs.

Table 1: Nurse participants

<b>Nursing group</b>	<b>Target recruitment</b>	<b>Actual recruitment</b>
Generalist	N = 30 (community matrons = 10, district nurses = 20)	N = 28 11 community matrons 15 district nurses 2 ward nurses
Specialist	N = 20	N = 17 7 community-based LTC specialist nurses 4 acute-based LTC specialist nurses 4 acute-based cancer specialist nurses 2 acute-based PCSNs

In addition to these core groups, we sought to recruit a range of other key stakeholders whose perspectives could inform our understanding of the context in which specialist and generalist nurses worked with cancer and LTC patients. These included managers in both community and acute sectors, General Practitioners (GPs), social services staff, patients and carers. The numbers from each of these groups recruited are shown in table 2.

Table 2: Participants from other stakeholder groups

<b>Participant group</b>	<b>Numbers recruited</b>
Community managers	N = 11
Acute managers	N = 4
Cross-sector posts	N = 1
GPs	N = 2
Social services	N = 3
Patients	N = 6 (3 cancer, 3 LTC)
Carers	N = 6 (3 cancer, 3 LTC)

Participant recruitment materials are presented in Appendix 1, including information sheets for professionals and patients/carers and consent forms.

#### 2.2.4 Interview procedure

All interviews with professionals were held in private and quiet settings within participants' workplaces, as chosen by the participants themselves. Interviews with patients and carers were held in their own homes at their request. The great majority of interviews were between 50 minutes and 75 minutes in duration. Interviews were digitally recorded with participants' consent, and transcribed in full. The interview topic guides for professionals and patients/carers are provided in Appendix 2.

Interviews with professionals were in three main parts. First we asked them to describe their own role and provide some background information about their professional experience and career history. Next we used the Pictor technique (King, Bravington et al, in press) to explore a particular case (or cases) of collaborative working. Pictor is a visual method that we have developed at Huddersfield for exploring experiences of collaborative working and which we have used in several other studies broadly in the area of palliative and supportive care (Ross et al 2005; King et al 2010; Hardy, King & Firth, 2012). It requires the participant to select a case of collaborative working that is fresh in their mind. They are asked to think about all the people involved in the case –

professionals and lay people – and write the name, role or other identifier for each on a separate arrow-shaped ‘Post-it’ note. They then lay the arrows out on a large sheet of paper in a pattern that helps them explain what happened in the case and their own and others’ roles in it. The ‘chart’ thus produced serves as a focus for discussion of the case between the interviewer and participant.

For professionals whose work included a substantial element of direct patient contact, we asked them to choose where possible two cases: one based on a cancer patient and one on a long-term condition patient. In a minority of cases participants were only able to provide one type of case due to the nature of their work. (Only six of our 45 nurse participants were unable to provide a cancer case, and a further six were unable to provide a LTC case.) Three of the acute-based managers were able to provide patient cases due to their regular involvement in clinical work with patients and families. One community-based manager had very recently worked as a community nurse specialist and also provided a patient-based case. Those who did not have clinical roles provided examples of specific collaborative projects on which to base the Pictor section of the interview. After discussion of each Pictor case in turn, the final part of the interview focused on the participants’ hopes, fears and expectations for the future of their service in relation to the care provided for cancer and/or LTC patients.

In the interviews with patients and carers, the focus was on the patients’ own case. We started with a discussion of the course of their illness and the services they accessed, and then asked the participant to produce a Pictor chart based on their own experience. After discussion of this, we concluded with questions about how they would like to see services develop in future.

### **2.3 Analysis**

In our analysis we drew on both types of data generated in this study: the interview transcripts and the Pictor charts. Transcripts were analysed thematically following the template analysis style (King, 2012), and utilising the NVivo software package. Subsequently, Pictor charts were examined for features

of their construction that pointed to important issues regarding collaborative working – especially for the core nursing participant groups.

### 2.3.1 Template analysis

The template style of thematic analysis involves the construction of an initial version of a hierarchical coding template of themes and subthemes, based on a subset of the data. This is then applied to further data, modified as required to clearly and effectively capture important aspects, and reapplied in an iterative process. For the present study the approach taken by the team was to develop an initial template through group analysis of early interviews undertaken with different participant types. Codes were defined in the light of the stated aims of the project and through drawing on priority areas covered in the interviews. Over the next eight months, and in parallel with ongoing data collection, the team then met at regular intervals to analyse further interviews, again using interview data from different participant types. At several stages in the development of the template we used 'blind' coding of transcripts to test out our common understanding of the themes we had defined. We found this kind of collaborative working strategy valuable as it necessitates clear agreement and justification for the inclusion of each code, and a clear definition of its use. The top two levels of the final template are shown in table 3 and the full final template is in Appendix 3.

Table 3. Top two levels of final coding template.

1 <sup>st</sup> LEVEL THEMES	2 <sup>ND</sup> LEVEL THEMES
<p><b>What affects collaborative working?</b>  <i>Factors perceived to have an effect on the quality and/or extent of collaborative working</i></p>	<p>Role definitions and distinctions</p> <p>Collaborative working practices and systems</p> <p>Impact of intra-team dynamics</p> <p>Impact of inter-personal relationships</p>
<p><b>Condition-specific involvement</b>  <i>The specific ways in which practitioners work with cancer or LTC patients</i></p>	<p>Beliefs about nature of conditions</p> <p>Nature of involvement</p> <p>How/what collaborative working happens?</p>
<p><b>Survivorship</b>  <i>Issues relating to cancer survivorship that have a relevance to collaborative working (and vice versa)</i></p>	<p>Nature of professional involvement in survivorship</p> <p>Signposting and information issues</p> <p>Patient and family perceptions of survivorship</p> <p>Non-cancer and survivorship</p>
<p><b>Current NHS re-organisation</b>  <i>Hopes, fears and expectations regarding current NHS reorganisation of relevance to collaborative working</i></p>	<p>Consortia</p> <p>Foundation Trust</p> <p>Other NHS changes</p> <p>Wishlist for NHS changes</p>

### 2.3.2 Analysis of Pictor charts

One of the main purposes of using the Pictor technique was its ability to encourage clear and concrete (rather than abstract) reflection of complex cases. Naturally these sections of the interviews were fully analysed in the template analysis described above, and we frequently looked at Pictor charts to help us in our interpretation of these data. However, the large number of charts we collected gave us an opportunity to consider whether there were patterns in the way charts were constructed that highlighted important features of collaborative working for different groups. We therefore systematically looked at chart

features for the core nursing groups we interviewed; details of how we did this are provided in table 4.

Table 4. Details of Pictor Chart analysis

Feature examined	Details of analysis
Total number of arrows used	This was simply a count of the number of arrows on the chart. It can give some indication of the complexity of collaborative working in the cases described.
Number and identity of unique agents included	By “unique agents” we mean individuals, teams and/or agencies represented by at least one arrow on a chart. This excludes repeated mentions of the same agent, as occurs in some charts. It also excludes arrows purely representing processes (e.g. “referral”), physical locations (unless they clearly represent services provided at that location and not captured on other arrows), descriptions of feelings (e.g. “carer anxious”, “frustration with services”) and the like.
Agent role in chart	For each unique agent, we made a judgment as to how centrally they were involved in the case depicted, which ranged from “centrally involved”, through “middling” to “peripherally involved”. To make this categorisation, we always looked at the section of the transcript discussing the case as well as the chart itself.
Format of chart	Across our studies we have observed a number of common formats that participants use when constructing charts. For the present analysis, we have identified three broad categories, though we recognise that there is considerable variation within each of these: <i>network charts</i> , <i>timeline charts</i> , and <i>mixed format charts</i> . (Examples of these are provided in Appendix 4). The distinction is principally based on the main organizing principle used by the participants in constructing their chart. Network charts are mainly organised around the relationships between the agents represented on the arrows. Timeline charts are organised around a depiction of the patient journey over time, with the involvement of particular agents shown at particular points on the line. Mixed charts have two (or more) distinct parts to them, organised on different main principles. Appendix 1 shows typical examples of each of these types.

## 2.4 Project governance

Monitoring of the project took place through two mechanisms. Firstly, we convened a project steering group, which included an independent academic, a user representative (LTC patient) and a health professional representative



(district nurse). The group met twice a year to consider progress on the project and offer advice on next steps. Secondly, we reported on progress regularly to meetings of the Macmillan Palliative Care Collaboration (MacPaCC).

### **3. FINDINGS**

Our findings are organised in relation to three main areas: *the importance of personal relationships between professionals, understanding and enacting roles and identities* and *“survivorship” in concept and practice*. Throughout we will highlight, wherever relevant, differences and similarities in perspectives on cancer and long-term conditions. Our main focus is on the “core” nursing groups with which the study is concerned: community matrons, district nurses, community specialist nurses and acute specialist nurses (cancer and LTCs). However, we will also make frequent references to other groups whose views and experiences shed significant light on our central issues of concern.

#### **3.1 The importance of personal relationships between professionals**

It should come as no surprise that good personal relationships amongst health (and other) professionals facilitate collaborative working. However, close examination of the interviews and Pictor charts showed that such relationships did not simply oil the wheels of interprofessional interactions. In many cases they also played a crucial role in enabling professionals to access support (broadly defined) for patients and their families, and to overcome barriers to the effective coordination of care. Conversely, poor relationships could make the task of helping patients significantly more onerous than it otherwise might be. Perceived threats to good networks of relationships were an important aspect of the fears many participants had about current and impending NHS changes. Below we summarise findings in relation to aspects of inter-professional relationships that emerged as important for collaborative working. Note that there was no evidence that particular relationship issues differed in prevalence or importance according to whether cancer or LTC patients were being discussed. Equally, the kinds of issues arising were similar across the

acute/community divide and between Cancer and LTC specialist nurses, though *who* issues arose in relation to did vary. We consider this further in section 3.2 when we look at roles and identities.

### 3.1.1 Accessibility and availability

This was the most commonly-mentioned aspect of interprofessional relationships, occurring in most interviews across all the main staff groups. Participants stressed how important it was that they could rely on being able to contact other professionals as and when they needed to. Simple proximity was a key factor in many cases; being located in the same setting allowed professionals from different teams to communicate well – often on an informal basis – and to get to know each other and build relationships.

Working here in this building has been a real bonus because I'm working alongside, you know, physically working next to other specialists: dermatologists and heart failure nurses, COPD.  
SN7 (Lymphoedema CNS)

Where professionals did not share a base, or work in close proximity, positive relationships were still possible where colleagues made themselves available on the phone, and/or where they were willing and able to organise joint visits to patients. Relationships were also strengthened when new staff – or staff in new roles – were willing to come and introduce themselves to colleagues and learn about each other's work. A Community Specialist Nurse provides an example of this in relation to the community matron service:

The community matron service was established after my service was already here; each one of them has come and spent time with me to know what my service does, so I know them all and they know they can pick up the phone to me. So we've got a good rapport there.  
SN5 (COPD CNS)

Note that many participants emphasised their preference for face-to-face contact, and regretted the fact that workloads and organisational structures sometimes got in the way of this.

I think sometimes when you phone somebody – over the phone, it depends on your communication skills, often things are forgotten. But face-to-face they're brought to mind a little bit better, and if you've got a good relationship with somebody – another professional – then they know where you're coming from in terms of patient referrals.

DN12

The Specialist Nurses and Ward Nurses tended to be more positive about telephone or electronic contact – especially with doctors – so long as they felt those they needed to contact genuinely made themselves readily available. This was not just a matter of answering phones (or other forms of communication) promptly; it also meant giving nurses the feeling that their calls were welcomed and valued (see also our discussion of “Respect” in 3.1.4, below).

Rapport with them [*Consultants*] is really good, we can contact them at any time [...] I was going home at 9 o'clock, I needed something from him. I e-mailed him because he said he picks his e-mail up quicker [...] within ten minutes he rang the ward, you know, for consultation. Very, very easy; nothing like “Oh what are you ringing me at this time for?” It works really well.

Ward Nurse 2

It is worth noting that in examples like this one, participants are talking about good telephone or electronic communication with people they already see face-to-face regularly, even if only intermittently. In contrast, some district nurses expressed regret that they did not have more face-to-face contact with Specialist Nurses.

I don't feel we have a strong enough link with the specialist nurses. I would like to have, you know, more communication with them – definitely – and to do more joint visits [...] But it's nice to put a face to a name, or somebody at the end of a telephone. I've found that very, very helpful, if I've ever managed to join up. Work doesn't always allow – the timescales and stuff, the caseload of the day doesn't always allow you to go and do a joint visit.  
DN1

Formal meetings were often seen as a valuable way to get to know colleagues from other teams and disciplines. These included multi-disciplinary team meetings (MDTs) which featured particularly in accounts from Specialist Nurses and Gold Standards Framework (GSF) meetings that were mentioned by many of the district nurses and community matrons.

Because we're palliative care, we will work with all the tumours, all the site-specific nurses, specialist nurses, because as their patients come to be palliative, to end-stage, they'll refer them on to us. So we go to everyone's MDTs as well because we'll pick patients up from there [...] So we work really well with them, and it's important that we work with the site-specifics – and the consultants as well, you know, the consultants find it quite easy to refer to us.

Acute Macmillan Nurse 1

Several district nurses made the point that they wished there was wider attendance at GSF meetings – for example, including Specialist Nurses and the out-of-hours district nurses. Although GSF meetings seemed well-embedded within primary care, there was still variation in how well GPs understood their importance for communication about patients with palliative care needs:

Some of my teams have really good connections with the GPs and good GSF meetings; some of the GPs aren't as proactive and [...] I know of one Practice, we've just, we've gone in and we've had to tell them how to put the GSF register together and encourage the meetings, and said "we

[*district nurses*] are vital, you can't have the GSF meetings without us 'cos we're the ones who probably see your patients more than you do". So we're getting there with them...

DN Locality Manager

### 3.1.2 Longevity of relationships and shared job history

Many interviewees made the point that long-standing relationships with other professionals enabled mutual understanding and trust to develop. This factor was often referred to in an almost throw-away fashion, as if it were obvious why relationship longevity was of value to collaborative working, though some people did elaborate on the issue. A Community Diabetes Nurse Specialist described "very, very close" relationships with the equivalent service in the acute sector:

Because I've known [*name*] who's the manager for so long we have a very close relationship, so that if I ever have any problems that I can't manage I can refer to the Acute Trust for specialist care with the Consultants [...] We have close links with all the services really, and I think because a lot of us have worked together over the years we know names and faces.

SN3 (Diabetes CNS)

One community matron complained about difficult interactions with a community Palliative Care Specialist Nurse (PCSN) in her LTC Pictor case. She speculated at the end of the story as to whether her lack of any previous relationship with this nurse contributed to the problems between them:

I do know the other nurses [*PCSNs*], but this nurse I didn't know. Sometimes it's easier fighting your corner with someone that you do know, and who knows you, but I think with this one because we didn't know each other, when we was both being assertive it came across as a bit of an argument.

CM9

Having a shared job history was also an important facilitator of relationships for some participants. By this we mean occasions where a participant had previously worked in the same role as a professional with whom they now needed to work collaboratively. The most common examples were in relation to those who moved from district nursing to a community matron role, and were able to draw on their previous job history when working collaboratively with district nurses and GPs. However, there were similar examples from other groups, such as a Community Diabetes Specialist Nurse who had previously worked as a Practice Nurse.

I was a practice nurse for so long and we used to have regular studies [*i.e. shared study days*] and things, I know how they operate and I know most of the practice nurses.

SN 3 (Diabetes CNS)

This quote illustrates how “shared job history” often overlaps with “longevity of relationship”, because participants often maintained relationships with those they had worked with in their previous role. The common thread here is the advantage for collaboration that comes from knowing an individual and/or knowing a role first-hand over a significant period of time.

### 3.1.3 “Stepping on toes”

In complex cases where a wide range of services are involved – often from across acute, community and social care sectors – it is inevitable that there will sometimes be overlapping roles to be negotiated. Blurred boundaries between roles do not always result in tensions in relationships, but they can do. This is particularly likely where people feel valued aspects of the roles – or even their very jobs – are threatened. For example, in other studies, including our own previous work, it has been noted that district nurses feel that their role has been eroded by new nursing roles. In the present study it was notable that a high proportion of the examples where role overlap was perceived as “stepping on toes” involved district nurses. One district nurse provided a vivid example of the personal and inter-team conflict that arose from her perception that the Hospital

at Home team were “stepping on her toes” regarding care for a discharged patient with palliative care needs.

Then I got this call from the Hospital at Home team saying “Oh, we’re going in now to see this gentleman”. And I said “I beg your pardon?” “Yeah, we’re going out to give him all the palliative care needs”. I said “excuse me, we’ve been going in for over a month here”, and we had a bit of a to-do, which went straight to top management [...] and they’ve never really been friendly with us since.

DN2

While the apparent lack of consultation here might be expected to annoy any professional, it is likely that the particular sensitivities of district nurses regarding their role in community palliative care fuelled the escalation of this conflict. Most examples of “stepping on toes” came from community generalist nurses (CMs and DNs), though one cancer specialist nurse described this experience in relation to a team at another hospital:

I would say initially it was quite a bad relationship [...] they didn’t really embrace us in terms of, you know, made it quite difficult, they didn’t really want such a wide team of core membership they were quite happy to have their own membership, they didn’t really want anybody from the outside. They were happy to take the patient and the referrals but they didn’t want our radiology involvement, they didn’t want our histology.

SN19 (Urological cancer ANS)

#### 3.1.4 Respect

Many participants referred to the importance of a sense of personal and professional respect in relationships. This had real practical consequences for professionals; if others you worked with respected you as a professional they would be more likely to trust your clinical judgement and allow you to act on it, or follow your advice. Discussion of respect most commonly related to relationships between nurses and doctors, with participants frequently

describing it as something that had to earn over a length of time. This was especially true for community matrons, who had to work hard to enable GPs to see the value of their role:

I think I've had to prove my worth. I've been here a bit longer than some of the people. I've had to prove me worth, and I think they can see the benefits of the service and they support me.

CM4

There are some similar comments from specialist nurses with regards to Consultants linked to or associated with their teams, though the overall sense of a struggle to be accepted is generally less intense here than in the context of community matrons and GPs.

And I think the [*Specialist COPD*] nurses' experience has grown, and your relationship with the Consultants – that they can trust your opinion because they've worked together for so long.

SN11 (COPD CNS)

The above examples are of participants' sense of being respected by others; when it comes to their own feelings of respect (or lack of it) for colleagues, willingness to share expertise and to take seriously that of the participant is mentioned frequently. This can be seen as part of a wider ethos of "give and take" in relationships, which also requires flexibility in roles and availability.

I've not got district nursing experience, if I'm struggling and don't know how to order incontinence pads or I'm worried about pressure sores, the girls [*district nurses*] will advise me. [If] they're struggling with the heart failure patients, they'll ask me. That works really well. We pool off each other's knowledge. You feel safe, you don't feel like a fool asking.

CM5



Very, very accessible [i.e. *Consultants*], even out of hours when they shouldn't be, you know, they leave their phones on. And I think that's because we don't mither them with silly things, so when we do ring them they know it's a problem that we can't sort out, so it's like respect really, isn't it?

SN12 (COPD ANS)

In contrast, where other professionals failed to communicate in a respectful and personal manner, participants reported difficult relationships. For example, one district nurse describes poor collaboration with a Social Worker in the case of a very challenging diabetic patient living in a warden-controlled flat:

...but she [Social Worker] keeps leaving succinct little messages on note pads when we go in saying "why have you not done this?" and I keep ringing her up and saying "how dare you say that when we're in four times a day trying to sort this guy out; he won't take a blind bit of notice of us".

DN2

### 3.1.5 Making an effort

Linked to the notion that respect needs to be earned was a more general recognition that sometimes relationship-building took a considerable effort. Participants felt this was worth doing, however, because the good collaboration it facilitated had direct benefits for patients. A Community Diabetes Specialist Nurse described the effort she went to in order to build a relationship with a Pharmacist involved in a case where a patient had been given the wrong prescription:

When I first rang up and said “oh, she’s got these disposable pens” he [*i.e. Pharmacist*] was quite - I think he thought I was criticising that he’d dispensed the wrong medication. I said “no, no, no, that’s not what I’m saying [...] the prescription’s been doubled-up, cartridges and pens, by mistake from the surgery. I’m not accusing you of dispensing the wrong item.” So I actually went in to meet him face-to-face, because I think it’s easier face-to-face to explain what was happening with this lady. So we’ve got quite a good relationship now, yeah.

SN3 (Diabetes CNS)

When asked what she feels helps facilitate collaborative working, one of the community matrons said:

Going and seeing ‘em. Lurk outside a Doctor’s room. I’m always lurking down here. Go in and see the Doctor. Nip over and see the district nurses. Go to the Hospice – I know the girls at the Hospice now. Go to Intermediate Care. You can’t go all the time, I don’t mean that, but go make your face known.

CM4

Participants also recognised when other professionals made an effort to develop personal working relationships with them, and were appreciative of this, as can be seen in the following example from a district nurse talking about one of the GPs she works with:

One GP regularly e-mails me to talk about, to arrange meetings for one particular lady that we’ve got on the caseload, who’s proving difficult to manage, and he wants to meet on Monday to discuss – which is brilliant. Face-to-face is much better than going through Reception.

DN6

In many cases, participants’ accounts suggested that collaboration required an effort because of unhelpful organisational structures, systems or cultures. For

example, one manager contrasted the attitudes of practitioners with those of senior managers:

On the ground there's such a willingness to work together, and people will get by despite some of the senior managers and not because of them, and you know at a higher level people are getting embroiled in ownership, power and finance and things like that, but on the ground people are generally working together with a genuine commitment.

Manager

### **3.2 Understanding and enacting roles and identities**

Previous research – our own and others' – has shown that the nature of professional roles and identities, and how these are enacted in practice, can have a major impact on collaborative working. This was also the case in the present study. In this section, we start by examining the common *patterns of collaborative working* for the core nurse participant groups, drawing particularly on the Pictor chart data. We then focus on two of the main issues that emerged within the broad area of roles and identities: *role understanding* and *coordinating care and support*.

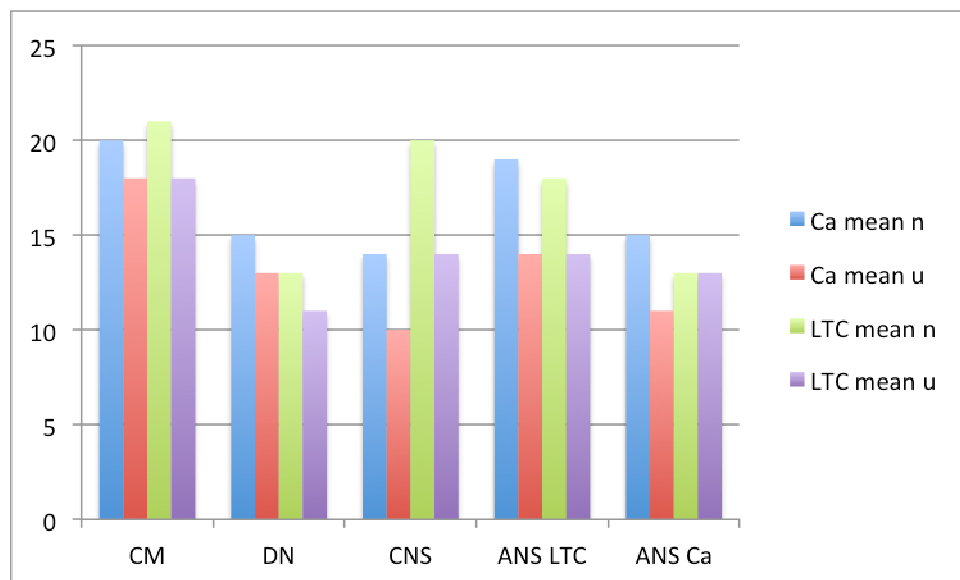
#### **3.2.1 Patterns of collaborative working**

Before we examine common patterns of collaborative working based on the Pictor charts, a word of caution is required regarding these data. Pictor charts are not, and do not seek to be, an objective “measure” of who works with whom. Rather, they are a representation of how collaborative working is experienced by those involved in it. Equally, the examples given are not a random selection of cases with which our participants have worked: they are chosen by participants as good examples of how they experience collaborative working in their role. Common patterns are therefore always subject to interpretation in the context of particular accounts in a particular research setting. Other than the simple count of the number of arrows used, any analysis of a specific group of charts required us as researchers to look at the related sections of interview transcript to arrive at a credible and trustworthy interpretation.

*Number of arrows used and number of unique agents.*

Figure 1 shows the mean numbers of arrows and unique agents for each of the core nursing groups<sup>2</sup>, with separate figures for Cancer and LTC charts.

Figure 1. Mean number of arrows and of unique agents for cancer and LTC charts from core nursing groups



n = number of arrows, u = number of unique agents

The main points to attend to from this are as follows:

- Community matrons have the highest number of arrows and of unique agents. This is consistent with our previous research and reflects the case management role they play for complex patients in the community.
- The specialist nurses tend to have the largest difference between number of arrows and number of unique agents. This partly reflects a different mix of chart formats between them and the community generalist nurses, which we discuss further below.
- There is not a consistent difference in numbers of arrows or unique agents between cancer and LTC cases, suggesting that neither disease

<sup>2</sup> Community matrons, district nurses, community nurse specialists and acute nurse specialists (LTC and Cancer). We did not look at Acute PCNSs and Ward Nurse charts here as we only had two participants in each of these groups. We did include three managers in the ANS group and one in the CNS group, because they discussed clinical, patient-centred cases in their charts.

type involves notably more complex collaborative working than the other. There is something of an exception in the case of community nurse specialists, who tend to include fewer agents in cancer than LTC cases.

- All these groups of nurses report working with a large number of different professionals and lay people in the cases they chose to describe for Pictor. We cannot tell whether the chosen cases are representative of what happens across their caseload as a whole, but the numbers are consistent with what we have found in previous studies and in training and development sessions run with similar nurses.

### *Agent roles in charts*

Having looked at the number of different agents participants included on their charts, we will now move on to consider who they included and in what ways. We noted which other people (professionals and lay people) were included on each chart, and whether they were shown as playing a central or peripheral role, or were in a “middling” role between these poles. Table 5 summarises this information in relation to the core nursing groups that are the focus of this study – that is, the extent to which they include themselves and each other on their charts. On this table, the rows represent the participant groups whose charts we have looked at (cancer and LTCs separately) while the columns indicate whether particular groups were included on each chart. One icon is shown in each cell for each time a chart includes the particular group. The size of the icon represents whether on that occasion the professional in question was placed in a central, middling, or peripheral role on the chart. Thus if you look at the top left cell, you see that community matrons included their own profession nine times in cancer case charts – seven times in a central role and twice in a middling role. In contrast they only included Acute Nurse Specialists four times on their cancer case charts – twice in middling roles and twice in peripheral roles.

Table 5. Agent roles in Pictor Charts

PTP GROUP	Chart type	INCLUDED ON CHART			
		community matrons	district nurses	Community Nurse Specialists	Acute Nurse Specialists
community matrons (n=11)	Ca = 9	⊙⊙⊙⊙⊙ ⊙ ⊙⊙	⊙⊙⊙ ⊙⊙⊙⊙ ••	••	⊙⊙ ••
	LTC = 10	⊙⊙⊙⊙⊙ ⊙⊙ ⊙⊙	⊙ ⊙⊙ •••	⊙ •	⊙⊙⊙⊙ •••
district nurses (n=15)	Ca = 14	⊙	⊙⊙⊙⊙⊙ ⊙⊙⊙ ⊙⊙⊙⊙⊙⊙ ⊙⊙	⊙⊙⊙ •	•
	LTC = 14	⊙⊙⊙ ⊙⊙ •••	⊙⊙⊙⊙⊙⊙ ⊙⊙⊙⊙⊙⊙ ⊙ ⊙⊙⊙⊙⊙ ••	⊙⊙ ⊙⊙	⊙ ⊙⊙⊙ ••
Community Nurse Specialists (n=8)	Ca = 6	⊙	⊙ ⊙⊙ •	⊙⊙⊙⊙⊙ ⊙⊙	
	LTC = 8	⊙ ⊙⊙ •	⊙ ⊙⊙⊙⊙	⊙⊙⊙⊙⊙⊙ ⊙ ⊙	⊙⊙ •
Acute Nurse Specialists (LTC) (n=7)	Ca = 5		••	⊙	⊙⊙⊙⊙⊙ ⊙⊙ •
	LTC = 7		••	•	⊙⊙⊙⊙⊙ ⊙⊙ ⊙⊙⊙⊙ •
Acute Nurse Specialists (Cancer) (n=4)	Ca = 4		••		⊙⊙⊙⊙ ⊙⊙⊙⊙
	LTC = 2		⊙⊙	⊙	⊙⊙ ⊙⊙

Level of involvement: ⊙= Central ○= Middling •= Peripheral

The key points we would highlight from this analysis are as follows:

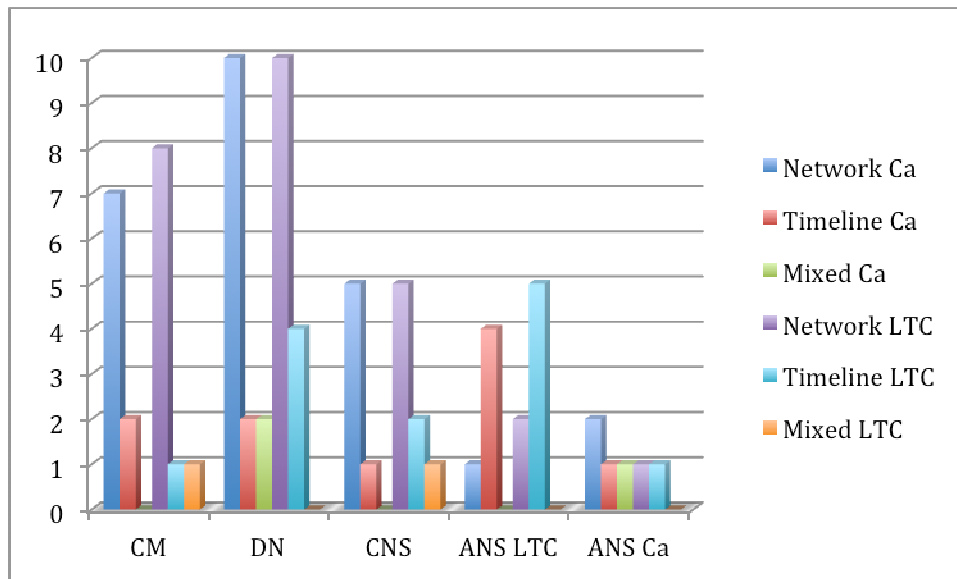
- Not surprisingly, all groups most frequently include their own group, and tend to place them prominently in charts. In almost all cases participants are referring to themselves here. However, quite often participants also include one or more other members of their own professional group on their charts. This was especially true for the ANSs (both LTC and cancer), where many mentioned referrals to other specialist nurses within the acute (secondary and/or tertiary) sector. (For example, in their LTC cases, the seven LTC ANSs included 13 ANSs, meaning that there were six references to ANSs other than themselves.)
- ANSs include relatively few community-based staff on their charts, and where they do include them they are mostly (7 out of 11) peripheral. Not one ANS chart includes a community matron.
- In contrast, community-based staff include ANSs quite often, though much more in LTC cases than in cancer cases.

The implications of these findings will be explored further in relation to the formats used for charts and to the template analysis of interview data, especially the material relating to *co-ordinating care and support*.

#### *Format of charts*

Figure 4 shows the distribution of each chart format type for each of the core nursing groups, for cancer and LTC charts separately.

Figure 4. Distribution of chart formats for core nursing groups



There is a very clear difference here in the types of charts produced by community-based staff (generalist or specialist) and acute-based specialist nurses. Amongst the former, the great majority of charts are in the network format, where the main organising principle is the nature of relationships amongst agents depicted on the arrows. In contrast, the majority of the acute-based specialists depict cases using a timeline format, which focuses on the patient trajectory over time, showing who is involved at which particular points on the journey. Our previous research using Pictor has predominantly been with community-based staff, as well as with patients and carers in the community. This has shown a similar pattern to that which we find here amongst community-based nurses, with a marked preponderance of network charts. It is possible that the different pattern for acute specialists is purely a matter of chance - that they happened to choose to discuss cases that were best described in terms of a timeline. However, given the strength of this difference, it seems likely that it does indicate a tendency for the acute-based specialist nurses to perceive cases in rather a different way from their community-based colleagues. There are several possibilities:

- The tendency for ANSs to represent Pictor cases as a timeline might reflect some aspect of their training – for example, reflective tools used on their post-registration courses, representations of specialist nurse roles in teaching and/or textbooks, and so on. We feel this is unlikely to be the main explanation though, for several reasons. Firstly, it is unlikely that they would all have been exposed to the same course material on different



training courses at different times, nor is it apparent why theirs should be different from CNSs' – who rarely used timelines. Secondly, in discussing their cases, none of the ANS interviewees referred to previous educational experience of reflective tools or role representations that might have directed them towards a timeline approach. It is possible that in at least some cases training/education experiences may have played a part in how they approached the Pictor task, but this would require further research to establish.

- Perhaps the acute setting in itself encourages staff to look at collaborative working in relation to the patient's place on an illness trajectory. We can test this possibility to some extent by looking at the charts produced by the other acute-based nurses we interviewed who were not part of the ANS group: two acute PCSNs and two ward nurses. We find that one of the PCSNs produced two timeline charts but her colleague produced two network charts, and the ward nurses each produced a network chart. These are small numbers, but they do not point in the direction of timelines being the norm for acute-based nurses.
- Rather than a simplistic link between the acute sector setting and the way nurses represent cases in Pictor, a more nuanced argument is that there is something about the way in which condition-specific specialist nurses work in the acute sector that encourages such a tendency. The involvement of ANSs with patients is generally episodic – they may see patients for check-ups or assessments related to interventions, and otherwise tend to have contact when there is a crisis or exacerbation in the condition. At these times the nature of their involvement can be quite intense – both in terms of the amount that is happening for the patient and their (and perhaps their families') emotional reactions. Thus the ANS's relationship with the patient may readily be conceptualised in terms of a series of distinct steps or phases in the trajectory of an illness. Alongside this, the nature of the collaborative interactions for ANSs may encourage a timeline perspective. Looking at who the ANSs include in their chart, we see that much of their collaboration is with other specialist nurses and/or with Consultants and their teams. Such interactions often involve referring the patient on for a particular intervention, or seeking advice and information in relation to the urgent situation for which they have consulted. In contrast, community-based nurses tend to describe a wider range of types of interaction with other agents – for example, negotiations over role or administrative/geographical boundaries, and attempts to persuade other professionals that their involvement is required. It may be that the more diverse types of

collaboration necessitated in community settings, and the fact that these are not necessarily linked to where the patient is on their illness trajectory, make it easier for community staff to represent cases as networks rather than timelines.

- ANNs – especially those working in LTCs – may tend to have longer term involvement with individual patients than is normally the case for community nurses, and timelines may simply be a more convenient way to represent cases of long duration than network charts. Our evidence offers some support to this explanation – ANNs do tend to describe a longer involvement with their chosen cases than is the norm for CNSs and community generalist nurses, including some LTC cases that go back many years. However, there is not an entirely consistent relationship between the duration of cases and the type of Pictor chart created to depict them; some of the ANNs' timeline charts describe cases with which they were involved for only a few months, and some network charts produced by community staff describe cases with a duration of well over a year. We would not, therefore, argue that the choice of timeline format is determined by the duration of the case, but rather that long term involvement is another typical feature of ANNs' role (particularly in LTCs) and in combination with the other features discussed above tends to influence them towards the use of timelines.

In contrast to the clear difference in typical chart formats between ANNs and community-based nurses, when we compare chart formats between cancer and LTC cases they appear broadly very similar. This suggests that the way in which collaborative working is conceptualised is not particularly dependent on the type of condition involved.

### 3.2.2 Role understanding

In discussing collaborative working, participants often reflected on what they and others understood a particular professional role to entail. As one would expect, it was frequently the case that clear understanding of professional roles facilitated collaborative working, whilst uncertainty about the role of a particular professional involved in a case could serve to inhibit it. In the main, participants reported good levels of inter-professional understanding; however, there were a significant number of exceptions to this. We focus here on two main examples: problems related to *understanding and integrating new roles (with particular reference to community matrons)*, and *understandings across the acute/community boundary*.

### *Understanding and integrating the community matron role*

Problems around role understanding were most apparent with comparatively new professional posts, and the most commonly mentioned of these was the community matron. Problems understanding and integrating this new role into existing practices and services were mentioned both by the community matrons themselves and other professional groups. A particular problem identified by participants in this context was understanding where this new role fitted in with existing services – specifically, how the role of community matron was distinguishable from that of a district nurse (see also the theme ‘Stepping on toes’, 3.1.3 above). This could create tensions between professionals and added to the difficulties for staff in the new role.

Initially they [DNs] didn't really understand our role. Nobody briefed them really on where we were coming from. I don't think anybody really understood our role, to tell them what our role was. Because it was a new post, I think it was very much a case of you devise it as you see it really, so I think trying to explain your role that you perhaps didn't fully understand yourself, or others didn't understand was very difficult.

CM1

To some extent, community matron respondents felt that this initial lack of understanding was entirely understandable reaction to a new role and several reported that they themselves had been unclear about what their post involved.

I didn't really know what it was going to be like, I don't think anybody did, because we had no job description and nobody could actually tell us what a community matron actually did. You know, they said it was looking after long term conditions, but we didn't actually know what we would be doing, none of us actually knew what we were supposed to be doing and we still didn't know what we were supposed to be doing for the first couple of years... just kind of make it up as you go along

CM9

Community matrons' previous job history had an impact on their own understanding of the role. Many of them had been district nurses, but a substantial number came from other backgrounds – including the acute sector – and had little prior direct experience of community nursing. For

the former group, experience of the community setting was an advantage, but there was a danger that they (and others) could struggle to differentiate their new role from their previous one. The latter group perhaps had fewer preconceptions about the new role, but could face a steep learning curve regarding the way community nursing operates.

When you find somebody's come from different backgrounds, I've been from the acute, N's a physio, and S was a cardiac specialist nurse, we haven't got any preconceptions about being district nurses, and that is a big problem in the service [...] Although they [*former DNs*] can be good and some people have integrated well, but they are more here because they have to be, and we've not come with that baggage really.

CM4

Several district nurses reported that they were still somewhat unclear as to how the role of community matron should fit with their own role in providing patient care.

I've been out with the matrons when I've been doing my practice and the couple of patients I've seen I've thought 'Well, why are the matrons going because that would be, I would have thought would have been more our remit?'

DN15

Despite such continuing uncertainties, the overall picture was that misunderstandings had largely dissipated over the years as the role had become better known amongst other services. community matrons reported that often this had been achieved through their own efforts. Once their own role was clearly established, community matrons often reported that they then made significant efforts to advertise and inform other services about it and to learn about other services, and these efforts were felt to have been generally successful (see also the theme 'Making an effort', 3.1.5 above). Additionally, the more established community matron service now had in place their own criteria that they felt confident in describing and applying to referrals from other professionals.

The district nurses and myself – wonderful, we have a really good relationship because I went in and then the district nurses went in the afternoon for me, I went in the following morning, they went in the afternoon with me. So almost we was [...] linked like that, yeah.

And then I could call on the evening and night service to go in as well. I knew she [*patient*] was covered all the weekend. Monday morning I went in, went back up to the district nurses and we had a little meeting over what had happened over the weekend so very much felt this lady's care was covered for her.

CM8

*Specialist Nurse:* When I first started to do this job there was confusion over the community matrons ... because it was a new role it was like 'Well, what do they actually do?'

*Interviewer:* Do you think that still exists?

*Specialist Nurse:* No, because we know what they do now and we know the role and we know who to refer to, you know, if a patient needs them

SN4 (Diabetes CNS)

#### *Understandings across the acute/community boundary*

Issues of role understanding across the acute/community boundary include understanding of the community matron role, but are wider than just this. We saw in the Pictor charts that ANSs rarely included community nurses on their charts – and never included community matrons – and this is mirrored in the lack of understanding of community services shown by some (though not all) the acute-based nurses. For example, one cancer Specialist Nurse states:

I don't know much about what their [*community matrons*'] role would entail, I suppose they're sort of overseeing what district nursing services [do], so occasionally you will get, erm, I don't believe I've ever spoken to a community matron, I've spoken to people in district nursing services who are, I don't know, head of whatever, sort of, I don't know how the hierarchy works in district nursing, one of the sisters I suppose.

SN19 (Urological cancer ANS)

Ongoing reorganisation, in the wake of NHS reforms, has led to changes in community and primary care services that are hard for acute-based staff to keep up with. The most powerful example of this was from the acute COPD Nurse team. Both members we interviewed expressed concern that "new" nurses employed by GP Consortia were sometimes giving advice to COPD patients that contradicted that given by their own team. The extent to which this is really

happening is not the point here; what is striking is that the COPD Specialist Nurses know almost nothing about who these nurses are, and yet patients on their caseload are clearly having contact with them.

*Interviewer:* So are they [*the GP Consortia*] employing their own Specialist Nurses?

*Specialist Nurse:* The Consortia is; it's, we've actually had patients say that they've told them to reduce medication that we've put them on, we've put them on medication in here, and to use a nebuliser less because it might work better - and I don't know where their evidence is behind that to make a statement like that.

*Interviewer:* Where have these nurses come from?

*Specialist Nurse :* I don't know, I don't know where they come from but I think, I don't know, I don't know, it's, I mean I don't know. I'm not talking about Practice Nurses, I'm talking about these extra nurses that are doing community visits.

*Interviewer:* Right, are they Specialist nurses though?

*Specialist Nurse:* They say they are, yeah. Again, I don't know what training they've got.  
SN11 (COPD ANS)

It's worrying because we've had, you know, a few patients actually physically come in to the Unit and say 'Oh, she's told me to do this' and what they've told them is totally wrong [...] we've had patients that have been told by the new COPD team out there not to ring us anymore [...] well no, our patients want to come to us, you know, and they're not getting as good a service out there by these new nurses. Now I don't mean tier 2 by this, I don't mean the [*Community COPD team*] girls

SN12 (COPD ANS)

Just as acute-based nurses' understanding of community nursing roles can be variable, the same is true of role understanding in the other direction. However, at least in some cases limitations in role understanding are not only associated with the community/acute boundary but rather constitute a more general confusion about what an ANS does. One acute-based diabetes specialist nurse lists a range of examples of ways in which her role is misunderstood, referring to both hospital and community-based colleagues.

The ward staff ringing up saying “Can you come and review this patient?” and we say “Yeah, what’s the problem?”, “Well they keep drinking Lucozade and they’re not eating the right things” so then I would say “Well, don’t you think that’s more for a dietician than myself?” so people presuming that the Nurse will do everything and there is a big thing with Nurses, historically Nurses have always taken everything on ... They’ll [*i.e. ward nurses*] ring up “Can you refer them to the Community Diabetes team?” so I would say “Well, why can’t, I’ll give you the number and you can do it directly”, things like that. But other than that, “Could you go and check on the blood sugars?” “No, that’s not our job”. Practice nurses – “Can you see this patient at home?”, “Well they’re only on diet and tablets, can you not do that?” “No, my GP doesn’t allow me to do home visits.” I said, “Well sorry, I’m not doing it for you” [*laughs*]. Things like that.

SN9 (Diabetes ANS)

Some specialist nurses reported that the different roles of community and acute-based services working in the same specialism were not always well-understood by other professionals with whom they had contact. For example, one ANS is puzzled why some GPs refer patients to her for interventions that could be done by the community team:

There are some times that the GPs will write in and do written referrals asking me to see them in the heart failure clinic - which is a little bit, I feel a little bit bizarre sometimes. Because I assume that GPs would write to the community heart failure nurses within primary care for the simple reason that I’m quite happy to see patients in the hospital – however, they incur a cost. If they use the PCT nurses I don’t think the same occurs.

SN13 (Heart Failure ANS)

### 3.2.3 Coordinating care

In this section we will consider participants’ accounts of what they and others do to coordinate care for patients across services. The first sub-section looks at *who does what* in terms of co-ordination, and highlights differences between cancer and LTC patients. Next we will consider perceptions of *how information systems impact on coordination*. The final section will look particularly at issues raised in *coordinating care across boundaries*.

### *Who does what? Cancer compared to LTCs*

We will consider first the roles of our core groups of nurses in coordinating care within community and acute settings, with an emphasis on differences in relation to cancer and LTC patients. This includes how they coordinate with staff from outside their sector, and with social care staff employed by the local authority or private agencies. However, the emphasis here is on the nature of their coordinating activities around the care of patients *within* their sector; we will examine specifically cross-boundary issues in more detail below.

Turning first to community generalist nurses, we see a pattern that is very similar to what we found in our previous study of community nursing roles in palliative care (King et al, 2010). Community matrons see the case management of LTC patients as central to their role, especially those with complex co-morbidities. They see themselves as uniquely well-placed to perform such a function, because of the way their role is defined and the skills they have developed. As we have seen, getting others to understand this role has sometimes been a struggle but on the whole they feel that they are now being recognised for what they could do for this group of patients.

I think I've managed her case quite well. Seeing it all on paper [*i.e. on Pictor chart*], like this, you could go away, and think, well, I haven't actually really done anything, but when you actually put all these, these people I've been involved with, or started something rolling with, I think I've had a key role in managing, or at least trying to manage some of her problems.

CM2

Whereas this role as a community matron, it's more about I suppose really, working on the medical side. The fact that you're listening to the chest, you're diagnosing, you're referring then on to other services, almost like a gatekeeper of that patient if you like, so that you're bringing in trouble-shooting for them, and bringing in other health professionals, because I haven't got the in-depth knowledge of a heart-failure nurse. So in that aspect, I would bring in maybe [*name of nurse*], who I deal with, if I have a problem with heart-failure, who I feel I can't manage alone.

CM8



This case management role is now recognised and valued by many other professionals, especially some of the LTC specialist nurses:

The community matrons are fantastic and they are the glue out in the community and they do make sure that dialysis treatment is not forgotten in the big mix of home help services going in and district nurses going and podiatry and everybody else going in who would normally go into the home by the relationship that we have with community matrons [...] I would say the community matron is a key figure for our patients who need joined up care.  
SN8 (Renal ANS)

In contrast to their role with LTC patients, community matrons do not see the care of cancer patients as central to what they do. Nevertheless, almost all of them report that they do have cancer patients on their caseloads. (We saw earlier that most of our CM participants provided a cancer as well as a LTC Pictor case). CMs describe such involvement as happening in instances where an existing LTC patient develops cancer, or because their case management skills are called upon (for example, by a GP) to help with a particularly complex case. They tend to step back at the very end of life, when there is a high level of district nurse involvement:

The people I've managed with cancer tend to be the ones who are more complex. Maybe their GP's gone out, identified that there's no co-ordinations of care and they need somebody to pull it together. The district nurses may be struggling, so they'll ask me to get involved or you may be involved and then they develop cancer, and then obviously you go down the pathway of cancer care, that way.

CM1

Very often, if the district nurses are involved, if it's more end-stage, there's not a lot that I need to do because they're you know, they're in charge of it, although we do work together, you know we do. Sometimes I might be involved with a patient and not the district nurse, but when it comes to a certain stage, I think they need to be involved then, I'll ask them to.

CM9

district nurses strongly assert the importance of their involvement with cancer patients, and describe themselves as engaged in care coordination tasks for them.

But I would say we tend to be quite central in terms of the cancer patients cos we're the ones generally that are referring on to other agencies, similar as the community matrons are for long term conditions as like a portal aren't they?

DN12

Managing it really to make sure everything was, you know, to assess - to see what was needed. Sort of negotiate with the patient and the husband as to what they felt their needs were, because very often we see things differently. And then to get the help in that they needed, just to make it so they can stay at home.

DN11

There are two important caveats here, though. Firstly, they are very much focused on involvement with cancer patients who are near the end of life. Although they are now expected to contact all patients with a new cancer diagnosis, many are sceptical as to the value of this and unhappy at the extra workload it involves. (We will return to this issue in relation to Survivorship in section 3.3, below). Secondly, the task-based nature of the modern District Nursing role, coupled with increasing workloads, can limit the extent to which they can genuinely play a proactive role in coordinating care.

We were not able to collect data from community PCSNs, as noted earlier, but their presence on Pictor charts and comments from other staff we interviewed suggest they were quite often involved in cases of patients in the community who were at or near the end of life. They appeared to be more likely to be involved with cancer than LTC patients, and comments from DNs in particular suggested varied experiences in how well they worked with other services, from excellent to occasionally problematic. They were not generally described as taking a coordinating role, but rather as providing advice and support both to patients/carers and other professionals. It must be recognised, though, that their own perceptions of the kind of role they play might be different from those of other staff.

With a few exceptions, specialist nurses - both in the community and the acute sector - do not describe care coordination as central to their role; at least, not the kind of case management that

community matrons undertake. However, their role does involve a good deal of liaising with other professionals, negotiating referrals, and passing patients on to other services. It should be noted that the particular details of patterns of collaboration do vary between specialisms and settings.

Somewhere around this time as well a link was made with the community matron, now I can't remember whether I made that referral just off the top of my head or whether the GP made the referral cos the matrons obviously linked in with the GPs as well. But community matron involvement was there as well, who then kept that regular review of the lady - whereas I have to discharge, the community matrons can do more case management with them.

SN5 (COPD CNS)

People that have Oxygen Assessments they can be actually exacerbating and they might be sent in for an Oxygen Assessment for COPD, the Nurses actually have the skills to think 'well it's not just purely COPD this' so we can actually on the day that that patient comes in get a Consultant to say "we are a little bit concerned about this patient that's come for this assessment" and they will see that patient for us and advise us on do they need to go to Cardiology? Do they need to go to somewhere else?

SN11 (COPD ANS)

For the acute-based nurses, it is important to note that the Trust's community liaison service acts as an intermediary between specialist services and community generalist nurses (DNs and CMs); for example, ANSs put a request for DN support for a discharged patient through this service. Nevertheless, all the ANSs report some direct contact with community colleagues – most often DNs and GPs. The extent to which the acute-based nurses initiate such contacts themselves varies. The two specialist nurses who appeared to be most consistently and centrally involved in care coordination across sectors were both cancer ANSs – working in upper GI cancer and gynaecological cancer respectively. The other cancer ANSs also talked about contacts with community services and made occasional home visits, but did not appear as proactive in cross-boundary coordination. On this small sample it would be risky to judge whether this difference reflected personal working styles, the needs of particular types of cancer patients or the way teams were organised. It may well be that all of these factors played a

part. Overall, cancer ANSs placed a strong emphasis on understanding the patient's response to their illness, and recognised that this meant understanding what they could about the social and physical circumstances in which patients lived.

It is interesting to note that five out of seven LTC ANSs and two out of four cancer ANSs provided Pictor cases for the condition type for whom they were *not* responsible. This reflects the prevalence of cancer and LTC co-morbidities – something which is also apparent in many of the interviews across different staff groups. Such co-morbidities can raise challenges for the coordination of care within the acute sector. In some cases where specific co-morbidities are expected, there are well-established procedures to ensure the correct professionals are brought in and that different staff groups are clear about their roles. Perhaps the best example of this is with regard to the clear links between COPD services and Lung Cancer services. In other instances, the impression can be that the patient is in effect parceled up amongst different services, each taking charge of their own area of specialism, but without a clear sense of overall coordinating responsibility. The effectiveness of collaborative working in such cases can be influenced by the strength of personal relationships and role understandings amongst different specialist nurses and with other professionals.

[If] district nurses need to come they pop in, we've had GPs pop in, we've had Physiotherapists drop in because we are local and that's what we expect for our patients - to keep it all local almost streamlined and seamless which doesn't happen in a lot of areas cos they get caught up with red tape [...] we've been able to meander our way around that, because a lot of our patients' GPs are in the building so we have access to that.

SN8 (Renal ANS)

#### *How information systems impact on coordination*

The current project was not concerned with evaluating the effectiveness of information systems, and such a task would not be within the competence of the research team. However, it is important to examine the perceptions of the staff we interviewed about the way in which information systems – both electronic and paper-based – impacted on collaborative working.

A strong impression from interviews across many different professional groups is that at the point we were carrying out this study there was considerable change happening or about to

happen in information systems. This included large scale changes, such as the implementation of a new national IT system within Community services. It also included much more localised changes – for example a system to ensure better information-sharing between hospital wards and community matrons. Responses to such developments were very varied, and of course related to details of specific systems and how they were integrated (or not) with specific job roles. However, there did appear to be some general patterns in how participants reacted that were not purely a product of these particularities. Those who are optimistic about recent and/or forthcoming developments in information systems tend to point out how these have a direct bearing on improving collaboration in their day-to-day clinical work. For example, one CNS describes the recently-acquired ability of her team to access hospital electronic patient records (EPRs) as “a massive change that made a huge difference” (SN5). The community matron who discussed the improved system of liaison between hospital wards and her service says:

It's only just started up and running, but it's working, and it's the fact that they [*patients on, or appropriate for, the CM caseload*] are actually logged on the IT system, before we actually get them. We get a written referral and the team in the hospital makes sure that the referrals are not only appropriate but that they've got all the information we need as well. So you get good quality referrals through, and it tends not to be people who don't meet our criteria...

CM7

In addition, participants who were positive about information system developments almost always said that they had been involved in – or consulted about - the planning of them, or at least that there had a proper assessment of the relevant information requirements for their role. The decision to allow CNS teams to access to hospital EPRs mentioned above emerged from a working party of which the nurse we quoted was a member. A Cancer ANS describes an improved system for communicating with GPs about discharged patients as an initiative rooted in her team's examination of their practice:

I think it came on the back of peer review, to be honest [...] so we developed a proforma fax that goes straight off to the GP's surgery and it's got my contact number or the key worker's contact number, and we've just started to get a few more GPs ringing us up...

## SN19 (Urological cancer ANS)

Contrasting with examples such as these, we found at least as many instances where staff were pessimistic and quite often cynical about developments in information systems. In these cases, participants described new or changed systems whose benefits for clinical practice – including collaborative working - were not evident, and might even hamper day-to-day work through additional demands on staff time. This was often coupled with a sense that systems were imposed without consultation or proper consideration of the roles of those affected. Discussing the local roll out of a new national NHS IT system, one participant describes an “us and them” situation between the managers and IT experts responsible for designing the system and overseeing the implementation, and the district nurses who will have to use it.

I do think it's an IT system for commissioners and other people, rather than for actual clinicians on the ground, or for the Government or whoever wants the numbers, rather than, you know – they've not done it for “this'll make life easy for you [i.e. clinical staff]” but it's “this'll give you this report”[...] I think the moans will come once they've [i.e. DNs] been trained up, because they're promising us jam tomorrow, you know. And at first we'll have to do *this*, but it will be able to do *this* – but when?

DN Locality Manager

A further issue that emerged in our analysis as a source of dissatisfaction related to information systems was a sense of inequity in access to information. This is potentially damaging to collaboration: if one staff group feels that others it works with have privileged access to information there is a danger of suspicion and mistrust, alongside practical problems stemming from the fact that they do not share the same informational resources. In the present study, expressions of this sense of inequity almost exclusively came from district nurses. They complain that they often had to “go in blind” because of failure to pass on information about patients referred to them. This is in contrast to other colleagues working in the community who are perceived to have greater access to patient information:

I'm sure the GP gets a lot of information that we never see – well hopefully they do – and that would be extremely beneficial if we got the same channel of letters and communication that they did, because we do 70% of the time go in blind.

DN2

We don't have any access to patient information unless we wanted to go into a GP surgery and look in their case notes – we don't have computer access to anything [...] I know that sometimes the *[Community]* Matrons have access to blood results and that, and I think that would be beneficial sometimes, yeah.

DN3

### *Co-ordinating care across boundaries*

The difficulties in communication and care coordination across boundaries in the NHS – and between the NHS and social care – are widely recognised, both by policy-makers and researchers. Reference to “boundaries” here includes both geographical boundaries and boundaries between sectors (community and acute, health and social care, and so on). Often these overlap; for instance, when a patient on the caseload of a DN team is referred to a hospital outside the geographical area in which the team works. In some respects this setting has advantages in comparison to many other areas of England and Wales in that its population is largely served by a single PCT (now Community Foundation Trust), a single Acute Trust, and a single local authority's Social Services. Nevertheless, its location in a large conurbation means that it shares borders with many other organisations and authorities, which inevitably necessitates cross-border collaboration for some patients.

Our focus here is on how cross-boundary issues impact on the day-to-day experiences of collaborative working of our participants. Perhaps the most immediately evident aspect of this is that cross-boundary co-ordination simply creates more work for the professionals involved. Problems with information systems are often greater across boundaries, and where staff are liaising with organisations with whom they do not have regular contact there are likely to be fewer opportunities to draw on existing relationships to facilitate collaboration. Processes and procedures can be unfamiliar and experienced as unhelpful. A good example of the complexities

that staff can face when trying to coordinate across boundaries –and the effort involved – comes from one of the community matrons, discussing a patient with Parkinson’s disease.

The complication with *[name of patient’s]* care is that he is under a consultant at *[name]* Hospital, which is out of our area, so the community matron that deals with *[name of town]*, for Parkinson’s, won’t see him, because he’s out of the locality. The Parkinson’s nurse who has to deal with *[name of hospital]*, she won’t visit him cos he’s out of the locality, so the only liaison we get with the Parkinson’s nurse, is if *[wife]* takes him to the hospital to *[name of hospital]*, then we try to liaise with *[name of nurse]* who then will set up a meeting when they’re there [...] it’s me really that does all the liaising and I think if they hadn’t had me, then perhaps they wouldn’t be on this path, journey. They certainly wouldn’t be on that as quickly.

CM1

A district nurse describes the impact of a change in the organisation of her service, and the initiative she had to take to mitigate the effects of the boundaries this had created:

When I started work we used to be GP attached so like here I would see every, all their patients and nobody else’s but obviously we’ve moved to geographical working now, so some of the patients that belong to this practice are out of our boundary so other nurses see them and that’s when the communication’s not quite as good [...] I have actually devised like a form for when the nurses go out to do the visits they fill in the main things and then they fax to the district nursing team that is involved in their care you know to go to, when they go to the GSF meetings, the Gold Standard Framework meetings.

DN11

The procedures and processes that participants had to follow in order to work collaboratively across boundaries were quite often experienced as unhelpful. As in the previous quotes, staff often had to be willing to be flexible and take initiative to ensure patients could get appropriate care as promptly as possible. A Community Diabetes Nurse Specialist describes a case where both she and a hospital consultant had to go to some lengths to enable a potentially very ill patient to get admitted:



I was very concerned; he looked for all intents and purposes as if he was going to die in the office that I had him in. I was very concerned about him so I rang the Hospital, and was fortunate enough to actually speak to the Gastro Consultant, I made myself quite clear that the man was very, very poorly and I thought he was dying, he actually got up the blood results on the Electronic Patient Records in the Hospital and looked, because I'd actually got some bloods done before he'd come to clinic, and his liver function tests had rapidly deteriorated. The Consultant said, "well all you can do is get his GP to refer him to me", so I said "well can you not take the referral from me because I am really concerned, I think you need to see this man today" and he said "no I can't take the referral from you, basically you're a Nurse. He would have to see his GP." So I rang the GP Surgery, got him an urgent appointment that afternoon to see the Doctor, meanwhile the Consultant had actually done a letter to the GP as well, [...] the Consultant had very kindly done a letter to state my concerns and the rapid deterioration of his bloods. So the Consultant faxed the GP, I rang the GP, and also faxed a letter, the patient went in later that day to see the GP who was quite shocked that I was so concerned, but, quite severely shocked at the rapid deterioration of the patient. So the patient was then admitted by the GP to Hospital.

SN3 (Diabetes CNS)

This case shows that difficulties in cross-boundary working can have a direct impact on patients' treatment and support. If the professionals involved had not been willing or able to put in the effort to work around the system, this patient could have been delayed in receiving treatment, to potentially disastrous effect. Similarly, a nurse working on a cancer ward explains how limitations in the coordination of care with GPs for discharged patients can affect the quality of care they receive:

When the patients have had their chemotherapy they're out in the community and they're dealing with the side effects of chemotherapy and they can ring us, that's not a problem, and we will try to offer advice over the telephone but it would be nice if the GPs had more of an input in that and you get patients coming in saying "well the GP didn't know really what to do with me, and he didn't think about this". Say, for instance, we've had a couple of patients who've gone into the GP surgery unwell with a pyrexia possibly in the neutropenic phase of their treatment and the GP told them to take paracetamol and sent them home. So that could be fatal for patients who had the possibility of developing neutropenic sepsis by masking the temperature with paracetamol and not having their bloods checked to make sure they're not neutropenic or having an admission into hospital if needed.

Ward Nurse 1

Examples such as these highlight aspects of organisation that can hamper or complicate working across boundaries. In addition, several participants felt that collaboration was sometimes inhibited because of political issues within and especially between organisations. One CNS describes setting up regular meetings with her acute-based colleagues working in the same speciality, to help get over the "never the twain shall meet" attitude that she felt prevailed when she took up her post. Despite initial success and enthusiasm, she felt the initiative was undermined by politics above the level of individual clinicians:

Initially we met every month and then it went down to quarterly, to look at respiratory as a whole and have input really across [*boundaries*]. Now, that was sporadically attended and it was I think, how can I put it, I think there were different agendas being brought to it - different political agendas - as in, you know, whether people wanted to work jointly or if they didn't want to work jointly.

SN 5 (COPD CNS)

This story is corroborated in an interview with one of the COPD ANSs:

*Specialist Nurse:* The idea was that we'd work integrated between each other, you know, we'd cover each other, they could come and work in the Unit, we'd go and work out there with them, perhaps run satellite clinics, so we would have the chronic management, they'd have the acute management, because the acute and chronic management for COPD's totally different, you know, but we'd all have our skills up-to-date in both areas so we can cross-cover really, didn't work like that, they're very much on their own, very much.

*Interviewer:* Why did it not work, because that just makes sense?

*Specialist Nurse:* The managers, it was the managers.

*Interviewer:* Two different managers?

*Specialist Nurse:* Two different managers, we had our manager here and they had their manager and we had different operational managers as well, so never the two met. [...] So they do what they do, we do what we do, we communicate, scantily, you know, we do send them a fax of all our patients that we want them to follow-up but we don't get any feedback, you know, and it's very much them and us, at the minute which is a shame, isn't it? Because it would run so much better.

SN12 (COPD ANS)

Political barriers to collaboration could be intractable because they stemmed from issues of power and finance at high levels in the organisations involved. One manager emphasises the differences in power and resources between the acute Trust on the one hand and community services and local authority adult social care on the other:

It's a much bigger organisation [*the Acute Trust*], it's in its own right it's a business, whereas the Community has always been an arm of another organisation and they've never had the level of autonomy and basically the Acute Trust, I mean, there is a suggestion that acute trusts do drain economies so they've had a lot more power in the past. In terms of the Local Authority we only work with adult social care so for them it's not their, that part of the organisation's core business, the Local Authority in itself is a much bigger beast - they've got bigger fish to fry so they're not really bothered in that respect round who's got the power and who's got the control, they just get in, do the job, deliver, respond. But I think the biggest challenge is between the two health organisations,

but it does reflect the fact that one is bigger than the other and bigger organisations quite often subsume smaller ones so that's one thing.

Manager

Finally, politics on a national scale had an impact on the way many participants thought about future collaboration. The White Paper that announced the current NHS reforms was released early in the course of this study, and provoked considerable uncertainty and often anxiety about the future of local services, including future collaboration across boundaries. Indeed, some feared that a proliferation of GP Consortia could create new boundaries:

It will interfere dramatically; it will have a dramatic effect because we won't be talking to one commissioner, we could potentially be talking to eight consortia who will want vastly different things for their area.

DN Clinical Lead

I think communication is gonna get tighter. I think there's – I've seen it already – sharing of information is drying up and people are becoming very protective of what they've got.

SN5 (COPD CNS)

Concerns about the particular changes to the NHS being proposed were compounded by a general sense of weariness and disillusion with change:

It's only been two years since you had a shake-up before – PCTs amalgamation happened about the same time, didn't it, as a change around? And now we're going, you know, into another world of change again, and I think for staff it's difficult sometimes.

DN Locality Manager

### **3.3 Survivorship in concept and practice**

In this section we will consider how our participants understood cancer survivorship and issues related to it. We will look first at the extent to which they see cancer as now having characteristics in common with long-term conditions, before examining the nature of professional roles with cancer survivors.

### 3.3.1 Cancer as a chronic condition?

Central to the case for a concept of “cancer survivorship” is the argument that longer survival times for cancer patients mean that the illness for many people is no longer a matter of “kill or cure”. Equally, the need for professional care and support is not restricted to initial diagnosis and treatment on the one hand, and end of life care on the other (e.g. Artherholt & Fann, 2012). In these respects, cancer can be seen to share characteristics with chronic conditions. This is, of course, a simplification: within both of these illness categories, expected disease trajectories vary enormously. All the same, if professionals were buying into the notion of survivorship, we would expect them to recognise parallels between cancer and LTCs.

What we see in our interviews is a very varied picture. Some staff are very comfortable with the notion that cancer is increasingly like a long-term or chronic illness, while others reject the idea outright. Many appear to be between these two poles and are somewhat uncertain or ambivalent about the status of cancer in this respect. One of the main ways in which cancer patients are seen to be different from those with LTCs is in terms of the perceived curability of cancer.

The vast majority of patients have this curative thinking – which is a good thing because otherwise what is there to live for as far as these people are concerned? So they do not look at it as a long-term condition, it’s a curative phase that “I’ll get better soon”.

DN2

One day I went - it was only just when I’d been diagnosed and I was quite upset - and I said to her [*GP receptionist*] I said “I don’t know what’s the matter with me” I said, “I’ve had those cancers” I said “and it didn’t bother me, I just got on, I coped with it and I got over it but” I said “this diabetes has knocked me for six”. And she very wisely said “well” she said “you had a hope of the cancers being cured, you’ve no hope of the diabetes being cured” and I thought that was a very wise statement, you know, and that was, that probably was the reason.

LTC Patient (Diabetes)

In keeping with the patient experience highlighted in the quote above, there was quite a widespread view that cancer patients had advantages over those with LTCs. These included easier access to benefits, continuing care packages, and at end of life to palliative care. Some also mentioned a more intangible sense of cancer attracting a more sympathetic response from society as a whole than LTCs.

Any patient who's dying we can access continuing care, we can fast track them through, but when you look at it more, it's supposed to go on a needs basis, but actually there's a thing on the continuing care, if they've got a cancer diagnosis, it goes straight, I wouldn't say they always get it, but they do seem to get it funded more so than these long-term conditions patients, but the problems are the same. Pain, breathing, mobility, everything's the same, it's just the diagnosis is different at the end of the day.

CM5

We always say our COPD patients have got a terminal illness, long term illness, but it's going to get them in the end. Lung cancer patients are the same but unfortunately the Lung cancer patients are quite rightly streamlined into the benefits system where they get benefits under special rules and things like that, whereas COPD patients don't. Because no-one can put an approximate date of death on so no-one is prepared to do that, but our patients miss out then, they miss out on the extra benefits that quite rightly you should get, but our patients don't get them.

SN12 (COPD ANS)

I think there's a difference in general public perception of needs of patients [*i.e. between LTC and cancer*] - for patients that have got cancer and their needs that they've got for like palliative care and specialist care, I think the same needs should come into play for the patients who do have long term conditions such as heart failure - which *is* terminal care but doesn't always get the same kudos as cancer does, as cancer patients.

SN13 (Heart Failure ANS)

### 3.3.2 Professional roles with cancer survivors

All the professionals we interviewed were familiar with the term 'survivorship' in reference to cancer patients, though understandings of the term varied widely amongst individuals, even within the same professional groups. Specific developments in practice linked directly to survivorship were limited: as one manager acknowledged: "...as far as addressing it [*the survivorship agenda*] we haven't done anything, you know, I'll be completely honest with you" (OK11, Cancer Lead).

One potentially important initiative which can be seen as stemming from concerns about survivorship was the requirement that district nurses make contact with all newly diagnosed cancer patients:

[*Any cancer*] referral will come through to us and at the moment the Trust have put a policy in that we do contact every single newly diagnosed patient

DN6

Any new cancer diagnosis comes to the district nurses and then we normally make telephone contact, and a lot of people don't need us, but they'll have a telephone number to ring if they *do* need us for anything.

DN3

This referral process was not always felt to have been fully embedded in terms of transfer from acute to community care.

Sometimes people don't know who to refer to or they forget to refer people to us, that's a big breakdown in communication, from hospital terrible communication, you know like people get sent home that need things and we won't get to know about them, cancer patients slip through the net, they get diagnosed, sent home and we don't know about it.

DN4

I think that's something that we probably haven't been doing in terms of ticking that box, certainly I would say the more advanced ones that we refer to palliative care automatically are referred to district nurses but every patient with a new cancer diagnosis at the moment doesn't get referred to the district nurses and without really looking into that, erm, I don't know what all district nurses think about that whether, because you'd have a lot of people referred to them.

SN19 (Urological Cancer ANS)

The policy of referral from diagnosis was described by managers as a welcome move but the role their staff were expected to play with such patients seemed poorly delineated and not well understood by district nurses themselves. Many described the early referral of patients as needlessly adding to their caseloads, and as a source of confusion and potential concern for patients themselves. Managers recognised that there continued to be problems with the implementation of this policy:

We get a lot of new referrals from GPs because they have to notify us of any new cancer diagnosis which has greatly increased our caseload for cancer patients even though they may not need us because there are no identifiable nursing tasks ... They (GPs) just see cancer - refer - cancer - everything comes to us and the patients don't really ... I'd say out of the ten that I have phoned, seven didn't want to know, they didn't want to know a district nurse, they didn't want to see the uniform, they didn't want the neighbours to see them coming round.

DN2

We're now getting patients referred when they've got a diagnosis of cancer, and we've fought long and hard for this to happen, because it wasn't, we were just getting them at the end and others were keeping them, nobody else was visiting, it was just that they weren't getting the support. Now it's gone the other way, we're getting everybody and some patients we're finding they don't like it, because they've been told, well they've had cancer but they're clear, so why's the nurse ringing me up, and they're getting worried [...] if you had a breast lump and it's fine and everything's OK they actually don't want the nurse to visit because they're OK, so we've gone perhaps too far now.

DN Locality Manager



One carer of a cancer patient reported the involvement of district nurses after her husband came out of hospital, but did not feel able to call them with queries or concerns once they were no longer attending for specific nursing tasks:

When they stop coming they're not there for you to ask questions, they just stop coming and you're sort of switched off after that, you know, you couldn't ring them and say, "well this is a problem" and say, "is this right?". No, I found that once they'd done their job that was it and they were on to the next patient.

Carer (Cancer patient)

There was a strong sense that the main purpose of early referral was not to address survivorship issues per se. Rather, managers perceived it as a way of ensuring a relationship with patients had already been established before they reached end of life care:

For the last few years we've been trying to get referrals from a very early stage, whereas I would say when we first came onto the community in '93 we were getting them more towards the later stages of life, right at the palliative care end, whereas now we're trying to actively encourage GPs and the hospital to refer patients as soon as they've got a diagnosis so we can build up a relationship with that patient and the family so we're not getting to a home in the last stages of life and it's harder to build up that relationship.

DN Locality Manager

District nurses were generally unclear as to the purpose of their involvement with cancer patients in the community, unless it was specifically for palliative nursing needs or for particular nursing tasks, and most saw themselves as only playing a significant role in the care of cancer patients towards the end of life.

*District nurse:* As soon as a patient is diagnosed we get the initial referral from the doctor just as information only, we have to keep files and we put that referral in there and then as the patient's condition changes and it deteriorates then they'll send us an update, but really we only get those referrals when they're coming to end of life, when they start having lots of problems

*Interviewer:* So really you're not in the cancer survivorship side?

*District nurse:* No

DN15

*Interviewer:* Do you think cancer patients can be described as long-term condition patients?

*District nurse:* No, I don't actually, no, I think they should come under the palliative care bracket

*Interviewer:* Even if they're not in the palliative care phase?

*District nurse:* Then they wouldn't be on our caseload

DN2

It should be noted that not all the DNs we interviewed expressed this view so unambiguously, though there was really only one who overtly described a proactive engagement with cancer survivors unrelated to specific nursing tasks. This might just represent her personal view, but her use of "we" suggests that perhaps her team as a whole is particularly engaged with survivorship:

We never discharge a patient who's had cancer we always keep them on our caseload and once they've actually gone into remission and they've actually had the all clear we ring them periodically to make sure that they are ok and that they don't need any intervention and we offer them, the case is still open if they've got any problems they can phone us whenever they need to and we never, we never discharge them.

DN14

In the community setting, a case management role is assumed by community matrons in the care of long-term condition patients (demonstrated by the high number of arrows on the Pictor charts produced by this participant group). This role seemed to have no obvious parallel in the care of cancer patients. As we have observed, district nurses are uncertain of their role with cancer patients prior to end-of-life, and would struggle to cope with the caseload implications of a significantly greater involvement. Community (i.e. hospice) based PCSNs too are seen by other staff as focused on end-of-life. Unfortunately we do not have data directly from this group, though it is worth noting that one of the reasons they gave for declining participation was that they were "not involved with survivorship". community matrons do get involved with cancer

patients, as evidenced by the fact that almost all of our participants provided a cancer Pictor case as well as a LTC one. Furthermore, CMs' cancer and LTC Pictor charts did not differ substantially and consistently in how they were formatted and the number of agents included on them, suggesting that the kinds of collaborative working demands are not significantly different in across disease types. However, as discussed in section 3.2.3 above (Coordinating Care) while community matrons did case manage some cancer patients, they did not see this as a core part of their role. The absence of a role with clear responsibilities for cancer survivors in the community might explain why the cancer specialist nurses in the acute sector felt the need sometimes to take on coordinating responsibility for patients that may have been beyond a strict definition of their role:

We have phone calls [*from patients*] – “we’re struggling with this” and then we intervene with the district nurse “listen, they’re struggling with this, this and this” but we seem to have that relationship with the patients, I don’t know how come but I think it’s because we’ve met ‘em right at the beginning and we’ve done a lot of big impact interventions at the beginning so that relationship then follows through don’t it? And they remember that first person, don’t they? [...] Sometimes we’ll liaise for ‘em cos it’s easier for us to do that in’t it? Which is not always right for us, but sort of you get caught up a bit in it don’t you? But if they need help, they need help, don’t they?

SN17 (Upper GI cancer ANS)

As the previous example illustrates, specialist cancer nurses attribute considerable importance to the support of cancer survivors and to the need for professional follow-up of cancer patients who are not at the end of life. This final quote from a gynaecological cancer ANS illustrates the position well:

I think you can feel very lost and very vulnerable stuck at home without any contact. It’s almost like a safety net really that you’re ok as long as you know there’s somebody you can call if there’s a problem and I think that’s the difficulty that we have with the district nurses really, particularly when you discharge from the wards and they say “but they don’t need anything” and you say “yes, but they’re out there on their own and they need to know that there’s somebody they know they can call” [...] the difficult bit is the first year or two

and then the further away they get from being diagnosed the better they feel in terms of distance means the chances of it coming back are less and less. Certainly and quite understandably their lives are never ever the same again, issues like that you know, some of them that are off on holidays and all sorts of things, a totally different perspective on life. I think there's an element particularly within families which is understandable "well you know that's done, it's dusted, forget about it and move on" and it's not always easy for the patient to do that, you know, they've still got that hanging over them, if their big toe hurts they'll worry then is the cancer coming back and it's understandable and that's why we as a team try to make ourselves quite accessible - that if they've got a concern just ring up, come and let *us* tell you it's nothing.

SN14 (Gynaecological Cancer ANS)

## **4. DISCUSSION**

This has been a large and complex qualitative project, addressing a wide range of issues relating to collaborative working in the nursing care of cancer and LTC patients. In this final section, we will draw together the main lessons learned in relation to our three research questions and consider what they imply for practice, policy and future research.

### **4.1 What helps and hinders effective collaborative working for generalist and specialist nurses?**

Our findings highlight many factors that impact on the experience of collaborative working for generalist and specialist nurses. These principally include:

- Interpersonal and inter-team relationships
- Role understanding
- Professional identities
- Communication issues, including the effectiveness of information systems
- Organisational structures and processes within the NHS (locally and nationally)
- The political context of NHS changes
- Wider societal attitudes towards and understandings of cancer and LTCs

Such findings are in keeping with previous research, and illustrate the multi-level nature of the phenomenon (e.g. San Martin-Rodriguez et al, 2005; D'Amour et al, 2008). The quality of collaborative working in any one instance may be influenced by whether two professionals work in adjacent offices, whether information systems allow them to access the same details about patients, the decision-making autonomy they are allowed by their organisation, and political imperatives to change how services are commissioned. With such a range of factors operating at many different levels, it is not surprising that the task of improving collaborative working is a difficult one. Large-scale, top-down interventions are likely to generate unintended consequences once they hit the particularities of specific settings. Locally-focused, bottom-up interventions can find themselves derailed by intractable organisational and systemic forces

If enduring and effective collaborative working requires all these levels to be addressed effectively, this might sound as if our findings offer a counsel of despair for those concerned to make things work better for patients on the ground. Against this we would argue that while our findings do show the broad range of influences on collaborative working, they also strongly make case for the centrality of relational factors. Without the need for direct prompting from us as interviewers, participants repeatedly emphasised the importance of personal relationships in their experiences of collaborative working. Good relationships enabled them to get round some of the organisational and systemic inhibitors to collaboration, be they geographical or sector boundaries, limitations of information systems or issues of power and authority linked to professional identities. Equally, even where enduring relationships did not exist, the quality of *relating* between professionals could make a significant difference. (Note that we use the notion of “relational” here to cover both *relationships* as ongoing personal connections between individuals and *relating* as the process of personal interaction.)

We are not suggesting here that all the influences on collaborative working can be reduced to relational issues, nor that attempts to improve collaboration can neglect any higher-level considerations. Quite clearly, collaboration can fail despite good personal relationships when all the other factors are stacked against it. What we would argue is that relationships and relating are the core of collaborative working, and as such all those concerned with this phenomenon – researchers, practitioners and policy-makers - should view it through a *relational lens*. This is a different position from that of previous writers such as D'Amour et al (2008) who, as we have

seen, stress the importance of relationships but see them as one of a range of factors. We take the view that whatever the level at which an intervention or change is made, its impact on relational issues must be taken into account. In particular, when changes to services and/or organisations are proposed, people should ask the question: “how is this likely to impact on relationships amongst the professionals involved in delivering services, and between professionals and patients and their families?” All too often in the NHS this question has not been considered, and changes have proved harmful to effective collaborative relationships. The tensions between community matrons and district nurses when the former role was introduced are a prime example of this (King et al, 2010).

Our research has not only confirmed the key role of relational issues in collaborative working; it has also shown those aspects of relationships and relating that are of particular importance. We have seen that effective collaborative work is associated with how accessible and available other professionals are seen to be, by relationship longevity and the existence of a shared job history, by a sense of mutual respect and the perception that people are willing to “make an effort” to work together. A preference for face-to-face interaction emerged very strongly; something that has been found in previous research not only in health and social care but in areas as diverse as aerospace engineering (Mark, 2002) and economic geography (Storper & Venables, 2004).

#### **4.2 How do experiences of collaborative working in relation to cancer patients compare with those relating to LTC patients?**

In terms of the kinds of factors that impact on the effectiveness of collaborative working, both the Pictor chart and the interview analyses suggest that there are no real differences in what makes for good (or bad) collaborative working according to whether the focus is on cancer or LTC patients. In particular, the argument that relationships are at the core of collaboration absolutely holds true regardless of the type of condition under scrutiny. However, the detail of who is involved and what they do for patients does differ in significant ways between condition types, and this has an effect on experiences of collaborative working. These differences reflect aspects of service organisation and also wider societal perceptions of illness.

Organisationally, perhaps the most striking difference between condition types is with regard to the nursing services available to patients in the community. LTC patients may have input from CNSs, community matrons, district nurses and practice nurses. In contrast, cancer patients have

contact with district nurses at diagnosis, and again at end of life, alongside community PCSN input. A minority will have some involvement with a community matron, but only if they have LTC co-morbidities, or someone (probably a GP) has recognised the value of CM input for a particularly complex case. This situation can be seen as a reflection of the historic “kill or cure” view of cancer, which appears to remain an influence on many of our participants. Cancer survivors for much of the time do not require the same kind of task-based nursing involvement that is received by many LTC patients with their typical trajectory of exacerbations and recovery. However, growing research on survivorship shows that cancer survivors may well have care and support needs, especially with regard to the psychological impact of the disease and the late effects of treatment (recent examples include: Curico, Lamb, Schneider & Khan 2012; Grover, Hill-Kayser et al 2012; Loerzel & Aroian, 2012). Psychological issues are well-recognised by cancer specialist nurses and also by community service managers who are starting to wrestle with the challenge of how to translate such awareness into practice. Our findings suggest that cancer ANSs do try to fill the gap in support for cancer patients in between those episodes of intensive involvement around diagnosis, treatment and the referral on to palliative care services at end of life. However, the nature of their links with the community sector, and the demands of their workload within the acute sector, limits what they can do.

Underlying the ways in which the NHS deals with cancer and LTC patients are long-established societal views of illness. The reference by one of our LTC specialist nurse participants to “the kudos of cancer” is telling here. It remains the case that cancer has a grip on the popular imagination unequalled by chronic illnesses such as diabetes, COPD and heart failure (Goreb, Brophy & Greenstone, 2000; Traue & Ross, 2005). This translates into charitable support and prioritisation by policy makers: thus we see policies to ensure rapid investigation of suspected cancer cases, extensive and highly specialised services in secondary and tertiary care, and very well-known and well-developed support organisations in the voluntary sector (including of course Macmillan). This wider context may help explain why our cancer patients and their carers –despite the gap in community support – were notably less likely to complain about the services they experienced than the LTC patients and carers. Such deep-seated common perceptions of cancer in comparison to other illnesses will not be easy or quick to change. The small contribution that research such as ours can make is to emphasise that when we look at collaborative working to support seriously ill patients, there is a great deal in common across

disease types in what helps or hinders good practice. Sharing of lessons learned across divides between cancer and non-cancer is to be encouraged.

### **4.3 Developing services to support cancer survivors**

The discussion above draws attention to the two main areas relevant to cancer survivorship. Firstly, there was a limited recognition amongst many staff of survivorship issues – or at least, recognition of how such issues were relevant to their roles. Secondly, there is a gap in services for cancer patients within the community outside the end of life stage, other than a rather undeveloped attempt to provide support after diagnosis through district nurses. From our own previous research and knowledge of other services, we feel it is unlikely that these limitations are simply the product of local circumstances. This therefore raises the question of how cancer survivors can be better supported in general. Our study cannot provide definitive answers to this, but viewed in combination with previous research it does help to inform the available options. Broadly speaking there are two strategies: to extend existing roles or to introduce new roles. Starting with the former, the likely pros and cons of extending particular roles are summarised below.

*District nurses:* They are very well-established as a community service, recognised by both patients and professionals. They also have existing skills and knowledge regarding cancer care, though mainly with a focus on the palliative stage. Capacity would be an issue for all groups, but DN services seem particularly stretched – and this does not appear to be a situation unique to our setting (see Meehan, 2010, for discussion of these issues). The task-based nature of the current DN role is also a potential barrier to effective involvement in survivor support – as this study has found regarding the attempt to involve DNs at diagnosis. That said, our own and other previous research suggests that many DNs would welcome the opportunity to become less task-focused.

*Community matrons:* The main arguments for greater CM engagement with cancer survivorship are that they have case-management skills and are not task-focused. Some are already involved with complex cancer cases before the very end of life. However, a more general role in cancer survivorship would require a major redefinition of what is expected of CMs, away from the focus on maintaining patients with multiple co-morbidities at home. Some CMs might lack confidence in dealing with cancer patients if they have had relatively little training in the area, though most



of our interviewees did not express this concern. It is interesting to note that just as our study was ending we learned that responsibility for CMs was passing to the Acute Trust. We are aware of this happening in other locations as well. The implications of this for any increased involvement in cancer survivorship are unclear, but it could be problematic if it leads to an even greater focus on preventing LTC repeat admissions as the over-riding purpose of the CM role.

*Acute nurse specialists:* Cancer specialist nurses have some very clear strengths with regard to an expanded role in survivorship. They have excellent understanding of specific cancers – and it is important to recognise that there are likely to be differences in the challenges faced by survivors according to the type of cancer they have had. For example, research by Maughan and Clarke (2001) found that clinical nurse specialist interventions had a significant effect on sexual functioning and quality of life in gynaecological cancer. The major challenge would be to strengthen acute-based cancer specialist nurses’ understanding of and links with community-based services – and of course the organisational and commissioning implications of working across the acute/community boundary. There is also a danger that they could be seen to be “stepping on the toes” of existing community services.

A further group who might be considered for an expanded role in cancer survivorship is Practice Nurses. Although we did not include them in our sample, many of our participants referred to their involvement with LTC patients – and for some this included case management responsibilities. There does seem to us to be some potential for extending this option to cancer patients, especially with regard to the more highly skilled Nurse Practitioners employed in some practices. The challenge, other than the ubiquitous one of finding capacity, is the difference between the more holistic support role that cancer survivors may need and the typical duties of most Practice Nurses in routine monitoring and advice on LTCs. Macmillan have recently supported the development and implementation of training for Practice Nurses to enhance their role in the support of cancer patients (BMJ Learning/Macmillan, 2012).

Research on survivorship, and more widely on cancer care services, can provide some good indications as to how one might design a new nursing role to support cancer survivors. The possibility of designing such a role from scratch, rather than facing the challenges of expanding existing roles as described above, has a strong appeal. Ideally such a role would encompass an excellent understanding of cancer and its effects – physical, psychological and social. It would

require skills in liaising with other services across sectors, and strong interpersonal skills for working with patients and their families. Naturally there would be significant organisational challenges in implementing a role like this, not least in spanning the acute and community settings, but there are also other reasons for caution regarding the new role option. Above all, the impact of new roles on existing networks of relationships amongst professionals needs to be taken seriously. As with the expansion of acute roles into the community, a new role of this type can very easily make people feel threatened, and staff in the new role could face suspicion or even hostility. The experience of the introduction of community matrons can offer a salutary lesson here (King et al, 2010).

We are not in the position, on the basis of this research, to make a firm recommendation for one of the above options – and it may well be that there is not a one size fits all solution for the NHS as a whole. Our aim is simply to highlight the likely pros and cons of different ways of addressing the need for survivorship support in the community. Whatever strategy is adopted, we would stress the need to give importance to facilitating good collaborative working, and as we have argued above, this means keeping in focus the relational essence of collaboration.

#### **4.4 Implications for practice and policy**

In the light of our findings, the wider literature and the discussion above, we would suggest the following points for consideration by policy-makers, managers and practitioners. We have focused here on implications that are likely to have wide relevance within the NHS, rather than those that may be particular to the setting of this research.

- For those involved in designing and implementing change at any level in services for cancer and LTC patients, it is important to think carefully about the impact on relational aspects of collaborative working. One possibility might be to carry out something like a “relationship audit” prior to implementing change – mapping out the networks of relationships that are important to the way particular services function. The Pictor technique and similar tools could play a useful role in such an exercise. We would also recommend that special attention is given to the value placed by staff on face-to-face interaction on collaborative working. In financially straitened times opportunities for this may diminish as workloads increase and managers understandably seek

“efficiencies”. However, such things as occasional joint visits by generalist and specialist nurses can have great benefits in terms of relationship building as well as sharing of knowledge and skills.

- There needs to be more sharing of knowledge between nurses who are mostly involved with cancer patients and those mostly involved with LTC patients (we mean this more broadly than just condition-specific specialist nurses). This could help to facilitate better coordination of care for those patients with both cancer and LTC co-morbidities, who at present can find themselves “parcelled up” into different illness components without a clear sense of who has an overview of their whole experience. Such coordination needs to be determined in a flexible way, responding to the circumstances of the particular patient.
- It is dangerous to assume that because the term “cancer survivorship” is becoming common currency in health care, staff necessarily have a good understanding of its implications for their practice. Without thorough education, there is a danger that initiatives to promote the survivorship agenda can be seen as “tick-box” exercises whose purpose is not understood – as appeared to be the case for many district nurses with regard to the policy that they contact all cancer patients on diagnosis.

#### **4.5 Implications for future research**

This study has raised numerous potential topics for future research. The list below is by no means exhaustive, but it does represent issues that appear particularly pressing to us.

- More research is needed to examine the nature and quality of relationships and relating in collaborative working for cancer and LTC patient care. In particular, research investigating relationship networks over time would be valuable. Specific topics could include: how relational networks are built and maintained; how conflicts are managed; how organisational, systemic contingencies impact on inter-professional personal relationships. In the longer term, the impact of such relationships on patient care should be systematically examined.

- As the survivorship agenda grows in influence, research needs to examine the knowledge and understanding of different staff groups, especially with regard to how it relates to their everyday practice.
- Linked to the previous point, research is needed to examine health professionals' personal perceptions of cancer and long-term conditions, and how this relates to their understanding of their professional role. We emphasise the "personal" here – we believe this may well be quite distinct from clinical or technical knowledge about conditions and their management and treatment.
- Where organisations are changing or introducing new nursing roles to address survivorship, these need to be evaluated in a rigorous and independent manner.

In addition to the above, there remains considerable potential for further analysis of the large volume of rich data collected in our study. At present we are looking in more detail at the Pictor chart data from this and previous studies to examine how representations of experiences of collaborative working may reveal key aspects of the phenomenon within and across staff groups. Other additional analyses may include closer examination of the experiences of particular participant groups, and a more focused consideration of the impact of NHS changes – taking advantage of the serendipitous timing of the study to coincide with the introduction of the current set of major NHS reforms.

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# APPENDICES

**APPENDIX 1:  
PARTICIPANT INFORMATION SHEETS & CONSENT FORMS**

## **PARTICIPANT INFORMATION SHEET (interview - nurse)**

### **Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

You are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Our contact details can be found at the end of this information leaflet. Take time to decide whether or not you wish to take part.

### **Why is this study being done?**

Recent Department of Health policies have drawn attention to the importance of joint working between different professionals in health and social care teams. Key workers within these teams are the specialist and generalist nurses involved in the care of patients with cancer and other long-term conditions. Yet, to date, we know very little about how these nurses work with each other and with other team members to provide daily supportive patient care. This information is important because the extent to which nurses and their teams work well together is likely to impact on the quality of care provided for patients and their families.

As a result, this research study aims to

1. Find out how specialist and generalist nurses work together and with other team members in supporting cancer survivors
2. Compare the working practices and relationships of cancer support teams with teams supporting patients with long-term conditions
3. Help improve future good practice guidelines for health and social services

### **Why have I been approached?**

In this study we will be interviewing professionals involved in the delivery of local health and social care services. You have been approached because you are a nurse with experience of working with patients, carers and other professionals in providing supportive care for patients with cancer or long-term conditions.

### **Do I have to take part?**

No. Taking part in this study is entirely up to you. If you do not want to take part, you do not have to give a reason. If you do agree to take part you will be asked to sign a written consent

form. Even after this, though, you are free to withdraw from the study at any time, with no further consequences for you.

### **What will happen to me if I take part?**

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A secretary employed by the research team will transcribe the information. At this point, your name, the names of other people mentioned in the interview, and any other information that might identify you will be anonymised. We may wish to use quotes from your interview in articles and talks arising from this research. Again, we will ensure that these are anonymised.

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### **Who has reviewed the study?**

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## **PARTICIPANT INFORMATION SHEET (interview - non-nursing staff)**

### **Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

You are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Our contact details can be found at the end of this information leaflet. Take time to decide whether or not you wish to take part.

### **Why is this study being done?**

Recent Department of Health policies have drawn attention to the importance of joint working between different professionals in health and social care teams. Key workers within these teams are the specialist and generalist nurses involved in the care of patients with cancer and other long-term conditions. Yet, to date, we know very little about how these nurses work with each other and with other team members to provide daily supportive patient care. This information is important because the extent to which nurses and their teams work well together is likely to impact on the quality of care provided for patients and their families.

As a result, this research study aims to

1. Find out how specialist and generalist nurses work together and with other team members in supporting cancer survivors
2. Compare the working practices and relationships of cancer support teams with teams supporting patients with long-term conditions
3. Help improve future good practice guidelines for health and social services

### **Why have I been approached?**

In this study we will be interviewing professionals involved in the delivery of local health and social care services. You have been approached as one of the key informants identified in the design of this research as someone who may be able to shed useful light on matters relating to the provision of supportive care for patients with cancer or long-term conditions.

### **Do I have to take part?**

No. Taking part in this study is entirely up to you. If you do not want to take part, you do not have to give a reason. If you do agree to take part you will be asked to sign a written consent form. Even after this, though, you are free to withdraw from the study at any time, with no further consequences for you.

### **What will happen to me if I take part?**

Tick the box indicating “Yes, I would like to take part in this study”. Please also fill in the contact details section and return the form to us.

A member of the research team will contact you, and arrange to carry out an interview with you at a time and place of your convenience. To ensure accurate recording and so as not to interrupt the interview with note-taking, we would like to audio-record it, with your permission.

A secretary employed by the research team will transcribe the information. At this point, your name, the names of other people mentioned in the interview, and any other information that might identify you will be anonymised. We may wish to use quotes from your interview in articles and talks arising from this research. Again, we will ensure that these are anonymised.

### **What are the possible disadvantages of taking part?**

There are no significant risks in taking part in this study. We do not expect the interview to give you any difficulties or to cause you any distress. In the unlikely event that you find a question distressing, you will have the chance to ignore the question, take a break before going on, or to stop the interview.

### **What are the possible benefits of taking part?**

It is unlikely there will be any direct benefit to you from taking part in this study. However, we expect that the information we get from this study will help improve good practice guidelines for local health and social services, enabling both better collaborative working between professionals and better support of patients in the future.

### **How will my information be used?**

You will receive a summary report at the end of the study. You can also request a full copy of the final report if you wish. You will also be told about any events taking place in your area in which the results of this study are being presented.

A full report will be sent to Macmillan Cancer Support, who fund the study. The research team will produce articles about the results of the study for academic and professional journals and present findings at relevant conferences.

No names of people taking part will be mentioned in any reports, articles or conference presentations about the study. Care will be taken to ensure that you cannot be identified.

### **Who is funding and running the study?**

This study is funded by Macmillan Cancer Support and is sponsored by the University of Huddersfield. The principle investigator of the research team is Professor Nigel King from the Centre for Applied Psychological Research at the University of Huddersfield. Also working

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### **Who has reviewed the study?**

The study was reviewed initially by the Research Commissioning Group for Macmillan Cancer Support. The review involved contributions from health professionals, cancer service users, as well as academic researchers. The study has also been reviewed by the School Research Ethics Panel at the University of Huddersfield. The study was also given a favourable ethical opinion for conduct in the NHS by South Yorkshire Research Ethics Committee.

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**Thank you for taking the time to read this.**



## **PARTICIPANT INFORMATION SHEET (interview - patient)**

### **Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like to find out more. Our contact details can be found at the end of this leaflet. Take time to decide whether or not you wish to take part.

### **Why is this study being done?**

It is important that doctors, nurses and social workers work well together to give patients who have cancer or other long-term conditions the best possible quality of care. The purpose of this study is to find out how patients have found using their local health and social services during their treatment. To do this we wish to interview patients and their carers about the care they have been given from nurses and other health professionals during the patient's treatment.

### **Why have I been approached?**

In this study we will be interviewing groups of patients, carers and professionals involved in local health and social care services. You have been approached to take part because you have been identified as a patient who has been diagnosed with (enter illness here). As a patient, you have experience of using your local area health and social services. Part of this research study is to help us to better understand how patients think and feel about working with the health and social service professionals they have met during their treatment. While the study is mostly about how professionals work together, patients have very important views about how they have found using their local services. These views can help us to improve good health care practice in the future.

### **Do I have to take part?**

No. Taking part in this study is entirely up to you. If you do not want to take part, you do not have to give a reason. If you do agree to take part you will be asked to sign a written consent form. Even after this, though, you are free to withdraw from the study at any time, with no further consequences for you. The health care team looking after you will not be upset and your treatment or follow up will not be affected.

### **What will happen to me if I take part?**

Tick the box beside “Yes, I would like to take part in this study”. Please also fill in the contact details section and return the form to us.

A member of the research team will contact you, and arrange to carry out an interview with you at a time and place of your choice. This is usually done by a researcher visiting you in your home, but it could be elsewhere if you wish. We would like to tape-record the interview, with your permission.

We are also interested in the views of someone who helps care for you on an informal basis (for example, a family member or friend). For that reason, we will also ask you to suggest the name and contact details of someone who cares for you who may be willing to take part in the study as well. You may wish to talk to the person you have in mind first to find out if they would be willing to volunteer.

### **What are the possible disadvantages of taking part?**

There are no significant risks in taking part in this study. If you do decide to take part you will be asked to take part in an interview. The interview will last about 1 hour and would be carried out at a time and place of your choice.

We do not expect the interview to give you any difficulties or to cause you any distress. If you do find a question distressing, you will have the chance to ignore the question, take a break before going on, or to stop the interview.

### **What are the possible benefits of taking part?**

It is unlikely you will receive any direct benefit from taking part in this study. However, the findings from this study will help improve good practice for local health and social services. This will enable better support of patients in the future.

### **How will my information be used?**

At the end of the study you will get a short version of the final report. You can also ask for a full copy of the final report. You will also be told about any events taking place in your area in which the results of this study are being talked about.

A full report will be sent to Macmillan Cancer Support who are funding this study. The research team will write articles about the results of the study for academic and professional journals. The results of the study will also be presented at academic and professional conferences.

No names of people taking part will be included in any reports, articles or conference talks about the study. Care will be taken to ensure that you cannot be identified.

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## **PARTICIPANT INFORMATION SHEET (interview - carer)**

### **Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

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### **Why is this study being done?**

It is important that doctors, nurses and social workers work well together to give patients who have cancer or other long-term conditions the best possible quality of care. The purpose of this study is to find out how patients have found using their local health and social services during their treatment. To do this we wish to interview patients and those close to the patient about the care provided from nurses and other health professionals during the patient's treatment.

### **Why have I been approached?**

In this study we will be interviewing groups of patients, people close to the patient and professionals involved in local health and social care services. You have been approached to take part because a person close to you who has recently received treatment has suggested you as someone who may be willing to take part in the study. As someone who is close to a patient, you have your own experience of your local area health and social services. Part of this research study is to help us to better understand how those close to patients think and feel about working with the health and social service professionals treating the patient. While the study is mainly about how professionals work together, people close to the patient have very important views about how they have found using their local services. These views can help us to improve good health care practice in the future.

### **Do I have to take part?**

No. Taking part in this study is entirely up to you. If you do not want to take part, you do not have to give a reason. If you do agree to take part you will be asked to sign a written consent form. Even after this, though, you are free to withdraw from the study at any time, with no further consequences for you.

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**CONSENT FORM (interview – professional/carer)**

**Title of Project: Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

Name of Researchers: Prof. Nigel King, Ms Jane Melvin, Dr. Joanna Brocki, Mr. David Wilde

**Please initial box**

1. I confirm that I have read and understand the information sheet dated v4 - 05-2009 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without any consequences for me.
3. I understand that relevant sections of the data collected during the study may be looked at by individuals from the University and from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I understand that all information I provide will be treated as confidential, and will be anonymised.
5. I agree to the use of anonymised direct quotes from my interview in publications and presentations arising from this study.
6. I agree to the interview being audio recorded.
7. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**CONSENT FORM (interview - patient)**

**Title of Project: Unpicking the threads: How generalist and specialist nurses work with patients, carers and each other in the community to support cancer survivors**

Name of Researchers: Prof. Nigel King, Ms Jane Melvin, Dr. Joanna Brocki, Mr. David Wilde

**Please initial box**

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4. I understand that all information I provide will be treated as confidential, and will be anonymised.
5. I agree to the use of anonymised direct quotes from my interview in publications and presentations arising from this study.
6. I agree to the interview being audio recorded.
7. I agree to my General Practitioner to being informed that I am taking part in this study.
8. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



**APPENDIX 2:  
INTERVIEW TOPIC GUIDES**

## **WORKING TOGETHER TO SUPPORT PATIENTS: EXAMINING NURSES' ROLES IN CANCER AND LONG-TERM CONDITIONS**

### INTERVIEW TOPIC GUIDE (nursing/professional staff)

As is standard practice with semi-structured interviews, the list below represents the main areas that the interviewer will explore with each interviewee. The exact phrasing of questions, and the use of additional probe questions, will be responsive to the context of each individual interview.

1. Nature of own nursing role and those of colleagues
  - Grade and job title
  - Organisation of Nursing services in this work setting
  - Own main duties and responsibilities
  - How own role compares to those of colleagues
  
2. Extent and nature of own involvement with patients with cancer/ long term conditions
  - Personal history of working with these patients
  - Any formal training
  - What, if anything, do you find to be distinctive about working with this patient group?
  
3. Pictor briefing
  - Explanation of the Pictor Technique
  - Production of participant-generated graphical representation of a specific case of collaborative working
  - Explain chart – reflection on and discussion of role, identity and relationships in this case
  - What worked well in collaborative working in this case?
  - What could have been done better in terms of collaborative working in this case?
  
4. Collaborative working in general
  - How typical were the issues raised in this case?

Why do you think these issues are/ are not typical in collaborative working?

Have you undertaken any training/ development in collaborative working?

IF YES - what?

- how useful?

IF NO - would you like to?

- why/ why not?

5. The future – what would you like to see?

In terms of development of your own role

In terms of development of the service for which you work

In terms of development of collaborative working arrangements

## **WORKING TOGETHER TO SUPPORT PATIENTS: EXAMINING NURSES' ROLES IN CANCER AND LONG-TERM CONDITIONS**

### INTERVIEW TOPIC GUIDE (patients/carer)

As is standard practice with semi-structured interviews, the list below represents the main areas that the interviewer will explore with each interviewee. The exact phrasing of questions, and the use of additional probe questions, will be responsive to the context of each individual interview.

1. Tell me a little about yourself  
(prompt where necessary – family, work, interests etc.)
  
4. Can you tell me something about your/ your {partner/ relative/ as appropriate}'s illness condition  
(diagnosis and history, significant other's involvement as carer)
  
5. Pictor briefing  
Explanation of the Pictor Technique  
Production of participant-generated graphical representation of a specific case of collaborative working  
Explain chart – reflection on and discussion of role, identity and relationships in this case  
Can you identify an example of a professional on the chart whose role in helping you was clear to you? Why was it clear?  
Can you identify an example of a professional on the chart whose role in helping you was not clear to you? Why was it not clear?  
How good did you feel the professionals in this example were at sharing necessary information? - with you/ those close to you?  
- with each other?  
What was good about your experience in this example? What could have been done better?

6. Overall experience of care

Have you experienced gaps in care when you weren't sure which professional to go to?

How did this affect you?

Have you ever felt that there were too many professionals involved in care? How did this affect you?

What has been your experience of different professionals use of your care notes?

Based on your experience, are there any changes that you think should be made in the services you have accessed? Any services that you think should be provided which are not?

**APPENDIX 3:  
FINAL CODING TEMPLATE**

## **1. What affects collaborative working?**

### 1.1 Role definitions and distinctions

#### 1.1.1 Inter- professional understanding

##### 1.1.1.1 Level of understanding

1.1.1.1.1 Clear understanding of professional role

1.1.1.1.2 Poor understanding of professional role

##### 1.1.1.2 Managing boundaries and defining territory

1.1.1.2.1 Role flexibility

1.1.1.2.2 Role duplication

#### 1.1.2 Understanding of own professional role

#### 1.1.3 Organisational definitions of role

### 1.2 Collaborative working practices and systems

#### 1.2.1 Access to information and information exchange

##### 1.2.1.1 Facilitators

###### 1.2.1.1.1 Inter-professional meetings

1.2.1.1.1.1 GSF

1.2.1.1.1.2 Other inter-professional meetings

###### 1.2.1.1.2 Information sharing initiatives

1.2.1.1.2.1 Roles/ posts facilitating information exchange (*e.g. liaison DNs*)

1.2.1.1.2.2 Specific schemes (*e.g. 'Good to talk' sessions*)

1.2.1.1.3 Good procedural and case record information available (*e.g. EoL drug info sheets*)

1.2.1.1.4 Effective use of IT systems

1.2.1.1.5 Joint visits

##### 1.2.1.2 Inhibitors

1.2.1.2.1 IT system problems

1.2.1.2.2 Failure to pass on information

1.2.1.2.3 Lack of knowledge about available resources

1.2.1.2.4 Boundary issues in information exchange

##### 1.2.1.3 Inequities in access to information

## 1.2.2 How to manage the co-ordination of different professional groups working together on a case?

### 1.2.2.1 Extent of integration between different teams and services

### 1.2.2.2 Challenges for managing the co-ordination of services

#### 1.2.2.2.1 boundary issues

#### 1.2.2.2.2 cross sector issues

#### 1.2.2.2.3 'too many cooks'

##### 1.2.2.2.3.1 managerial

##### 1.2.2.2.3.2 sheer number of different services

## 1.2.3 Resource issues that affect collaborative working

### 1.2.3.1 Workload issues that affect collaborative working

### 1.2.3.2 Financial resource issues that affect collaborative working

## 1.3 Impact of intra-team dynamics on collaborative working

## 1.4 Impact of inter-personal relationships on collaborative working

### 1.4.1 Longevity of relationship

### 1.4.2 'Stepping on toes' (role overlap)

### 1.4.3 Respect

### 1.4.4 Making an effort

### 1.4.5 Shared job history

### 1.4.6 Accessibility and availability

### 1.4.7 Personal chemistry

## **2. Condition specific involvement**

### 2.1 Beliefs about nature of conditions

#### 2.1.1 Manageability of illness

##### 2.1.1.1 Predictability of illness course

##### 2.1.1.2 LTCs more manageable than cancer

#### 2.1.2 Understanding of conditions

##### 2.1.2.1 Is cancer a LTC?

##### 2.1.2.2 Equation of palliative care with cancer



### 2.1.3 Societal valuation/ priorities of different conditions

#### 2.1.3.1 LTCs as poor relation to cancer

## 2.2 Nature of involvement

### 2.2.1 Level of professional involvement

#### 2.2.1.1 Key involvement

#### 2.2.1.2 Significant involvement

#### 2.1.1.3 Peripheral involvement

#### 2.1.1.4 No involvement

### 2.2.2 What do professionals do?

#### 2.2.2.1 Taking/ passing on responsibility

##### 2.2.2.1.1 Filling gaps between services

##### 2.2.2.1.2 Referring on

##### 2.2.2.1.3 Responding to discharge from acute sector

#### 2.2.2.2 Discrete 'clinical' tasks

##### 2.2.2.2.1 Assessment

##### 2.2.2.2.2 Symptom control

##### 2.2.2.2.3 Prescribing

##### 2.2.2.2.4 Providing/ managing equipment

##### 2.2.2.2.5 Treatment

#### 2.2.2.3 Providing support

##### 2.2.2.3.1 Involvement with wider family/ social support network

##### 2.2.2.3.2 Bereavement visits

##### 2.2.2.3.3 Personal care

##### 2.2.2.3.4 Building rapport with patients

##### 2.2.2.3.5 Long term support of patients

##### 2.2.2.3.6 Assistance with benefits claims

##### 2.2.2.3.7 Breaking bad news

#### 2.2.2.4 Providing expert knowledge

##### 2.2.2.4.1 Patient/ carer education

##### 2.2.2.4.2 Signposting of services and resources

##### 2.2.2.4.3 Sharing expertise with other professionals

#### 2.2.2.5 Going out to where the patient is

##### 2.2.2.5.1 Home visits

##### 2.2.2.5.2 Visiting patients in hospital

#### 2.2.2.6 Paperwork

#### 2.2.2.7 Keeping patients out of hospital

#### 2.2.2.8 Providing a safe service

#### 2.2.2.9 Case management

- 2.2.3 Patient and family involvement in care
  - 2.2.3.1 Extent of lay support
    - 2.2.3.1.1 Support groups
  - 2.2.3.2 Carer responsibilities in condition management
    - 2.2.3.2.1 Wanting to take responsibility
    - 2.2.3.2.2 Drug administration
  - 2.2.3.3 Patient independence and autonomy
    - 2.2.3.3.1 Rejecting particular service involvement

### 2.3. How/ what collaborative working happens?

- 2.3.1 Sharing responsibility
- 2.3.2 Joint visits
- 2.3.3 Co-ordinating services
- 2.3.4 Patient and family experiences of collaborative working

## **3. Survivorship**

### 3.1 Nature of professional involvement in survivorship

- 3.1.1 Involvement from diagnosis
  - 3.1.1.1 All cancer diagnoses referred to DNs
  - 3.1.1.2 Uncertainty re. role in survivorship
- 3.1.2 Support for survivors and families

### 3.2 Signposting and information issues

### 3.3 Patient and family perceptions of survivorship

- 3.3.1 How patient understand professional roles in survivorship
- 3.3.2 Fears around 'cancer'
  - 3.3.2.1 Need for hope
  - 3.3.2.2 'Macmillan' scares

### 3.4 Non-cancer and survivorship

## **4. Current NHS reorganisation**

### **4.1 Consortia**

- 4.1.1 Issues about commissioning
  - 4.1.1.1 Doubts re. suitability of GPs as commissioners
  - 4.1.1.2 Complexity of commissioning
- 4.1.2 Power of consortia
  - 4.1.2.1 Need to be allied with consortia
  - 4.1.2.2 Threats by consortia
- 4.1.3 Impact on services
  - 4.1.3.1 Fragmentation of services
  - 4.1.3.2 'Going backwards'
  - 4.1.3.3 Impact on communication between services
  - 4.1.3.4 Replication and overlap between services
    - 4.1.3.4.1 Encroachment on roles
  - 4.1.3.5 Changes in line management
- 4.1.4 Impact on patients and families
  - 4.1.4.1 Threats to patient confidentiality

### **4.2 Foundation Trust**

- 4.2.1 Redefining professional roles
- 4.2.2 Uncertainty re. implications of Foundation Trust status

### **4.3 Other NHS changes**

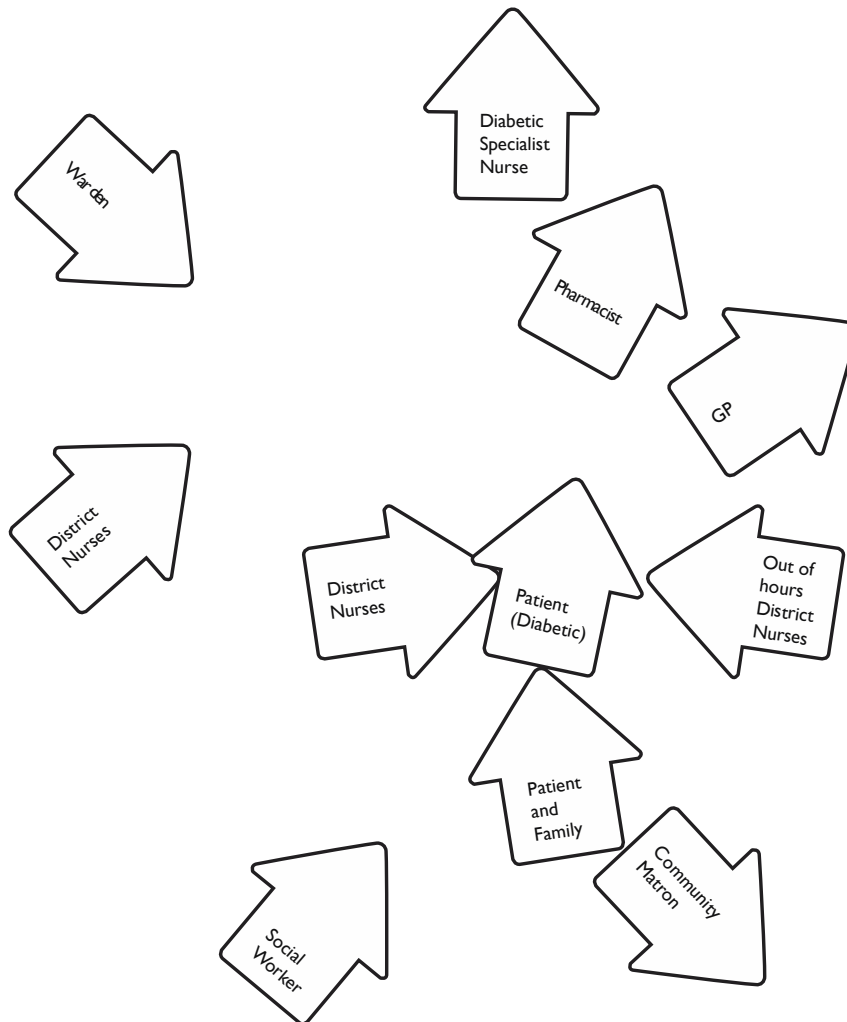
- 4.3.1 General pessimism re. NHS changes
  - 4.3.1.1 NHS changes as continual
  - 4.3.1.2 Sense of futility
- 4.3.2 Lack of explanation
  - 4.3.2.1 Lack of explanation re. changes to roles
  - 4.3.2.2 Lack of explanation re. new roles
- 4.3.3 Déjà vu
- 4.3.4 Sense of powerlessness

### **4.4 Wishlist**

- 4.4.1 Management structure of teams
- 4.4.2 Improved collaborative working
- 4.4.3 Integration of health and social care services

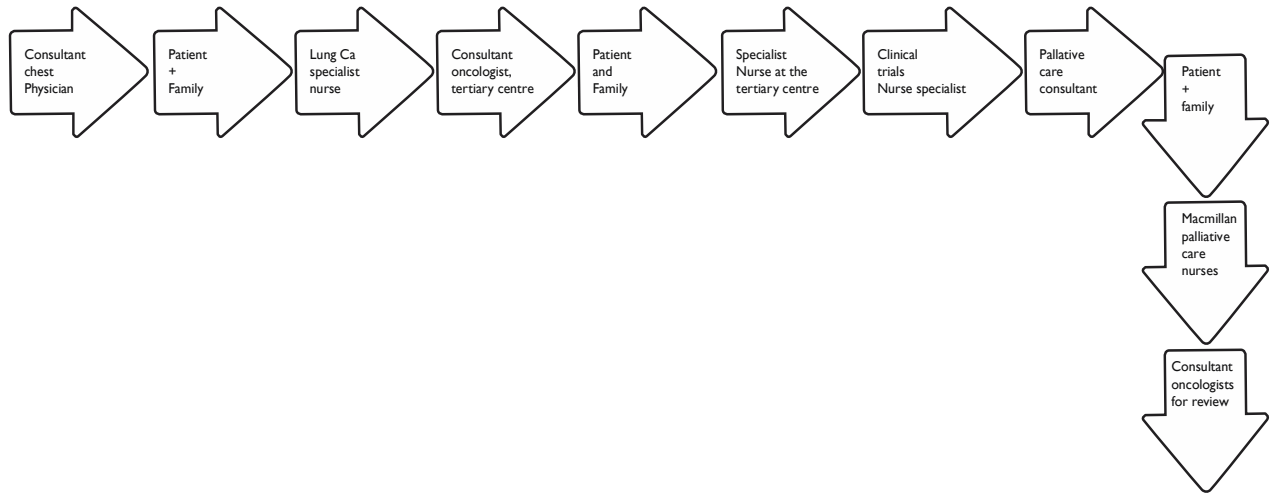
**APPENDIX 4:  
EXAMPLES OF PICTOR CHARTS**

## 1. Network format



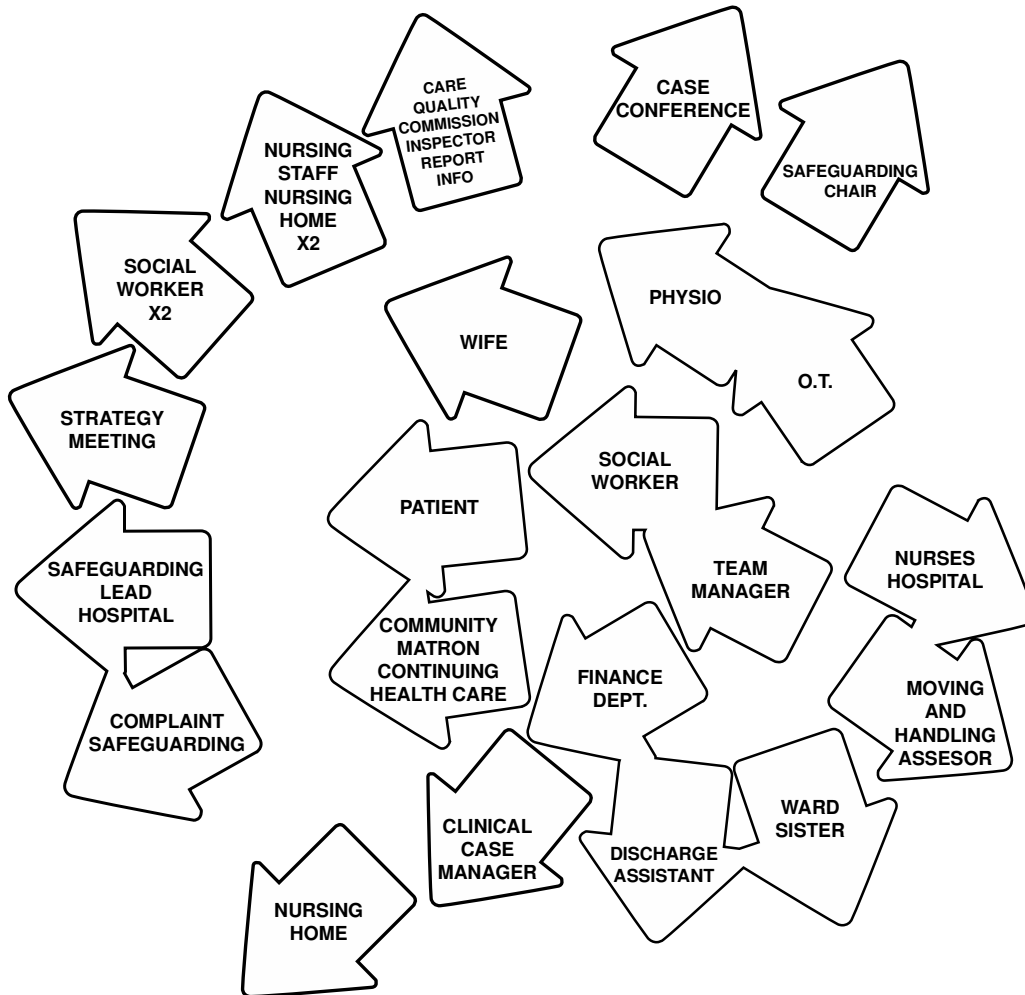
This chart was produced by a district nurse (team leader) describing a patient with very poorly controlled diabetes, living in a warden-controlled flat. It is a typical 'network' chart, where the arrows are arranged to depict aspects of roles and relationships between the patient, the participant and other agents. In this case, the patient refuses to do anything to help himself and the participant describes other services as having given up on him because of his attitude. Arrows pointing away from the patient represent this. In contrast, the Warden and Social Worker remain involved but often not in a way found to be helpful by the participant; their arrows point in but are some distance from the patient. The district nursing service is providing four visits a day, hence the arrow close in to the patient.

## 2. Timeline format



This chart is from a Lung Cancer Specialist Nurse, describing the journey of a young woman with lung cancer plus bone and liver metastases, from the point of referral to a chest physician, through different cancer nurses and consultants to final referral for palliative care. It is clearly organised as a 'timeline' showing each professional in the order in which they became involved.

### 3. Mixed format



This chart is from a hospital-based social worker. It describes the case of an elderly patient who was brought into hospital from a care home. The participant was alarmed at his physical state and instigated a safeguarding complaint (the patient died before this happened).

The central part of the chart depicts those involved with the patient while he was in hospital. This is in typical 'network' format. The arc of arrows on the left of the chart represents the complaint investigation process and is organised in temporal sequence, showing the main steps of the process and people involved. We would define this as a 'timeline' format, hence the overall description of the chart as 'mixed format'.