

**Why you should read this article:**

- To enhance your awareness of the unrecognised work involved in cancer care
- To recognise the challenges that primary care and community staff commonly experience in diagnosing and caring for people with cancer
- To understand the importance of recognising and recording hidden workload to improve cancer care delivery and coordination

# Uncovering the hidden workload involved in providing cancer care in the community

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**Abstract**

**Background** While the workload of primary care healthcare professionals in the UK is increasing, the precise nature of the work involved in caring for people with cancer has not been explicitly defined.

**Aim** To explore the opinions of a small group of primary and community healthcare professionals in London, England about the workload involved in caring for people with cancer, as well as to identify elements of the role that are unrecorded.

**Method** This evaluation used a mixed-methods approach that followed an exploratory sequential design to survey and interview primary and community care staff in London. Descriptive integration was used to merge the quantitative data from the questionnaires and the qualitative data from the interviews to enable comparison and analysis.

**Findings** The questionnaire received 92 responses and seven interviews were completed. Interviews revealed that the recording systems of healthcare organisations did not effectively capture healthcare professionals' cancer care workload. Participants reported the unpredictable nature of cancer care, with people often presenting with vague symptoms. Participants also reported the unrecognised but essential work that they often undertook, such as developing relationships with people with cancer and their families.

**Conclusion** Healthcare professionals working in primary care identified that there are elements of the workload involved in cancer care that are hidden and unrecognised, such as developing relationships with people with cancer and their families. Effectively recording and recognising the hidden workload involved in caring for people with cancer has the potential to improve cancer care delivery and coordination.

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**Keywords**

cancer, cancer research, cancer treatments, community, community care, primary care, professional, research, workforce, workforce planning, workload

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EVIDENCE SUGGESTS that there has been a significant increase in the workload of healthcare professionals working in primary care. However, while the evidence cites factors such as increasingly complex patient care,

escalating administrative tasks, and pressure to meet quality performance targets, the precise clinical nature of this increased workload has not been explicitly defined (Hobbs et al 2016, Thompson and Walter 2016). Furthermore,

research has emphasised the challenges involved in accurately measuring the work of primary healthcare staff such as GPs (House of Commons Health Committee 2016).

In England in recent years, the duration of GPs' and primary care nurses' consultations have increased, while data on the workloads of GPs and general practice nurses has shown that the number of consultations per patient per year in English primary care rose by around 10% between 2007-2008 and 2013-2014 (Hobbs et al 2016).

In the UK, the role of primary and community care services in the care of people with cancer is not well defined (Adams et al 2011), with little data on the volume and nature of primary care activity in the UK. There is also evidence of clinical variations in cancer practice in primary care (Swann et al 2018). Additionally, patients have reported a lack of collaboration in cancer care between primary and secondary care staff (Farquhar et al 2005, Adams et al 2011, Stegmann et al 2019); for example, there may be support services and groups that patients are not aware of and do not access because of a lack of communication between primary and secondary care (Roorda et al 2015, Puts et al 2018).

Some patients present to primary care services with symptoms that may indicate cancer, but which when investigated are found to be unrelated. However, the accompanying consultations and subsequent investigations still contribute to an extensive workload that is not always acknowledged (Hamilton 2010). Furthermore, GPs are judged on their diagnostic performance in identifying people who have cancer, but not on identifying those who do not have cancer (Hamilton 2010). There is little evidence from the UK on the numbers of people who present to primary care with a suspected cancer that is later ruled out, and this area remains largely undocumented (National Institute for Health and Care Excellence 2017).

Understanding the factors that have contributed to these increases in primary care workloads is essential if improvements to care are to be effective. Similarly, understanding the workloads of colleagues involved in providing cancer care, such as general practice nurses and GPs, is vital when seeking to ensure optimal practice and improve care delivery.

### **Aim**

To explore the opinions of a small group of primary and community healthcare professionals in London, England about the

workload involved in caring for people with cancer, as well as to identify elements of the role that are unrecorded.

### **Method**

#### **Study design**

This evaluation of primary and community services in London used a mixed-methods approach that followed an exploratory sequential design to explore the initial views of primary care staff, before a questionnaire and interviews were conducted.

As part of a larger study of soft system modelling (Checkland 1989) of cancer services in London, a focus group was held with seven primary healthcare staff in London. The focus group comprised GPs and nurses, and examined their involvement in the care of people with cancer. The focus group results, as well as a review of the literature on the subject, revealed that some of the cancer care work undertaken by healthcare staff goes unrecorded and unrecognised. These results were the motivation for this evaluation.

Following the focus group, a validated self-completed questionnaire was sent to primary healthcare staff in London, including GPs, general practice nurses, community nurses, district nurses, advanced nurse practitioners and healthcare assistants. The questionnaire was based on a similar questionnaire used in a previous study of unrecognised work undertaken in cancer nursing (Leary et al 2014, 2018, Stewart et al 2018). The questionnaire included three open-ended questions: participants were asked to estimate the number of patients they saw each week; of those how many had a diagnosis of cancer, even if the participant was not treating them for a cancer-related issue; and how many patients they suspected may have cancer and were being referred for diagnostic tests. The participants were also asked closed-ended questions about their cancer caseload, overtime working and professional development. The questionnaire was distributed through Health Education England's weekly London newsletter and was accessed through an online link.

Following the completion of the questionnaires, all of the participants were invited to be interviewed. Participant information sheets were given to those who expressed an interest in being interviewed and informed consent was obtained from those who participated. The semi-structured qualitative interviews were conducted by telephone and were audio-recorded. The interview questions covered participants' experiences and views concerning their involvement in cancer care

and sought to gain a rich understanding of their lived experience. The interview questions are detailed in Box 1.

### Analysis

The evaluation used a secondary analysis of data. The quantitative data from the questionnaire was summarised using descriptive statistics in Excel.

The interviews were transcribed and then thematically analysed using NVivo, a qualitative data analysis software package (Braun and Clarke 2006). A descriptive phenomenological framework underpinned the secondary analysis of the interviews. Identifying thematic aspects of an evaluation is frequently used in phenomenology (Vaismoradi et al 2013). Phenomenology examines subjective human experience and is concerned with gaining insights into individuals' personal experiences and perspectives; in this case, the perceptions of primary care healthcare professionals' work in cancer care (Lopez and Willis 2004).

Descriptive integration was used to merge the quantitative and qualitative data and make comparisons that would enable conclusions to be drawn. Triangulation (the cross-verification of several sources of data) ensured rigour and enabled the various data sources to be tested for consistency (Patton 1999).

### Ethics

The evaluation was subjected to review from the NHS Ethical Committee Health Research Authority (HRA); it was deemed that the evaluation did not require HRA ethical approval. Participants were provided with an information sheet and written consent was obtained from them. Participation was voluntary and participants were reminded that they were free to withdraw at any point. The data were anonymised to maintain participants' confidentiality.

### Findings

#### Questionnaire

The questionnaire was sent to 300 people and yielded a response rate of 31% ( $n=92$ ). Of the participants, 96% ( $n=88$ ) completed the open-ended questions. Therefore, the researchers were able to gain a wide variety of written answers.

Responses were received from GPs (partners, salaried, trainee, locum, portfolio) ( $n=35$ ), general practice nurses ( $n=5$ ), community nurses ( $n=6$ ), district nurses ( $n=17$ ), advanced nurse practitioners ( $n=22$ ), healthcare assistants ( $n=2$ ), advanced clinical practitioners ( $n=1$ ), care navigators ( $n=2$ ), and clerical and administration staff ( $n=2$ ). Ten or more

completed questionnaires were received from GPs (partner), GPs (salaried), district nurses (specialist practice qualification), and advanced nurse practitioners. Therefore, the findings were broken down into these four groups.

#### Estimation of cancer workload

From the completed questionnaires, the researchers were able to gain an average estimate of the percentage of patients with a confirmed or suspected cancer. Responses were divided into the largest respondent groups. Among all the GPs, 11% of their patients per week had a diagnosis of cancer and 3% had a suspected cancer diagnosis. In the case of advanced nurse practitioners, 12% of their patients had cancer and 3% had a suspected cancer. District nurses encountered the highest percentage of patients with a cancer diagnosis at 35%, while 7% of district nurses' patients had a suspected cancer.

GPs were further broken down into partners and salaried GPs. Of the partner GPs, 10% of their patients had a diagnosis of cancer and 3% had suspected cancers; of the salaried GPs, 14% of their patients had a diagnosis of cancer and 2% had suspected cancers. Combining all of the responses from all of the participants, 13% of all patients seen had a diagnosis of cancer, while 3% had suspected cancer. Figure 1 details the estimated numbers of patients seen each week by the questionnaire participants.

#### Interview

Seven interviews were undertaken with three GPs (one partner, one salaried and one locum), two district nurses, one advanced nurse practitioner and one care navigator. Themes identified from analysis of the interviews were:

- » Unrecordable work.
- » Working outside of contracted hours.
- » Vague symptoms (those that are potentially cancer related).

#### Box 1. Interview questions

1. Can you tell me about the type of work you do for people with cancer?
2. If you can recall your workload on a particular day in the past week, were you in contact with a person with cancer?
3. Are there any aspects of your work that you think go unrecorded or unrecognised?
4. Are you involved in work concerned with preventing cancers and risks of cancers?
5. If time and money was no object, what work would you like to be doing in cancer care that you are not able to do now?

- » Positive relationship development and overview.
- » Family and carers.
- » Interaction with secondary care.
- » Administrative work.
- » Unpredictability.
- » Cancer-specific knowledge.

**Themes**

**Unrecordable work**

The interviews revealed that the computer systems used by primary care and community staff did not enable them to effectively capture their workload. This made documenting their work challenging:

*‘The time that it takes to make the referrals or chase up GPs. Things like that aren’t necessarily documented’* (District nurse 2).

*‘I think the amount of support we give isn’t something that you can necessarily document...a lot of the support...is difficult to capture’* (District nurse 2).

*‘The systems that we use don’t allow us to capture that information, it doesn’t allow us to put time aside for those sorts of things on our computer systems. So, we do it, but it’s not visible’* (District nurse 2).

Furthermore, one GP (partner) considered that the lack of accurate documentation had led to an underestimation of the workload involved in primary care:

*‘I think GPs are underestimated in what they do and how much they do; not just GPs, primary care. And I think a lot of it is hidden and a lot of it is not recognised by NHS England. It is just assumed that it will be done without taking real consideration as to how much time it takes to do these things and to do these things properly’* (GP partner).

Psychological care was frequently identified as an area of participants’ ‘unrecorded’ work: *‘Psychological listening is the main*

*one. I mean, you can’t write that down... explaining the stages that they’ll go through after the diagnosis. Really, just speaking to them and just making them aware of what is available and who to contact’* (Advanced nurse practitioner).

*‘There’s a lot of the psychological element that isn’t picked up and it’s hard to quantify that, and it’s harder also to put a monetary value on that, so that goes unnoticed, but I think it’s recognised that it goes unnoticed’* (GP locum).

**Working outside of contracted hours**

Two GPs commented that they would plan to see people with cancer before their lunch break, or at the end of their working day, because they knew they would spend more time with these patients and to prevent delays to later appointments:

*‘It is not a ten-minute consultation, but we don’t seem to be able to do anything about that, so it just knocks on to the entire surgery. I will try and predict when these people are coming in and put them at the end of my clinic so I can spend longer with them and just eat into my lunchtime because then I don’t have to rush and worry about everyone else waiting’* (GP locum).

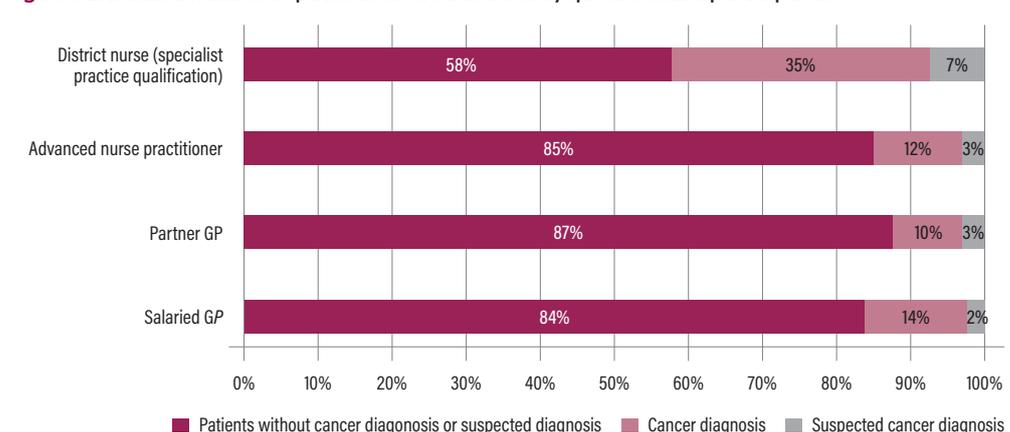
*‘I tend to bring patients in at lunchtimes, just to discuss what’s going on. To have a bit longer. This time is not recorded; this time is my own time for patients’* (GP partner).

Both district nurses interviewed also commented that they and their colleagues frequently worked outside of their contracted hours:

*‘I think most people go the extra mile, near enough every day’* (District nurse 1).

*‘Gosh, our nurses will do a whole lot of things that they’re not supposed to do, you know, they’ll go back and take a patient’s dog*

**Figure 1. Estimated number of patients seen each week by questionnaire participants**



for a walk after-hours and that kind of thing' (District nurse 2).

### **Vague symptoms**

The interviews identified that primary and community care frequently involved seeing patients with vague cancer symptoms. The workload involved in determining where to refer these patients was identified as being substantial. Some of the participants detailed initiatives that aim to guide healthcare professionals in diagnosing patients with vague symptoms; for example, the 'C the Signs' digital application and multidisciplinary diagnostic centres (MDCs) that provide referral pathways for patients with unclear cancer symptoms.

*'We have the multi-investigation and disciplinary centres, like MDCs where you can send [patients] if you are unsure of what type of cancer it is'* (GP locum).

Two GPs reported that when they were unsure of a patient's symptoms, they would ask for advice from a colleague or raise these cases at 'significant event meetings':

*'You'd get an opinion from a local colleague'* (GP partner).

The interviews with GPs revealed that they sometimes made a referral when there were no clear cancer symptoms, but instead they 'had a feeling' that cancer might be present. This could be noted in the 'clinical concerns box' on the two-week wait referral form. This practice was regarded positively by GPs because it acknowledged their understanding of a patient's history and enabled the referral of patients who might not conform to strict symptom criteria:

*'We know these patients, we've seen them for years, so then we are able to say, "Something is not quite right. I can't put my finger on what it is, but something isn't quite right"'* (GP locum).

Knowing when to refer was described by participants as a combination of experience and intuition, and they often found it challenging to define their rationale or to put an allocated time or value for this on the available systems:

*'If we just feel somebody's unwell and there's something not quite right, it's just intuition. There's nothing specific, we'll go back to the GP'* (District nurse 1).

### **Positive relationship development and overview**

According to participants, one area of cancer care that was often overlooked was their ability to develop relationships with patients,

as well as the continuity of care that they were able to offer. Participants also described the unique 'overview' that they have of patients, which could include elements such as being familiar with patients' histories or knowing their families:

*'We see the whole picture and there isn't really anybody else that does that. We have an understanding of family interactions and might be seeing other family members as well, and I think that's probably not captured anywhere. I think that's the important thing, that they're not just patients with cancer, but our job is to look at them a bit more holistically and I don't think that's captured really'* (GP salaried).

The relationships that the participants developed with people with cancer were often strengthened by being able to provide care in the person's home, and by developing long-term relationships with families over time:

*'I have met this person before, I know a lot about him... there's a lot of local knowledge which is nice'* (Care navigator).

*'The advantage of seeing people in their own houses is that they're a bit more relaxed, they know a bit more about what's going on. We also get to meet the carers and the husbands and the wives'* (Care navigator).

*'Most of the district nurses know their area inside out and back-to-front and they know their patients'* (District nurse 1).

### **Family and carers**

Participants recognised that the provision of cancer care was a wide-ranging role that was not limited to the person with cancer, but could encompass family members, friends and carers:

*'It sounds silly, but it can be the husband or wife; it could be the daughter, son, grandchildren, the person's children. It's the dog; it's the cat; it's the neighbour down the road. It's whoever needs that care'* (District nurse 1).

Some participants described the complexity of delivering complex care to people with cancer, while managing and respecting the needs of family members and carers:

*'They need a lot of support and advice. Different people cope in different ways. So, some people, we go in and we do absolutely everything. Some people, they want to help us, and some people just don't want to do anything because they feel completely overwhelmed by the whole situation. And that can change on a daily basis. So, you can never assume that what was right yesterday is right today. You always have to go in with a new pair of eyes'* (District nurse 1).

Another hidden area of cancer care identified by participants was the provision of bereavement care for family members and carers. This type of support was reported by participants as being challenging to access and time-consuming to locate.

Some participants also reported that they sometimes resorted to offering bereavement advice verbally to family members and carers, without having received formal training in this area.

#### **Interaction with secondary care**

Participants frequently mentioned communication challenges with colleagues in secondary care. A lack of structured communication between secondary and primary care meant that information was sometimes relayed through the patient, and miscommunication was common:

*‘Getting information back is very poor. Communication back from secondary care is renownedly terrible and it doesn’t come directly into our system. Letters are delayed in getting to us, so I will get patients to write down what the doctor is telling them, then I don’t have to wait for the letter’* (GP locum).

*‘I get delayed in being told that someone has a cancer diagnosis. And the patient is telling me, not the doctor, so I think that is not great’* (GP locum).

GPs raised the need for improved communication and coordination with secondary care colleagues. Challenges with the timing of information received from oncologists was frequently mentioned:

*‘I think better and more timely communication between us and [the patient’s] oncologist. Often you get letters a couple of months down the line when it’s not current or relevant anymore, which isn’t helpful’* (GP salaried).

Furthermore, participants commented that receiving advice from secondary care colleagues would improve care coordination. GPs, in particular, commented that they would like a person or resource that they could refer to when they were unsure about an individual’s cancer symptoms:

*‘I know that as a source of information I’m not always clear [about] the expected side effects of certain treatments. So, if a patient comes to me with a problem, is that a side effect? I don’t know. I’m not an expert. Where can we go to find information on different types of treatment and what might be an expected side effect?’* (GP salaried).

*‘It’s more just a support for me. I think it would really help, because people don’t fit in*

*these neat boxes and you want to be able to ring someone and say, “This patient was last seen at this time or they had this treatment”, or “Can you help them?” You just want a coordination in there’* (GP locum).

#### **Administrative work**

Participants also reported that a lack of communication with secondary care colleagues could result in unnecessary and hidden administrative work; for example, accessing necessary information about a person with cancer from secondary care colleagues or systems could be time consuming:

*‘I spend, I would say, hours of my time ringing, trying to get hold of the secretaries... if I’m following up regarding [a patient’s] investigation or results. Email is just so helpful. If there was an email specifically for each cancer, for each trust, that would be brilliant’* (GP locum).

Work that was regularly undertaken by primary care staff, for example taking regular blood samples during chemotherapy, but which they considered should be undertaken by secondary care staff, was also an example of hidden workloads.

Although taking blood samples in primary care was recognised as a method of avoiding patients having to attend secondary care appointments, it meant that blood test results were returned to primary care staff rather than the patient’s oncologist. This resulted in time being spent ensuring the results were sent to the correct oncologist, and not being able to take action on results quickly.

One GP (salaried) noted that they sometimes did not understand the significance of the blood results requested by secondary care, and they felt stressed and anxious if they were not able to get hold of the oncologist who requested the tests:

*‘There’s lots of going back and forth between secondary and primary care’* (GP salaried).

One participant, whose work was divided between two clinical commissioning groups (CCGs), reported the unnecessary administrative work caused by each CCG having different working practices. Another participant discussed the time spent on administrative tasks such as contacting GPs and secondary care departments for information about a patient:

*‘It’s the little things like ringing the GPs and trying to get hold of them, trying to get hold of specialists, or trying to get through to hospitals. That sort of thing is probably not captured very well’* (District nurse 2).

### Unpredictability

Participants commented on the unpredictability of caring for people with cancer, and the effect this had on their workload:

*'Because we're dealing with frail people, it doesn't take much for them to deteriorate... You can't always predict when people are going to die. We try our best to, but the human spirit is a wonderful thing and doesn't always abide by the rules'* (District nurse 1).

*'Cancer patients can be very unpredictable, and this can have a massive impact on the service for other patients and colleagues. I spent five hours with a patient a few days ago and could not get their symptoms under control. This meant some of my other visits had to be reallocated to colleagues'* (District nurse 1).

*'It might be that you're going in to do wound care but, because it's a cancer patient, this may take a lot longer because they've got other issues going on'* (District nurse 2).

This unpredictability also had a knock-on effect in patients accessing appropriate care:

*'The hospices are often a little bit wary of frail elderly people because the cancer maybe something they're dying with and it's just very unpredictable. Is the person dying or not?'* (Care navigator).

### Cancer-specific knowledge

All of the GPs interviewed commented that while they were increasingly expected to possess specialist cancer knowledge, it was not always possible to keep up to date with different treatments and side effects:

*'This is something else we're pushing back to secondary care, saying "You've got to give us clear guidance as to what to do." Because we're not oncologists, we're not neurologists and we're not specialists. We are generalists (GP partner).*

*'There's a lot of expectations of "Oh, the GP can do this; the GP can do that." But actually, there's no allocated resource or time for GPs to do this'* (GP partner).

*'A lot of the time, I'm not very up to date with my chemotherapy regimens, so I don't know if [a symptom] is attributable to the chemotherapy ... or if it is something new and ... how long it takes for them to get better'* (GP locum).

GP participants also commented that researching various cancer treatments was a hidden element of their workload:

*'Sometimes, the patients will come to us with random side effects, which we don't know about'* (GP partner).

*'I will end up trying to Google it because I don't know'* (GP locum).

## Discussion

### Workload and vague symptoms

The majority of people with cancer initially present to non-specialist healthcare staff (Mendonca et al 2016). In addition, patients often present in primary care with symptoms that have a low positive predictive value (PPV) (the proportion of people with a symptom, sign, or test result who go on to develop cancer), such as swallowing difficulties. Similarly, the challenge of diagnosing cancer can be exacerbated by the presence of vague symptoms such as back pain, which may not be immediately recognised as cancer related (Lyratzopoulos et al 2014).

Participants in this evaluation reported that a significant element of their workload comprised people presenting with vague symptoms that may be related to cancer. This emphasises the flexibility required when caring for people with cancer, whose symptoms may not always meet rigid diagnostic criteria. Participants in this evaluation also reported that they appreciated the acknowledgement of their expertise and unique overview of patients that was factored into work streams, such as the clinical concerns box on two-week wait referral forms, which acknowledged that vague symptoms could make diagnosis challenging. Similarly, the implementation of multi-specialist diagnostic services for patients with unexplained symptoms, as well as clinical guidelines covering the symptoms of various presentations, can contribute towards accurate diagnosis. It is important to recognise the challenges involved in investigating vague symptoms to fully understand why multiple consultations often take place in primary care (Lyratzopoulos et al 2014).

The effects of the unpredictable nature of cancer care on the workloads of healthcare professionals has not been widely explored in the literature. However, frameworks that detail typical illness trajectories, which are used in palliative care, can be useful in planning care timeframes and predicting levels of patient need (Murray et al 2005). Murray et al (2005) suggested that understanding patients' possible illness trajectories can be empowering for them and their carers. These authors also suggested that cancer, which is commonly characterised by a 'short period of evident decline' is broadly predictable in terms of anticipating patients' palliative care needs; however, resource constraints, particularly in community care, often limit the anticipation of these needs. Furthermore, Boyd and Murray (2014) found that providing people with lung cancer, their family members and carers with early

## Implications for practice

- Understanding the extent of primary care healthcare professionals' involvement in cancer care is essential to improving service delivery
- In the future, clarifying the roles of various healthcare professionals and identifying the services available will enable improved communication between primary and secondary healthcare professionals involved in providing cancer care
- This evaluation only explored the views of a small group of the primary and community care healthcare professionals working in cancer care in London. Future research should seek to explore the views of healthcare professionals across the four nations of the UK

information about their prognosis can improve quality of life.

In this evaluation, the district nurses in particular commented on the unpredictability of delivering cancer care and the negative effects this can have on their workload. The district nurses also commented that acknowledgement and recognition of this unpredictability could ease workload pressures.

The numbers of people who present to primary care with a suspected cancer that is later ruled out is an area that requires further research (Hamilton 2010). Across all of the participants in this evaluation, an estimated 3% of patients they encountered each week presented with symptoms that may have indicated cancer and were being referred for diagnostic tests. Many of these patients would subsequently be found not to have cancer; however, the work involved in processing these patients is not recorded or recognised as part of the healthcare professionals' workload.

### Effects on family members and carers

Elements that might not immediately be recognised as directly related to cancer, such as the effects on families and carers, were identified in this evaluation as an area of unrecognised workload for primary healthcare staff. The district nurses in this evaluation emphasised the challenges of balancing the needs of family members and carers with those of the people with cancer, particularly in the home. The interview participants also discussed how they often had to manage the cumulative effects of cancer; for example, the diagnosis, treatment and potential death of a family member, a finding that is reflected in the literature (Ullgren et al 2018). Murray et al (2010) suggested that family carers of people with cancer also experience these multiple effects of the illness and recommended that they are supported throughout the entire period of the individual's illness and not only in the bereavement phase.

Adams et al (2011) studied six UK primary care practices and found that a close relationship with a GP was an important factor in effective consultations for people with cancer. This was reflected by the GP interview participants in this evaluation, who stated that developing relationships with patients and their family members is an important element of care delivery.

### Interactions with secondary care

Concerns have been raised in the literature about the lack of improvement in communication between primary and

secondary care, such as the routine use of email, despite these improvements requiring minimal investment (House of Commons Health Committee 2016). Additionally, barriers between primary and secondary care such as suboptimal communication have been recognised for some time, specifically in cancer care (Farquhar et al 2005, Stegmann et al 2019). In Adams et al's (2011) study, people with cancer identified a lack of coordination between primary and secondary care services, while patients' views of the interface between primary and secondary care have been identified as an important indicator of healthcare organisations' performance (Preston et al 1999).

Barriers to effective care coordination between primary and secondary care – such as challenges with communication – were identified by participants in this evaluation, resulting in repetition of work and increased administrative tasks for healthcare professionals, as well as a lack of continuity of care for people with cancer. This evaluation would support improvements in the coordination of services and communication between primary and secondary care staff.

### Cancer-specific knowledge

In this evaluation, the interview participants identified that their cancer-specific knowledge could be improved and that they would like to improve coordination with healthcare professionals working in secondary care. The King's Fund (2018) recognised the need for greater support for primary care healthcare professionals in terms of healthcare organisations providing increased time for them to develop new skills. Differences in knowledge and practices in caring for cancer survivors have been identified between healthcare professionals in primary and secondary care, for example different surveillance care practices for monitoring patients, as has primary care healthcare professionals' lack of confidence in their knowledge of cancer treatments (Potosky et al 2011, Roorda et al 2015).

### Limitations

This evaluation was a secondary analysis of data from a larger study. Therefore, the questionnaire results were limited to three questions that focused on estimates of the workload involved in caring for people with cancer. The results are not generalisable or representative of other groups and only provide insight into the experiences of a small group of primary and community care

healthcare professionals in a limited geographic area of London. With a small group such as this, there is also a risk that the participants' views may be oversimplified.

Participants were interviewed once, which could be regarded as a limitation from a phenomenological perspective because it limited participants' opportunity to clarify their responses. However, the interviews were undertaken following the questionnaire, which enabled participants to reflect on their questionnaire answers.

## Conclusion

This evaluation used a questionnaire and interviews to explore the hidden workload

involved in cancer care for primary and community care staff. The findings suggest that healthcare organisations' systems do not enable the accurate recording of participants' cancer-related workload. Similarly, participants identified several aspects of their cancer-related workload that are not formally recognised. These include the unpredictability of cancer progression, diagnosing patients with vague symptoms and the care of family members and carers.

As well as managing challenges with communication between primary and secondary care services, participants were also expected to have specialist cancer knowledge.

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