Patients’ experience of integrated care

A report from the Cancer Campaigning Group

November 2012
We would like to thank all those who responded to the survey. Constructive and honest voices such as these, alongside mechanisms such as the National Cancer Patient Experience Survey, are vital in bringing about a patient-centred NHS.
Introduction

As a coalition of more than 50 charities campaigning for better services for people with cancer and their families, the Cancer Campaigning Group (CCG) believes that integrated cancer care—a seamless, well co-ordinated service, across GP, hospital and social services—is an essential component of high quality care for every patient. Organisations such as the Kings Fund and Nuffield Trust have published research on the importance of integrated care\(^1,\)\(^2\). It is an issue at the heart of the NHS reforms. The Secretary of State for Health told the Conservative Party Conference in October 2012: “Good care matters as much as good treatment. And I will expect the highest standards in both.”\(^3\)

In practical terms, integrated care can mean things like a patient’s GP having up to date records about their treatment, always seeing members of the same hospital team (for example doctor or specialist nurse), appointments and test results being provided quickly, and not having to keep explaining the same things to different people. However, many CCG members have found that cancer services are not fully integrated and that patients often have a frustrating experience as a result. We want to make sure that the voices of people living with cancer and their carers are heard as the Government works to make integrated care a reality\(^4\).

“We think that better integrated care, around the needs of patients, is crucial to providing higher quality, safer and more cost-effective services which improve outcomes and reduce inequalities”

Patient Experience Team, Department of Health (August 2012)

We wanted to understand what ‘integrated care’ really means to people living with cancer and their carers. We also wanted to find out what improvements patients and their carers believe should be made to ensure that treatment and care is joined up for all cancer patients in England.

We asked people living with cancer, or their carers, to fill in a survey to help us understand what matters most to them. It found only one in three respondents thought that they had experienced integrated care. The fact that some of these were very positive indicates that it is possible to provide an integrated pattern of care and that best practice exists in the NHS. However, the results of the survey also indicate that more could be done to improve the experience of cancer patients in the NHS.

Drawing on the responses, this report sets out a snapshot of patients’ and carers’ experience of cancer care and includes recommendations for future action to improve integration. We hope it will contribute to better assessment of the experience of patients and carers and encourage those working towards solutions and improvements in integrated care.

About the respondents

358 patients and carers completed the CCG survey, describing their experience of over 20 different types of cancer\(^5\). Of those that responded:

- 61 per cent were living with cancer or had been diagnosed with the disease at some point
- 39 per cent were carers or had cared for someone with cancer at some point
- Most patients fell into the 40-49 year-old age bracket
- Most of the patients were female
- The two most common types of cancer were brain tumours and breast cancer
Summary of recommendations for improving integrated care

- A working definition of integrated cancer care, such as the CCG’s statement, needs to be adopted by the NHS, working with organisations such as the CCG to support patients and carers to recognise what good quality care looks like and to encourage its spread across the NHS.

- The NHS Commissioning Board and clinical commissioning groups must prioritise tackling barriers to integrated care, involving all sectors and organisations which support the patient (such as local authorities and allied health professionals) as well as engaging directly with patients and carers.

- Commissioners and providers need to take a sufficiently broad view of integration to ensure that the wider elements of support and services that patients need are incorporated, including outside hospital and after treatment.

- Commissioners and providers need to take patients’ views into account to help set priorities for integrated care. Improvements patients want to see include:
  - Securing quicker referral from GPs to hospitals for testing and diagnosis
  - Ensuring patients find out the results of their tests as quickly as possible
  - Providing patients with access to a named clinical nurse specialist or other ‘key worker’ throughout the care pathway
  - Supporting patients to feel involved in key decisions about their treatment and care
  - Putting systems in place to make sure records and test results are available to all clinicians and staff involved in patients’ care

- It is important that the experiences of patients are taken into account across the NHS to maximise their positive outcomes and quality of life. Efforts must be made to ensure systematic use of the Department of Health’s Interim measures for patient experience at the interfaces between NHS services alongside the National Cancer Patient Experience Survey to enable effective monitoring of standards of integrated care.
Understanding integrated care

There is a strong consensus among policy-makers, parliamentarians and patient groups on the importance of improving integrated care in the NHS. Integrated care is seen as “essential to meet the needs of the ageing population” and an opportunity to “transform the way that care is provided”\textsuperscript{6}. It should ensure services are well co-ordinated around the patients’ needs by improving “the quality of care for individual patients, service users and carers”\textsuperscript{7}. Undoubtedly, integrated care is a policy approach that has gained significance throughout the NHS reforms, and it is now believed by many to be the solution to poor quality care.

Yet little has been done to communicate to the general public what integrated care means. Our survey found that most people (58 per cent) did not find integrated care to be the clearest term to describe the co-ordination of care across different care settings.

“A comprehensive understanding of what integrated care is, and more importantly, what it looks like, is key if the approach is to be implemented successfully. The need for further clarification on integrated care is demonstrated by the responses to the CCG survey. When asked whether or not they thought they had received integrated care, around one in five (21 per cent) of respondents said they were not sure. This highlights the uncertainty among patients on what the term integration means. Without understanding what integrated care is, or even recognising the term, patients and carers will not know for sure whether they have experienced integrated care.

There is a clear need for the term integrated care to be properly defined so that it becomes an image of the health service that is recognised by all patients. Once patients and carers understand what integrated care looks like, they can identify when they have experienced integrated care, and can call for it when it is not being delivered. There is a need for a working definition of integrated care and the CCG would like to work with the NHS to achieve this.
As a starting point, the CCG has developed a definition of integrated care based on the issues that were raised in responses to the survey, which is set out in the box below.

Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it. This includes ensuring people are informed about their particular condition, treatment options, side effects and care pathway. Care is best integrated when patients have access to a specialist nurse or other key worker, when they are actively involved in decisions about their treatment, when referrals across care services are efficient and when information is shared amongst relevant professionals involved in a person’s treatment and care.

Recommendation: A working definition of integrated cancer care, such as the CCG’s statement, should be adopted by the NHS, so patients and carers are supported in being able to recognise what good quality care looks like and can encourage its spread across the NHS.
Experiencing integrated care

The survey asked patients and carers whether they had experienced integrated care and the responses are set out in Figure 1, below. Patients were more likely than carers to say that they had not experienced integrated care. Nearly half of the patients surveyed (43 per cent) said that they had not experienced integrated care, compared to just over a third (36 per cent) of carers.

Views about whether cancer care seemed to be well integrated did not seem to vary much by the age of the patient. However, younger patients and their carers were more likely to say that they were not sure whether their care was integrated.

Those responding about common cancers (breast, bowel, lung or prostate) were more likely to say that they had experienced integrated care than those responding about less common cancers. Nevertheless, not even half of those with common cancers (46 per cent) said that they had experienced integrated care, and just under a third with less common cancers (32 per cent) said that they had.

“…When two hospitals share care there needs to be much better integration. Our experience is of a very disjointed service between hospitals, very much an ‘us and them’ culture.”

“I used to have a key worker that worked as an ‘in-between’ between my neurosurgeon and neurologist which worked well, but I moved hospital and now have to manage them separately myself. At the moment it is not a problem because I am stable but in the future this would be a problem.”

“I feel my care has been joined up, from the response from my GP, to the surgeon and my specialist nurse to the chemotherapy team who I know I can call at any time.”

“I feel that the ‘hand-over’ between lead hospital and local can be disjointed and not particularly joined up, ie the local hospital are not always aware of what the lead hospital have said and vice versa.”
Whether or not patients receive integrated care is not only important because of the impact it has on their experience of care, but because it can also have an impact on their treatment and their outcomes. Understanding the differences between integrated care and a disjointed care pathway will help patients to take control of their care and will allow them to push for improvements.

The responses to the survey also show what areas of care require attention. Not only does the division between primary and secondary care need to be addressed to deliver integrated care, but how care is managed between different hospitals, in the community and after treatment ends is vital to improving quality of care. In addition, wider services, such as education for younger patients or social care for older patients, also need to be considered; this is crucial to underpinning truly integrated care from patients’ perspectives.

Recommendation: The NHS Commissioning Board and clinical commissioning groups must prioritise tackling barriers to integrated care, involving all sectors and organisations which support the patient (such as local authorities and allied health professionals) as well as engaging directly with patients and carers.

Recommendation: Commissioners and providers need to take a sufficiently broad view of integration to ensure that the wider elements of support and services that patients need are incorporated, including outside hospital and after treatment.
Driving improvements in integrated care for cancer patients

Good quality cancer care should, among other things, ensure that patients are at the heart of service delivery, with services designed and planned to meet their needs. Integrated care is intended to achieve this and the CCG was keen to find out what patients thought was most likely to improve their experience of integrated care.

The survey included a list of 19 different changes designed to promote the integration of care and asked patients and carers to highlight the three that they thought were most likely to lead to improvements. Some clear messages emerged and the top five in order of preference were:

1. Quicker referral from GP to hospital for testing and diagnosis
2. Finding out the results of tests quicker
3. Having access to a named cancer nurse specialist or other ‘key worker’ throughout the care pathway
4. Feeling involved in key decisions about treatment and care
5. Having records and test results available to all clinicians and staff involved in care

The following comments taken from the responses to the survey make clear how important these changes are to patients:

“I think the move towards integrated care is long overdue ... better communication between hospital and GPs or a central records system is essential.”

“My father has seen a different doctor for every visit. None of them seems aware about what is going on ... My father should have received adjuvant chemo following surgery, but didn’t as the oncologist didn’t follow up and the surgeons didn’t refer back to the oncologist. His cancer has now recurred.”

“Constantly having to update relevant professionals about treatments etc ourselves was draining.”

“Being treated at four different hospitals, GP surgery and hospice during treatment resulted in confusion for [us] as to which professional to turn to at different stages of illness. Also we found that each professional within these different locations had no knowledge or communication with each other. This means great responsibility on the patient or carer to update each professional themselves.”

“There should be follow-up by someone, such as a health visitor, who has been shown records that can start the follow-up care with patients and families.”

“Having to wait weeks for MRI results is absolutely the worst.”
“It would be helpful if a specialist nurse allocated to a patient at the first appointment could follow the patient through the system.”

“[We] need excellent, efficient communication between all professionals involved and [the] patient and [their] family – poor communication causes more stress.”

“I have found it frustrating that it takes so long for information to come through from one person to the next.”

“Each person wants to feel that their case is special and that people care about their wellbeing. I believe that access to a trained nurse and/or other health professional is essential for this.”

“Someone that was with you all the way along, who could co-ordinate for and on your behalf ... would lead to a greater feeling of integration. I do not need to know all the different people or departments ... I just need one contact/supporter from the very beginning/diagnosis for the system of care to feel.

“The main [thing] is for the patient to not have to run through the whole scenario over and over again with each person who sees them. Detailed notes should be taken so the GP, consultant [or] nurse can read through before speaking to you.”

“I would like the communication between GP, hospital and patient to be quicker and the GP to be informed about tests/results taking place in hospital and vice versa. There seems to be a lack of communication and it can get a bit confusing.”

Our survey demonstrates that changes are needed throughout the system in order to improve the integration of care. The five steps that have been identified by the survey respondents would make a significant difference to patients. None of the areas for development that patients have identified are new to the NHS, and it is crucial that they are implemented swiftly across the service.

Recommendation: Commissioners and providers need to take patients’ views into account to help set priorities for integrated care. Improvements patients want to see include:

- Securing quicker referral from GPs to hospitals for testing and diagnosis
- Ensuring patients find out the results of their tests as quickly as possible
- Providing patients with access to a named clinical nurse specialist or other ‘key worker’ throughout the care pathway
- Supporting patients to feel involved in key decisions about their treatment and care
- Putting systems in place to make sure records and test results are available to all clinicians and staff involved in patients’ care
What else matters to patients?

The survey included a section for patients and carers to provide any additional information that they thought was important about the care they, or the person they care for, had received. The following comments highlight some of the issues that really matter to patients and the wider elements of integration that need to be considered.

“The key is the balance between timely treatment and allowing sufficient time and information to make decisions about what that treatment should be.”

“We find that different hospitals do things differently, which is confusing. If the care is going to be joined up then different hospitals should be following the same procedures. … There needs to be better communication.”

“When a district nurse visits at home it would be nicer to have the same nurse, or even just a couple rather than a different one each day so you don’t have to repeat your story every day to someone new, which can be distressing.”

“I would benefit from something written down. I have requested copies of correspondence but I am not getting everything.”

“I am fortunate that I was a registered nurse, only retired just over a month ago and am able to make valid decisions based on evidence based research, but a postcode lottery does still exist regarding treatment.”

“It would be a great idea, instead of the person with cancer getting in touch with support groups (some people don’t like to make the first contact) for someone from the group to contact them personally, it helps break the ice and they will feel more like joining a support group.”

“It is very important that weekend/out of hours services are up to speed and feel confident with your needs.”

“I didn’t know about different services that were available to me and had to find them out from different places or word of mouth. It would be good if you were given a pack, for instance with details of any services, including financial or support services available to you in your area.”

“Recommendation: It is important that the experiences of patients are taken into account across the NHS to maximise their outcomes and quality of life. Efforts must be made to ensure systematic use of the Department of Health’s Interim measures for patient experience at the interfaces between NHS services alongside the National Cancer Patient Experience Survey to enable effective monitoring of standards of integrated care.”
Conclusion

While there were a number of positive experiences reported through the survey, the majority of responses paint a mixed picture of whether patients are experiencing integrated care. The CCG believes these responses, particularly the fact that around a fifth of respondents said they did not know if their care was integrated, demonstrate that there is more work to be done to ensure that patients understand the standard of integrated care they can, and should, expect.

Healthcare professionals need to ensure that they listen to patients and carers to find out what is important to them and to support them to understand how their care will be provided. The survey results have demonstrated that there is still a lack of certainty among patients about terms such as integrated care. Health professionals can play a major role in communicating treatment and care choices and decisions in a timely and effective way.

The responses to the survey clearly show that many patients are still experiencing gaps in their care and, in some cases, this is affecting their outcomes, as tests or follow-up appointments are not organised. It is crucial that providers and commissioners work together, particularly during this time of transition, to make sure integrated care becomes the norm across the NHS.

The first steps to achieving this have been set out by the patients and carers who responded to the survey. There were five clear areas of change that the respondents thought would make the most difference to their experience of integrated care. The CCG believes that these recommendations should be prioritised for implementation to ensure cancer patients receive the best possible care. The key themes of swift access and sharing information need to be addressed promptly.

Patients’ wider needs beyond their cancer care can also have a major impact on their outcomes. Although some of this will be beyond the remit of the NHS, it is important that this is considered when integrated care is delivered. This could include working in partnership with CCG members to provide and signpost education services for young people, financial support and advice for adults and the social care needs of older people.

The survey responses have highlighted that there is a need for further discussion about integrated care for people with cancer and those who care for them. The CCG hopes that the survey provides a useful snapshot of patients’ and carers’ priorities. We will continue to highlight integration as a key priority during the authorisation process for clinical commissioning groups and beyond.
Annex

Methodology

Between 4 May and 25 May 2012, the CCG ran a web-based survey through SurveyMonkey. CCG members were asked to circulate the survey link to their supporters through their networks and social media outlets, and patients and carers were asked to respond to the survey based on their individual experience of integrated care.

The survey had been developed by the CCG Secretariat and the CCG Steering Group, which is made up of representatives from six member organisations.

The survey comprised nine questions, including some on demographic information, such as gender, age and cancer type, together with a free text box for comments. The results were then analysed by the CCG Secretariat.

Key points

- 358 people completed the survey
- 61 per cent of those who responded are living with cancer or had been diagnosed with cancer at some point (and answered for themselves)
- 39 per cent of those who responded care for someone living with cancer or had cared for someone with cancer at some point (and answered about the person they care for or had cared for)
- 67 per cent of respondents were female, while 33 per cent were male
- Most patients fell into the 40-49 age bracket, closely followed by those aged 50-59 years old. The percentage breakdown by age bracket was:

<table>
<thead>
<tr>
<th>Age bracket</th>
<th>Percentage breakdown</th>
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<tbody>
<tr>
<td>0 – 15 years old</td>
<td>12 per cent</td>
</tr>
<tr>
<td>16 – 24 years old</td>
<td>6 per cent</td>
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<tr>
<td>25 – 29 years old</td>
<td>3 per cent</td>
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<tr>
<td>30 – 39 years old</td>
<td>12 per cent</td>
</tr>
<tr>
<td>40 – 49 years old</td>
<td>28 per cent</td>
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<tr>
<td>50 – 59 years old</td>
<td>22 per cent</td>
</tr>
<tr>
<td>60 – 69 years old</td>
<td>13 per cent</td>
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<tr>
<td>70 – 79 years old</td>
<td>4 per cent</td>
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</tbody>
</table>

- The percentage breakdown by ethnicity was:

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage breakdown</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (British, Irish or other white)</td>
<td>96 per cent</td>
</tr>
<tr>
<td>Asian or Asian British</td>
<td>0.5 per cent</td>
</tr>
<tr>
<td>Black or Black British</td>
<td>0.5 per cent</td>
</tr>
<tr>
<td>Mixed background</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Other</td>
<td>0.5 per cent</td>
</tr>
<tr>
<td>Rather not say</td>
<td>1.5 per cent</td>
</tr>
</tbody>
</table>

- The two most common types of cancer were brain tumours and breast cancer, which made up nearly half of the responses. This was followed by leukaemia and sarcoma, which represented another fifth. The percentage breakdown by tumour type was:
<table>
<thead>
<tr>
<th>Cancer type</th>
<th>Percentage breakdown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Bowel cancer</td>
<td>3 per cent</td>
</tr>
<tr>
<td>Brain tumour</td>
<td>23 per cent</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>23 per cent</td>
</tr>
<tr>
<td>Hodgkin’s lymphoma</td>
<td>3 per cent</td>
</tr>
<tr>
<td>Kidney cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>13 per cent</td>
</tr>
<tr>
<td>Liver cancer</td>
<td>3 per cent</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Non-Hodgkin’s lymphoma</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Oral cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Other cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>3 per cent</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>7 per cent</td>
</tr>
<tr>
<td>Skin cancer</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Thyroid cancer</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Uterine cancer</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Other (bladder cancer, cervical cancer, laryngeal cancer, oesophageal cancer, testicular cancer and vaginal cancer)</td>
<td>2 per cent</td>
</tr>
</tbody>
</table>

- The percentage breakdown of respondents experience of integrated care was:

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with cancer</td>
<td>46 per cent</td>
<td>37 per cent</td>
<td>17 per cent</td>
</tr>
<tr>
<td>Carer</td>
<td>39 per cent</td>
<td>34 per cent</td>
<td>27 per cent</td>
</tr>
<tr>
<td>Common cancer</td>
<td>42 per cent</td>
<td>46 per cent</td>
<td>12 per cent</td>
</tr>
<tr>
<td>Rarer cancer</td>
<td>43 per cent</td>
<td>32 per cent</td>
<td>25 per cent</td>
</tr>
<tr>
<td>0 – 25 years old</td>
<td>27 per cent</td>
<td>34 per cent</td>
<td>39 per cent</td>
</tr>
<tr>
<td>26 – 59 years old</td>
<td>46 per cent</td>
<td>38 per cent</td>
<td>16 per cent</td>
</tr>
<tr>
<td>60 – 89 years old</td>
<td>48 per cent</td>
<td>32 per cent</td>
<td>19 per cent</td>
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About the Cancer Campaigning Group

The Cancer Campaigning Group (CCG) is a coalition of more than 50 cancer-related charities representing service providers, research, advocacy and campaigning groups for cancer patients and their families. Founded in 2002, the CCG campaigns for world class prevention, treatment, support and care for every cancer patient in England to bring all services up to the standards of the best in Europe. At this crucial time in the development of health and cancer services, the CCG enables cancer charities to speak and campaign with a single, unified voice, pooling expertise, amplifying the impact of individual organisations, and ensuring that our messages are heard and acted upon by the Government and the NHS. More information is available on our website: www.cancercampaigninggroup.org.uk.

The Cancer Campaigning Group Steering Group and Secretariat

The CCG’s campaigning strategy and activities are developed by an elected Steering Group of representatives from six member charities – Cancer Research UK, CLIC Sargent, Macmillan Cancer Support, Prostate Cancer UK, the Rarer Cancers Foundation and the Roy Castle Lung Cancer Foundation. MHP Health Mandate provides the Secretariat to the Group, including communications advice, support and implementation.

Supporters

The CCG’s work is supported by ten pharmaceutical companies – Amgen, AstraZeneca, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Lilly, Novartis, Roche, Pfizer and Sanofi. Supporting organisations do not direct or control CCG strategy, activities or literature in any way. The CCG ensures that all its relationships with supporter organisations comply with the Association of the British Pharmaceutical Industry (ABPI) code of conduct, governing the relationship between patient groups and pharmaceutical companies.
References


5 The full methodology is provided on pages 15 and 16


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