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Quality in cancer care: Nurse sensitive indicators for ambulatory chemotherapy

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1. Summary

Successive cancer policy documents have emphasised the role high quality intelligence about cancer services can play in improving clinical quality and encouraging scrutiny of clinical performance. Measuring variations in outcomes can contribute to enhancing quality by motivating and empowering clinicians to improve care. As a result we were commissioned by the National Cancer Action Team to identify, develop and test a suite of nurse-sensitive indicators that could contribute to the effective monitoring and quality improvement of chemotherapy services. Building on our earlier review, this report presents findings from the second phase of work aimed at developing and testing the proposed set of indicators in a small number of pilot sites.

The dimensions of quality covered by the nurse-sensitive indicators include:

- ***severity of subjective symptoms*** resulting from treatment, across a range of domains, including those that we identified as most sensitive to the quality of nursing services (nausea, vomiting, oral problems)
- perceptions of assessment, information and ***support to manage symptoms*** offered to patients by nurses who administer chemotherapy (support for self-care)
- ***safety of drug administration*** (extravasation and pain at infusion site) and
- ***patient experience*** of the administration process and informational support.

Specifications for each indicator were drafted and a data collection plan developed. Data on some of the indicators are routinely recorded (e.g. extravasations), however indicators in the effectiveness and experience domains are subjective experiences (e.g. symptom severity) and unlikely to be routinely recorded in a standard form. Because of this we decided that a major focus of the project had to be the design and development of a method for collecting such information and so we drafted a self-assessment / self-report questionnaire that patients could complete with each cycle of chemotherapy. We also identified workforce and contextual information that is likely to influence outcomes on the indicators.

The nurse sensitive indicators were piloted in ten cancer centres across England over a 12 week period. Patients attending for ambulatory chemotherapy were asked to complete the self-report questionnaire at each visit during the data collection period. Data were analysed to explore variability in scores between centres and were also adjusted for casemix. The indicator system that we have designed and reported here has real potential to be used now for local quality improvement efforts and for benchmarking between centres. We have shown substantial levels of adverse symptoms, large numbers of patients who perceive that support to manage symptoms could be better and unexplained variation between centres which all suggestion potential for improvement. Stakeholders in our pilot sites gave a clear indication of the potential to use these indicators to stimulate and evaluate quality improvement.

2. Background

Equity and excellence: Liberating the NHS [1] identified the central role that measurement of quality will play in driving improvement, productivity and efficiency in the NHS. 'Improving Outcomes: A Strategy for Cancer [2] reiterated the focus on delivery of critical outcomes rather than measuring the process by which outcomes are delivered. The success of this strategy will rely on high quality data that encompasses three domains of quality (our emphasis):

- the *effectiveness* of treatment and care provided to patients – measured by both clinical outcomes and patient-reported outcome measures (PROMS)
- the *safety* of the treatment and care provided to patients
- the broader *experience* patients have of the treatment and care they receive.

[1](p.22)

In cancer care the delivery of chemotherapy is changing to a situation where most is delivered in an ambulatory setting [3]. A recent report from the National Confidential Enquiry into Patient Outcomes and Death (NCEPOD) [4] highlighted concerns about the wide variation in quality and safety of chemotherapy services across England. This is supported by more recent findings from the 2010 National Cancer Patient Experience Survey which showed there was significant variation in the proportion of patients who felt that staff did everything possible to control the side effects of chemotherapy [5]. While in some Trusts all patients felt everything possible was being done, in others as many as 40% did not. Similar findings were also reported with regards to emotional support with significant variation also associated with different cancer diagnoses within the same Trust.

In the national survey patients who reported being cared for by a Clinical Nurse Specialist were significantly more likely to be positive about their care and treatment on a range of factors. This suggests nurses play a very influential role in patients' experience of cancer care. Other evidence points to the potential for nurses to influence the effectiveness and safety of care, in particular in minimising the symptoms and harms associated with cancer chemotherapy [6]. This effect is likely to be heightened in a nurse-led care environment, typified by the ambulatory chemotherapy setting.

There has been specific interest in developing metrics that more closely reflect the contributions of the whole clinical team [2, 7]. This commitment has been reiterated in relation to the nursing contribution in 'Front Line Care' [8] and 'The Nursing Roadmap for Quality' [9]. 'A High Quality Workforce' [7] signalled the development of a suite of metrics for care outcomes influenced by nurses as part of a range of measures that pertain to the whole clinical team. Development of these nurse sensitive indicators is progressing but the areas covered e.g. pressure ulcers, while of wide applicability, do not focus on core dimensions of quality in nursing services for specialist services, such as cancer care, particularly outside of an inpatient environment.

Successive cancer policy documents [2, 10] have emphasised the role high quality intelligence about cancer services can play in improving clinical quality and encouraging scrutiny of clinical performance. Measuring variations in outcomes can contribute to enhancing quality by motivating and empowering clinicians to improve care. As a result we were commissioned by the National Cancer Action Team (NCAT) to identify, develop and test a suite of nurse-sensitive indicators that could contribute to the effective monitoring and quality improvement of chemotherapy services alongside other methods, for example the Cancer Services Peer Review process.

A first phase of work aimed to assess the evidence for various indicators and identify a small number of priority areas for development of a pilot system [6]. A series of scoping reviews were undertaken and a number of clinical experts consulted. As a result a shortlist of 11 potential outcome areas was identified.

Overall, although a large number of potential outcomes were identified the evidence to support a link between nursing services and outcomes was often relatively weak. Where evidence did exist that an outcome might be attributable to nursing input, the precise nursing role in achieving the outcome was often unclear.

The clearest case for the direct impact of nurses in the ambulatory cancer chemotherapy setting related to the safety and experience dimensions of quality. Cancer nurses' impact on treatment effectiveness (in terms of successful treatment of the underlying condition) was indirect and mediated through their ability to support patients in managing toxicities from treatment including symptoms [6].

No detailed, readily available specifications for quality indicators were identified. It was recommended nurse-sensitive indicators covering each of the three domains of quality: safety, effectiveness and experience be developed

1) Effectiveness (symptom control): nausea and vomiting
2) Safety: chemotherapy administration
3) Experience of care

In developing quality indicators for chemotherapy nursing teams the aim is to identify measures that relate to important outcomes that are not just known to be sensitive to the contribution of nursing but which also fulfil a range of other criteria. Key features of successful indicators are that they measure important phenomena, are scientifically sound, provide useable information and are feasible to collect [11]. Where comparative performance measures are required, either to benchmark local performance against others for quality improvement or for external comparison purposes, any indicator system would need to permit risk adjustment for key mediating/confounding factors. For example the severity of symptoms experienced is likely to be dependent upon chemotherapy regimens delivered and potentially other patient factors.

Building on our review, this report presents findings from the second phase of work aimed at developing and testing the proposed set of indicators in a small number of pilot sites.

3. Aims and objectives

The aim of this project was to identify, develop and test a suite of nurse-sensitive indicators that could contribute to the effective monitoring of chemotherapy services. Specific objectives were as follows:

1. To develop an instrument to collect data to monitor performance of nurse-sensitive outcome indicators
2. To evaluate the feasibility, utility and acceptability of monitoring nurse-sensitive outcome indicators in clinical practice in a small number of pilot sites across England
3. To undertake preliminary validation of the nurse-sensitive outcome indicators
4. To determine the necessity for, and practicality of, risk adjustment for patient and treatment factors
5. To gather data on contextual factors that may moderate the effectiveness of nursing e.g. skill mix, staffing levels
6. To create a toolkit to support the use of nurse-sensitive outcome indicators in practice

All stages of the project were supported by a number of reference groups.

- Clinical reference group (CRG): This consisted of clinicians from the pilot sites (see Appendix A for full list) who provided insight into the practical aspects of the measurement system and its implementation
- User Reference Group (URG): A patient reference group was convened at the preliminary pilot site consisting of people with cancer who completed chemotherapy within the previous 12 months. This group assisted with assuring the relevance and importance of the domains selected for piloting and in particular the patient experience domain
- Technical reference group (TRG): International experts on patient safety, measuring symptom intensity, developing and testing patient reported outcomes measures and measuring patient experience were consulted (see Appendix B for full list). The primary purpose of this group was to advise on the technical specification of the selected outcomes

Development and testing of the nurse-sensitive outcome indicators was an iterative process whereby a number of overlapping pieces of work were undertaken as shown in Figure 3.1.

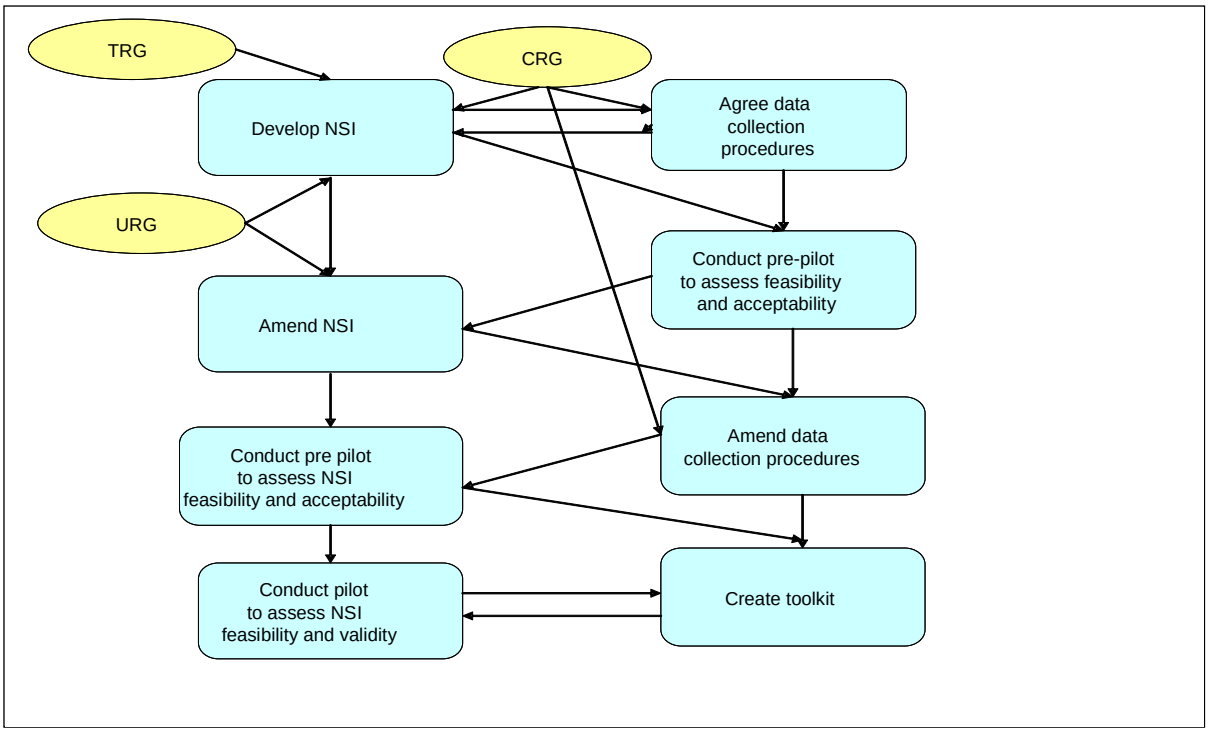
The project was undertaken in partnership with five specialist regional centres across England:

- Clatterbridge Centre for Oncology NHS Foundation Trust
- Guy's & St Thomas' NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Southampton University Hospitals NHS Trust
- St Helen's & Knowsley Teaching Hospitals NHS Trust

As all the partners were specialist regional centres we added a number of smaller units to represent a spectrum of size of unit and likely complexity of care delivered from the North Trent Cancer Network (NTCN) which provided satellite services to the oncology service at Sheffield Teaching Hospitals NHS Foundation Trust. They were:

- Barnsley NHS Foundation Trust
- Chesterfield Royal Hospital NHS Foundation Trust
- Doncaster & Bassetlaw Hospitals NHS Foundation Trust
- Rotherham NHS Foundation Trust

Figure 3.1: Project stages



NSI = nurse sensitive indicators

4. Stage One: Initial development

4.1 Developing nurse sensitive indicators

Based on the results of our phase one work [6], we presented a list of outcome domains and candidate indicators to the Clinical Reference Group to identify potential indicators that met the criteria of:

- Addressing an important topic
- Scientifically valid (including sensitivity to quality of nursing services)
- Possible and practical to collect meaningful data
  Source:[12]

The reference group was encouraged to make suggestions for changes and additions with these principles in mind. An iterative process was adopted whereby the clinical reference group independently rated the nurse sensitive outcome indicators selected using the criteria outlined above and suggested further amendments/improvements.

Tables 4.1-4.3 present the indicators considered during the first phase of the project. The tables include the rationale for including the indicator and what the Clinical Reference Group thought about it in terms of its acceptability, feasibility and interpretability. The final column shows whether at this stage the indicator was selected for further consideration.

Specifications for each indicator were drafted (see Appendices C-E) that included:

- definition
- rationale
- factors the indicators may be sensitive to (other than nursing behaviours/quality)
- potential data sources and assessment of their quality
- potential implementation issues.

A key aspect of selecting and drafting the specifications involved consideration of available data. Data on some of the indicators related to safe drug administration are routinely recorded (e.g. extravasations). Indicators in the effectiveness and experience domains are subjective experiences (e.g. symptom severity) and unlikely to be routinely recorded in a standard form. Because of this we decided that a major focus of the project had to be the design and development of a method for collecting such information. We decided that a patient completed self-assessment / self-report instrument was the most practical approach to gathering valid data.

We therefore drafted a self-assessment / self-report questionnaire that patients could complete with each cycle of chemotherapy. We based the symptom assessment on the widely used Chemotherapy Symptom Assessment Scale [C-SAS, 13] [13]. We included specific items about information and advice to support self-care for nausea and vomiting and more general questions about experiences of care received in the ambulatory chemotherapy setting which were adapted from questions used in national patient surveys [5, 14, 15]. These were adapted to focus on the specific care setting and the input of nurses. We also asked about perceived safety, using items from Schwappach and Wernl [16].

Because we recognised that case mix adjustment would be necessary we also sought information about class of chemotherapy received, mode of drug administration, age and gender. Discussion with the Clinical Reference Group revealed that the participating centres did not have resources to audit patients' medical records to readily provide this information. Therefore this was gathered from patients as they completed the self-report instrument.

Table 4.1: Safety – chemotherapy administration

Suggested measure	Source of data	Rationale	CRG Notes	Selected
Incidence of extravasation of cytotoxic drug per 1000 treatment cycles *	All reported incidents of extravasation	Indicator of poor clinical practice - /stressed overstrectched or inexperienced nurses	Potential underreporting How to classify suspected extravasation Needs risk adjustment for regimen Can be moderated by damage limitation actions (e.g. flushing procedures, administration of antidote)	Y
Extravasation resulting in ulceration per 1000 treatment cycles *	All reported incidents of extravasation	Rare but late indicator of unsafe practice	Potential underreporting Needs risk adjustment for regimen	Y
Pain or irritation at the infusion site per thousand cycles *	Patient self report	Can be caused by the speed of administration therefore indicator of poor practice or poor access to central line service	Potential recall bias Can occur during and after chemotherapy administration so time period patients asked to review important (e.g. time of infusion, 7 days, previous cycle) Needs standard mechanism for recording and collating Needs risk adjustment for chemotherapy agent	Y
Drug administration errors *	Safety reporting systems	Indicator of poor clinical practice	Unclear the extent to which available measures relate to nursing role Potential underreporting Personnel classifications vary on incident forms Drugs errors may not be reported by the person who made the error	N
Nurse assessment of venous integrity $	Patient record	Require prior to each treatment cycle to ensure appropriate route of chemotherapy administration	Potential negative rather than positive recording in patient records Potential process measure	Y
Change in route of chemotherapy administration (eg from intravenous to PICC or central line) $	Patient record	Ensure appropriate route of chemotherapy administration	Potentially unreliably recorded in patient records Availability of skilled personnel/radiology time for insertion of central lines How to account for patient and professional preference	Y
Planned dose on time $	Electronic prescribing system	For adjuvant treatment is an indicator of treatment efficacy	How to account for patient and professional preference	Y
Patient perceptions of safe medicine administration $	Patient report	Insight into detailed processes of care not routinely collected elsewhere	Ambiguous phrasing of some questions How to account for individual personality differences Questionable whether patients can properly judge important aspects of safety Items not relevant to safe chemotherapy drug administration e.g. ensuring venous patency, correct IV flow rate, observation of infusion site etc	Y

*Indicator generated from Phase 1 [6] $ Indicator generated from Clinical Reference Group

Table 4.2: Effectiveness - Nausea and vomiting

Suggested measure	Source of data	Rationale	CRG Notes	Selected
Documented assessment of severity of nausea and vomiting (% per cycle) *	Clinical audit record	Presumed link between assessment and management of symptoms	Documented assessment does not necessarily lead to improved outcomes Potential unreliability of recoding in patient records Potential negative rather than positive recording in patient records Process outcome Time consuming and costly to undertake	N
Patients reporting nausea following treatment (% per treatment) *	Patient self report	Detects severity and distress associated with nausea	Requires a standard mechanism for recording. Needs risk adjustment for regimen Exclude prior to cycle 1	Y
Patients reporting vomiting following treatment (% per treatment) *	Patient self report	Detects severity and distress associated with vomiting	Requires a standard mechanism for recording. Needs risk adjustment for regimen Exclude prior to cycle 1	Y

*Indicator generated from Phase 1[6] $ Indicator generated from Clinical Reference Group

Table 4.3: Patient experience

Suggested measure	Source of data	Rationale	CRG Notes	Selected
Confidence and trust *	Patient self report	Key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Communication *	Patient self report	Key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Ability to get answers to questions *	Patient self report	An aspect of communication and therefore a key indicator of a good patient experience	Needs to be specific to chemotherapy nurses Key issue is information given being in way that patients can understand	N
Information about appropriate self-care *	Patient self report	An aspect of communication and therefore a key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Emergency contact details $	Patient self report	Important specific information which needs to be communicated	Needs to be specific to chemotherapy nurses Process indicator	Y
Information on what to expect $	Patient self report	An aspect of communication and therefore a key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Nurses Rushed during treatment $	Patient self report	Known to deleteriously affect patients experiences	Needs to be specific to chemotherapy nurses	Y
Not wasting time $	Patient self report	Known to deleteriously affect patients experiences		Y
Privacy $	Patient self report	An aspect of communication and therefore a key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Nurses technical skills $	Patient self report	An aspect of confidence and trust and therefore a key indicator of a good patient experience	Needs to be specific to chemotherapy nurses	Y
Receive chemotherapy in 30 mins of arrival $	Patient self report	As wasting time above	Process outcome	Y
Nurses and doctors work together $	Patient report	Continuity of care is a key indicator of patient satisfaction	How will they judge it?	Y
Communication with family $	Patient report	An aspect of communication and therefore a potential indicator of a good patient experience	Patient may not know	Y

*Indicator generated from Phase 1[6] $ Indicator generated from Clinical Reference Group

We included a list of drugs based on classifications of extravasation risk (http://extravasation .org.uk/table.htm) and those known to be a high risk for causing vomiting [17]. Extravasation risk was classified as follows. The higher the grouping, the higher the risk of causing severe and serious tissue damage:

- Group 5: Vesicants
- Group 4: Exfoliants
- Group 3: Irritants
- Group 2: Inflammitants
- Group 1: Neutrals – only cyclophosphamide >1500mg included from this group

During this phase we also identified workforce and contextual information that would be required.

We undertook preliminary testing of the indicators with members of a patient reference group (n=9) who worked with one of our collaborating centres. They were asked to complete the questionnaire and comment on:

- difficulties in understanding the questions
- ease of completion
- appearance
- willingness to complete the measure with each cycle of chemotherapy
- potential improvements

On the whole the respondents found the questionnaires easy to answer and completion took approximately 10-15 minutes. They all said they would be willing to complete it each time they received chemotherapy, although one said they would only do it if it was used to guide care delivery.

In order to focus closely on patient experience that was most important to patients we also conducted five detailed individual interviews. This provided us with an in depth understanding of patients' perspectives so that we could develop the right questions for the self-report/self-assessment questionnaire to assess what it is the chemotherapy nurses did and said that promoted a positive experience of receiving chemotherapy.

On the basis of the feedback gathered during this phase of the project the content of the self-report measure was finalised. Appendix F provides details on the decision-making process and Table 4.4 outlines the items included. The main alterations to the measure were:

1. to add extra symptoms to the effectiveness domain, so that it was more comprehensive as the absence of some symptoms appeared to negate their importance
2. to remove the patient-reported items on perceptions of safe medicine administration because of lack of clarity on the meaning of subjective experiences of objective safety behaviours.
3. to reduce the number of items overall and shorten completion time
4. to reduce / avoid overlap with items covered by national surveys
5. to focus on elements of experience that were related to supporting self-care or were most strongly endorsed as important but problematic by patients

Table 4.4: Modifications to items on the self-report measure

Initial items	Added / adapted during development	Selected?
Safe medicine administration		
Incidence of extravasation of cytotoxic drug/1000 treatment cycles		√
Extravasation resulting in ulceration/1000 treatment cycles		√
Pain or irritation at the infusion site per thousand cycles		√
Nurse assessment of venous integrity		
Change in route of chemotherapy administration		
Planned dose on time		
Patient perceptions of safe medicine administration		
Effectiveness		
Patients reporting severe nausea following treatment (%/treatment)		√
Patients reporting severe vomiting following treatment (%/treatment)		√
	Patients reporting severe problems with mouth or throat following treatment (%/ treatment)	√
	Patients reporting feeling severely weak following treatment (% per treatment)	√
	Patients reporting feeling severely weak following treatment (%/treatment)	√
	Patients reporting feeling severely tired following treatment (%/ treatment)	√
	Patients reporting feeling severely low or depressed following treatment (%/ treatment)	√
Patients reporting nurses ask about symptoms		√
Patients reporting nurses provide practical advice about managing symptoms		√
	Patients reporting nurses ask about severity of symptoms	√
	Patients reporting nurses useful information of symptoms	√
	Patients reporting Confidence to manage symptoms	√
Experience of process of care		
Confidence and trust		
Communication		
Information about appropriate self care		
Information on what to expect	Information on what to expect with oral chemotherapy	√
Rushed during treatment		√
Unnecessary time waiting		√
Privacy		
Nurses skilled and gentle at cannulation		√
Receive chemotherapy in 30 minutes of arrival		
Nurses and doctors work together		
Communication with patient		√

The final set of indicators cover

- ***severity of subjective symptoms*** resulting from treatment, across a range of domains, including those that we identified as most sensitive to the quality of nursing services (nausea, vomiting, oral problems)
- perceptions of assessment, information and ***support to manage symptoms*** offered to patients by nurses who administer chemotherapy (support for self-care)
- ***safety of drug administration*** (extravasation and pain at infusion site) and
- ***patient experience*** of the administration process and informational support

Completion time was reduced to 5 minutes which we judged to be more acceptable for a questionnaire that was to be completed every 3-4 weeks (depending on treatment regimen).

4.2. Development of the data collection plan

As electronic systems varied across sites and were not generally used routinely to assess patient symptoms, a pen and paper based system was adopted. We envisaged that effectiveness indicators would be completed prior to each cycle of chemotherapy and that chemotherapy nurses would use them to guide the clinical assessments they make. Thus they would be used repeatedly with patients to explore change over time. Whilst symptoms may vary between cycles and could be phrased in a manner which could be asked at each cycle, this was more problematic with some aspects of experience of care. Thus we identified some of the experience indicators that would be completed only once during the course of chemotherapy.

The data collection plan we developed was informed by a detailed site visit to Southampton University Hospitals NHS Trust in which we mapped the flow of patients through the chemotherapy day centre in order to identify the best way of approaching patients so the maximum number completed the self-report/self-assessment questionnaire. Moreover we were mindful of the need to minimise the impact of data collection on chemotherapy day centre staff. In brief, the resulting data collection procedure was as follows:

- On arrival at the chemotherapy day centre reception staff would ask all patients to complete the self-report questionnaire
- Patients to return completed self-report questionnaire in a receptacle in the patients waiting area
- Local project lead to collect extravasation and contextual data weekly

At the same time a toolkit was developed to aid data collection. This outlined key tasks that needed to be performed and included a number of resources including a script for staff to use when approaching patients, a sheet on which to record reasons for non-completion, a weekly checklist for contextual data collection.

5. Stage Two: Pre piloting

The key task of this phase was to pilot data collection in a single centre so as to:

- assess the feasibility of asking patients to complete the questionnaire when they attend for chemotherapy
- monitor the data returns to identify potential problems
- make a preliminary assessment of the sensitivity and variability of the indicators
- assess the relevance and feasibility of collecting workforce and contextual information
- amend the toolkit as necessary

The preliminary pilot study was undertaken at Southampton University Hospitals NHS Trust over a week period (4/10/10 – 8/10/10). The self-report questionnaire was given to patients by receptionists as they checked into the chemotherapy day suite.

5.1 Results

Ninety-two patients were eligible to participate and of these 68 (74%) returned the self-report questionnaire. A heterogeneous sample was recruited in terms of sex, age, treatment cycle and class of chemotherapy drug received. The incidence of extravasation and ulceration caused by extravasation was zero.

Missing data varied according to the question being asked. For example 4% of people did not record which age band they fell into and 13% did not report the cycle of treatment. Across all items on the outcomes a quarter of respondents (24%) did not answer at least one question.

Overall levels of severe symptoms experienced were relatively low although substantial numbers did experience at least moderate symptoms for all areas assessed. More than 20% of patients reported experiencing moderate or severe tiredness, weakness and nausea. When patients were asked to rate what they perceived chemotherapy nurses did to manage their symptoms almost 30% said that nurses did not ask about whether they were experiencing symptoms and a similar number reported nurses were not aware of the severity of their symptoms. A smaller proportion felt that the nurses were not providing useful support for symptom management. In relation to other aspects of experience there was also significant variation on most items. Almost 20% of patients receiving oral chemotherapy said the chemotherapy nurses did not ask whether they felt able to manage. The majority said that to some extent at least they spent an unnecessary amount of time waiting for their treatment.

Respondents used the full range of scores for each item. A small number of changes were made to the questionnaire and these are indicated in Appendix F. The final version of the self-report questionnaire employed in stage three can be found in Appendix G. A number of minor amendments were also made to the toolkit.

6. Stage Three: full pilot testing

The final phase of the project aimed to

- test the feasibility, acceptability and utility of the indicators
- refine specifications of the indicators
- evaluate methods for providing feedback to centres
- amend the toolkit to incorporate lessons learnt from using the indicators in practice
- make recommendations for future development and use of the indicators

The main pilot study commenced in 15th November 2010 and continued till 18th March 2011. Each site was asked to run the pilot for 12 weeks. All measures were professionally printed and despatched to centres along with other relevant documentation. A member of the project team visited each site to familiarise staff with the indicators and the procedures for data collection. It was recommended that a project lead be identified at each site to act as a local champion and drive the project forward. Once data collection was underway the project team provided regular support via email/phone contact. Each week centres were asked to return data (completed self-report questionnaires, rates of extravasation and resulting ulceration, numbers treated, reasons for non-completion, staffing levels/skill mix and use of acute oncology services).

Measures were distributed to all patients by reception staff in the ambulatory chemotherapy areas. An exception was patients attending for their first treatment as they would not be able to reflect on their previous cycle of treatment. Those administering the self-report questionnaire were asked to note any reasons for non-completion so the acceptability of the measure could be assessed. The total number of patients treated each week who were eligible to complete the measure was used to calculate the response rate.

Mid way through data collection and at the end of the project, the project leads were sent a copy of the results, in the same format as Charts 6.1-6.5. Whilst they were informed of the code letter for their centre, results for the other centres remained anonymous. Thus they were able compare their results with those of other centres.

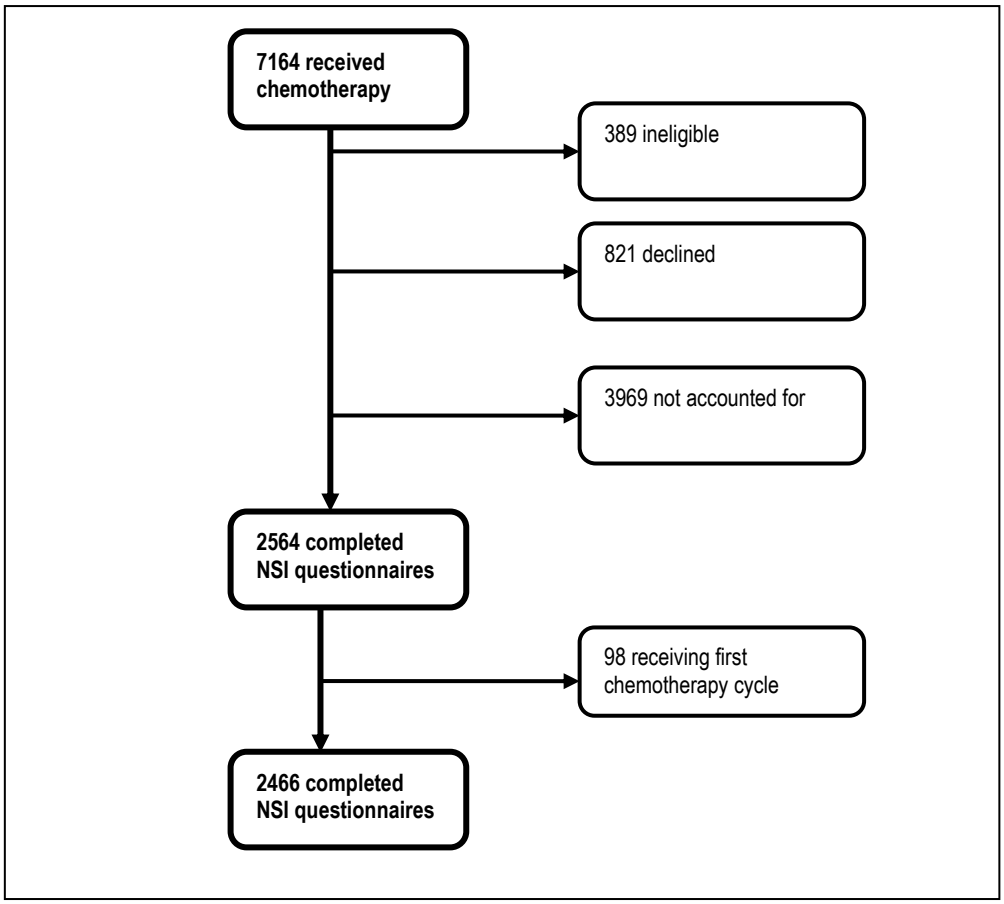
We formally assessed the experiences of staff by means of qualitative interviews either face-to-face or over the phone with the project lead at each participating centre to explore their assessments of data quality and the burden of data collection (see Appendix H for topic guide).

6.1 Results

Centres were asked to recruit for 12 weeks however few achieved this. The main reasons being poor weather conditions during December 2010 and staffing/scheduling issues over the Christmas period. Figure 6.1 outlines the flow of patients through the study.

In total 2564 completed self-report questionnaires were returned, however 98 were excluded as patients were receiving their first cycle of chemotherapy. Therefore analysis was conducted on 2466 self-report questionnaires. It should be noted that patients may have completed the outcome measure repeatedly and so it is likely that the number of people participating is less than the number of questionnaires returned.

Figure 6.1: Flowchart of recruitment



6.1.1 Participation rate

The sampling frame could not be precisely enumerated, as centres were able to provide us with estimates of patients currently receiving treatment over the data collection period but not cycles of treatment administered during periods when the questionnaire was being distributed.

Overall we achieved a response rate of 38% (that is an average of 0.38 responses per potentially eligible patient during the12 week pilot period). The response rate varied widely between centres with the lowest being 10% while one centre achieved a rate of over 161% (that is an average of 1.61 responses per patient). However, as we know that questionnaires were not offered to all patients and data was not collected for the full period in all centres, thus reducing the number of potential number of administrations, it is clear that this substantially underestimates the true response rate. We also calculated a response rate based on the number of patients we knew had been approached: that is where a questionnaire was returned or a response of ineligible or declined was recorded. Using this rate gave response rates of between 40% and 87%, with most centres achieving over 70%. As data on eligibility or refusal to participate may not have been consistently collected this could be an overestimate for some centres (Table 6.1).

Table 6.1: Response rates by site

	J	K	L	M	N	P	Q	R	S*	T	All
Patients receiving chemotherapy (n)	2464	140	244	187	153	593	706	487	402	1788	7164
Questionnaires completed (n)	*250*	*30*	*117*	*154*	*191*	*522*	*126*	*737*	*85*	*352*	*2564*
Ineligible patients (n)	60	8	18	22	20	74	85	33	-	69	389
Declined participation	98	9	19	119	45	93	188	115	-	135	821
Number of patients unaccounted for	2172	93	166	141			307	198	-	1232	3969
Rate for all patients (those known to be ineligible)	10%	23%	52%	93%	144%	101%	20%	162%	-	20%	38%
Rate among known approached	72%	77%	86%	56%	81%	85%	40%	87%	72%	72%	76%

*combined with Centre T

The personal characteristics of the sample are shown in Table 6.2. More men than women were recruited to the study, particularly at Centres K and P, although this was not the case across all centres. Of those recruited 53% were aged between 50-70 years and for all but one of the centres the proportion ranged from 53% to 61%. Whilst fewer (34%) were recruited from this age band at Centre J, this figure may not be accurate as 34% of participants did not provide this information. Ninety per-cent of the sample identified themselves as being of white ethnicity. The only centres that recruited a greater proportion of people from Black and minority ethnic backgrounds were Centres S (26%) and T (32%).

For the whole sample, 33% chose not to provide information on their cancer diagnosis although this rate varied across centres. Thus whilst only 13% of cancer diagnoses were missing at Centre Q, 50% were missing from Centre J. Of those who provided diagnostic information (n =1664) 46% were diagnosed with either breast, colorectal, lung, gynaecological or haematological cancers and almost half of these had a breast cancer diagnosis (48%). The types of cancer recruited varied between centres, for example Centre K only recruited people being treated for breast cancer and Centre S mainly recruited those with colorectal cancer. A wider variety of cancer diagnoses were reported from centres that recruited larger numbers (J, P, R, T). See Table 6.3. Full details are shown in Appendix I.

Table 6.2: Personal characteristics

Centre	J	K	L	M	N	P	Q	R	S	T	Total
N	250	30	117	154	191	522	126	737	85	352	**2466**
Sex N (%)											
Male	49 (20)	18 (62)	52 (44)	56 (37)	82 (44)	279 (55)	51 (45)	317 (45)	36 (42)	121 (36)	**1061(43)**
Female	92 (38)	6 (21)	48 (41)	66 (44)	73 (40)	135 (27)	57 (50)	249 (35)	26 (31)	128 (38)	**880 (36)**
Missing	99 (41)	5 (17)	17 (15)	29 (19)	30 (16)	93 (18)	5 (4)	142 (20)	23 (27)	86 (26)	**525 (21)**
Age N (%)											
18-30	2 (1)	-	2 (2)	7 (5)	4 (2)	4 (1)	1 (1)	2 (<1)	2 (2)	9 (3)	**32 (1)**
31-40	8 (3)	5 (17)	9 (8)	7 (5)	4 (2)	24 (5)	7 (6)	32 (4)	1 (1)	17 (5)	**113 (5)**
41-50	21 (9)	5 (17)	12 (10)	21 (14)	24 (13)	99 (19)	14 (12)	113 (16)	9 (11)	53 (15)	**368 (15)**
51-60	34 (14)	6 (21)	29 (25)	44 (29)	34 (18)	129 (25)	32 (28)	220 (31)	24 (40)	83 (24)	**630 (25)**
61-70	48 (20)	11 (38)	37 (32)	49 (32)	77 (42)	159 (31)	37 (33)	174 (25)	15 (19)	101(29)	**702 (28)**
71+	46 (19)	2 (7)	23 (20)	17 (11)	39 (21)	79 (17)	20 (18)	151 (21)	22 (27)	58 (17)	**456 (19)**
Missing	81 (34)	-	5 (4)	6 (4)	3 (2)	13 (3)	2 (2)	16 (2)	8 (1)	31 (9)	**165 (7)**
Ethnicity N (%)											
White	154 (64)	29 (100)	112 (96)	144 (95)	176 (95)	488 (96)	113 (100)	689(97)	60 (74)	229 (68)	**2213 (90)**
Mixed	-	-	-	1 (1)	-	-	-	1(<1)	3 (4)	8 (2)	**13 (1)**
Asian	1 (<1)	-	-	1 (1)	2 (1)	6 (1)	-	3(4)	2 (2)	5 (2)	**20 (1)**
Black	2 (1)	-	-	-	2 (1)	2 (<1)	-	-	5 (10)	37 (11)	**44 (2)**
Chinese	-	-	-	-	-	1 (<1)	-	-	-	2 (1)	**3 (<1)**
Other	1 (<1)	-	-	-		-	-	-	3 (4)	7 (2)	**11 (<1)**
Missing	82 (34)	-	5 (4)	5 (3)	5 (3)	10 (2)	-	13(2)	8 (10)	32 (9)	**159 (6)**

The most frequently administered class of chemotherapy drugs were exfoliants (21%) and inflammitants (19%). Eight percent were receiving highly emetogenic treatments. Staff distributing the questionnaires reported that patients found completing the section on chemotherapy drugs received difficult either because they did not know what drugs they were receiving or because they did not understand why their particular chemotherapy drugs were not listed. As a consequence it is possible that this data is incomplete. Almost 50% of the sample was receiving cycles 2, 3 or 4 of their chemotherapy treatment and the majority were receiving their treatment as an infusion or injection (66%) via a peripheral cannula (69%).

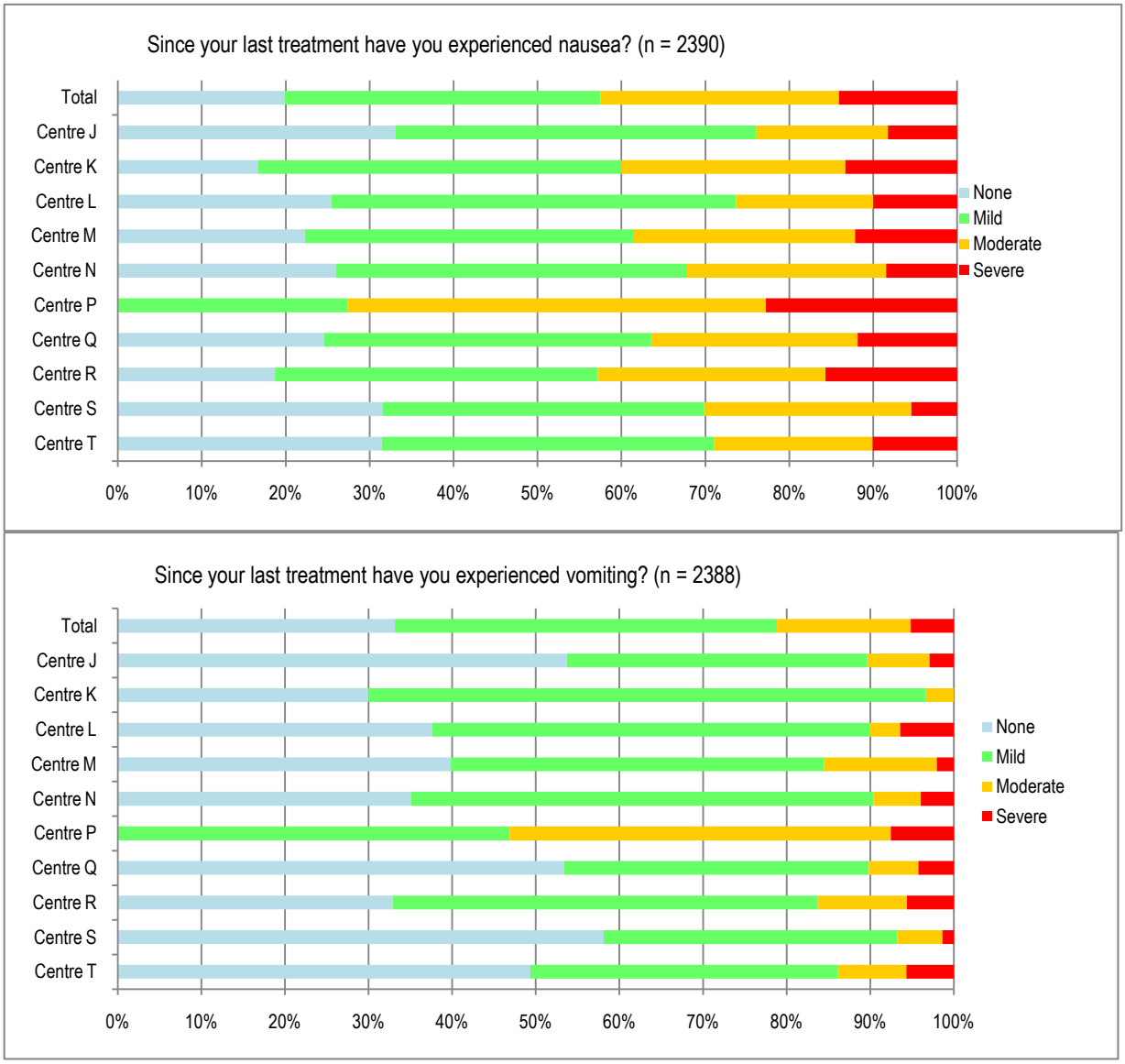
Table 6.3: Diagnosis and treatment received

Centre	J	K	L	M	N	P	Q	R	S	T	Total
N	250	30	117	154	191	522	126	737	85	352	**2466**
Diagnosis N (%)											
Colorectal	8 (3)	-	13 (11)	1 (1)	9 (5)	40 (8)	9 (8)	98 (14)	25 (31)	5 (2)	**208 (8)**
Breast	33 (14)	24 (83)	44 (38)	32 (21)	45 (24)	128 (25)	24 (21)	182 (25)	-	49 (15)	**561 (23)**
Lung	8 (3)	-	18 (15)	30 (20)	34 (18)	51 (10)	8 (7)	39 (6)	-	44 (13)	**232 (9)**
Gynaecological	15 (6)	-	2 (2)	4 (3)	-	39 (8)	20 (18)	50 (7)	7 (9)	18 (5)	**155 (6)**
Other	60 (24)	-	17 (16)	59 (38)	54 (28)	105 (20)	49 (39)	143 (19)	18 (21)	101 (29)	**508 (21)**
Missing	126 (50)	5 (17)	23 (20)	29 (19)	49 (27)	159 (30)	16 (13)	225 (32)	35 (41)	135 (41)	**802 (33)**
Received vesicant chemotherapy N (%)	39 (16)	3 (10)	2 (2)	17 (11)	8 (4)	50 (10)	30 (27)	84 (12)	5 (6)	57 (17)	**296 (12)**
Received irritant chemotherapy N (%)	27 (11)	-	17 (15)	44 (29)	32 (17)	155 (31)	24 (21)	99 (14)	18 (22)	54 (16)	**470 (19)**
Received exfoliant chemotherapy N (%)	41 (17)	5 (17)	5 (4)	11 (7)	17 (9)	128 (25)	35 (31)	129 (18)	28 (35)	118 (35)	**517 (21)**
Received inflammitant chemotherapy N (%)	17 (7)	14 (48)	27 (23)	30 (20)	35 (19)	89 (18)	15 (13)	103 (15)	26 (32)	29 (9)	**385 (16)**
Received highly emetogenic chemotherapy N (%)	18 (8)	-	27 (23)	30 (20)	35 (19)	89 (18)	15 (13)	103 (15)	26 (32)	29 (9)	**193 (8)**

6.1.2 Severity of subjective symptoms

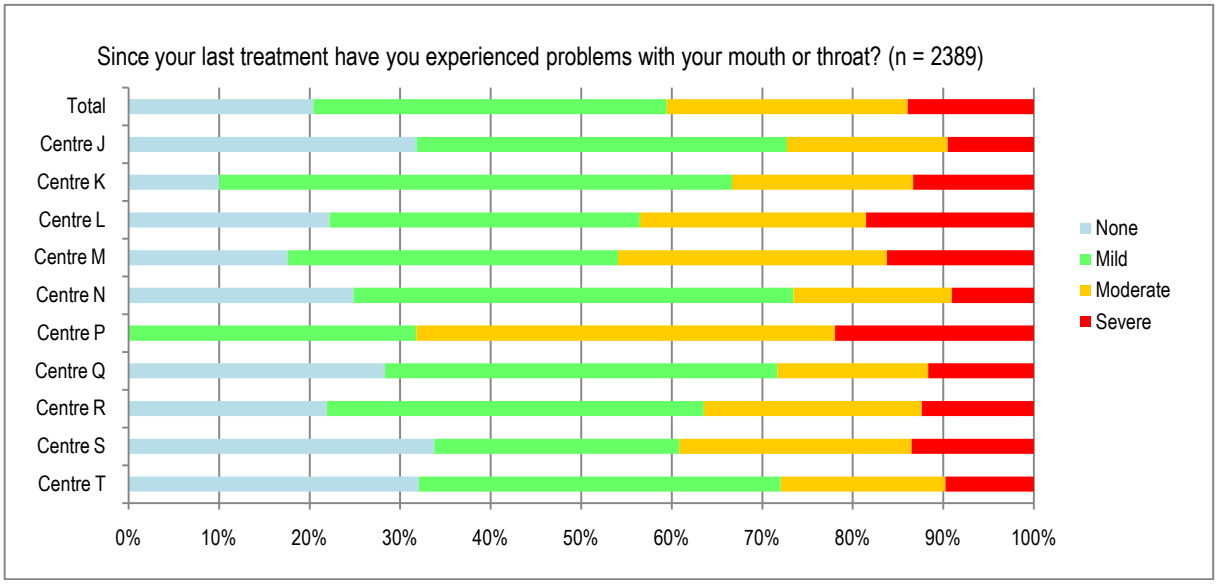
Forty-three per cent of patients reported experiencing moderate or severe nausea though this varied across sites (see Chart 6.1). For example, at Centre P 73% reported moderate or severe nausea whilst the proportion at Centre J was 24 %. Across the whole sample the proportion reporting no nausea was 19% however at Centre P there were no patients who did not report this symptom. At the remaining centres scores ranged between 17% - 33%. It is possible that these differences could be explained by between centre differences in treatment regimens. Moderate or severe vomiting was reported by 21% of the whole sample. For six centres the rate of moderate and severe vomiting was 10% or less (see Chart 6.1). Once again scores for Centre P differed substantially from the other centres with 53% reporting moderate or severe vomiting. On the whole there was a large number (approximately 40%) of people who said that they had not experienced any vomiting with their previous cycle of chemotherapy.

Chart 6.1: **Nausea and vomiting**



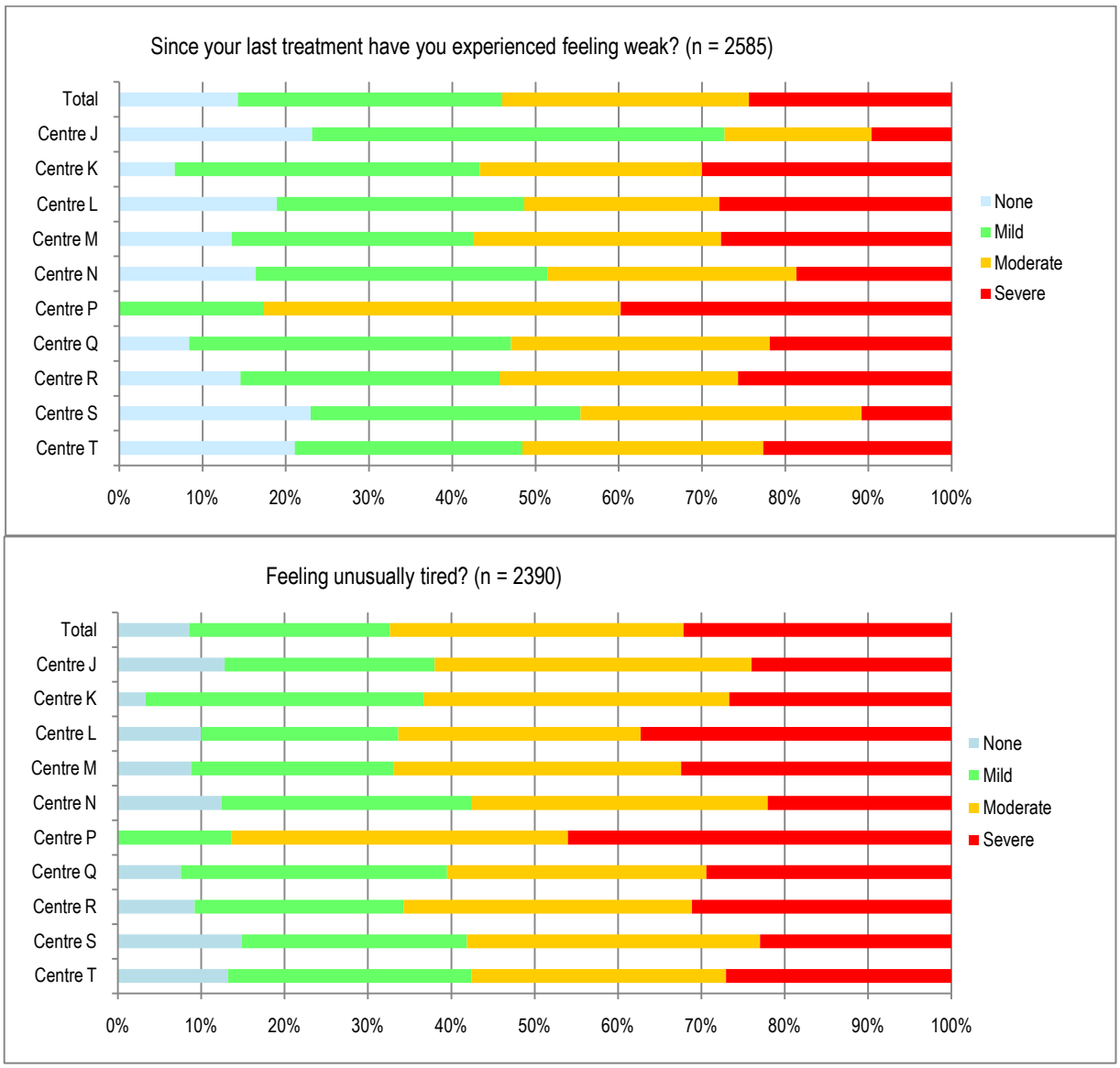
Moderate or severe oral problems were highly prevalent with 41% reporting it as a moderate or severe problem (Chart 6.2). There was variation between centres with the lowest proportion being 27% (Centre N) and the highest being Centre P (68%).

Chart 6.2: Oral problems



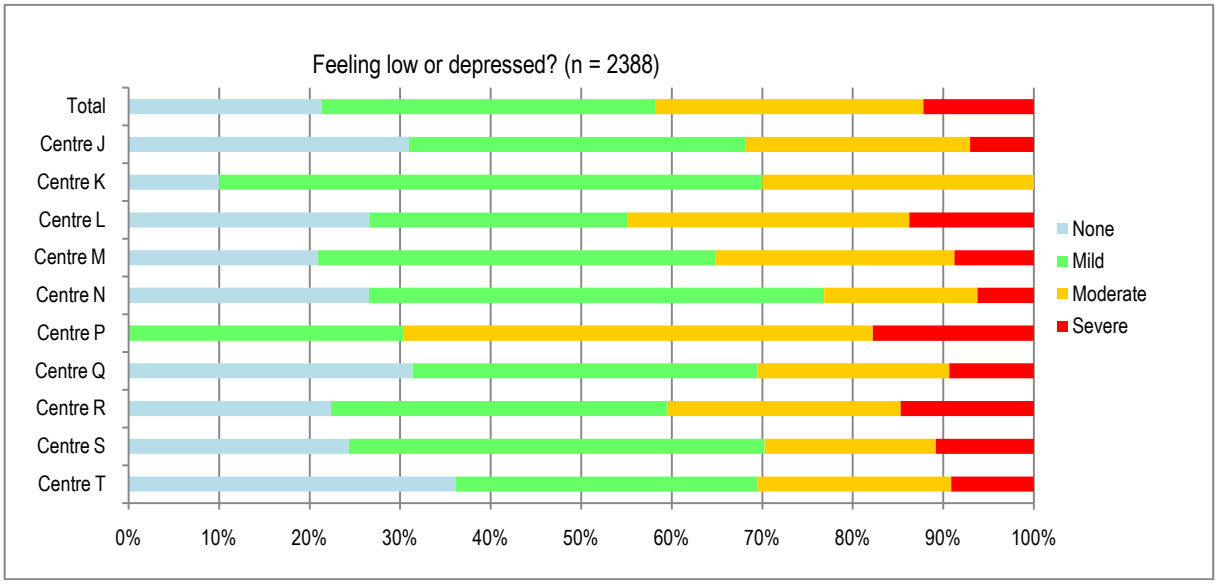
Moderate or severe weakness and moderate or severe unusual tiredness (Chart 6.3), were the most commonly reported symptoms, with reported rates of 54% and 67% respectively. At seven centres less than 40% rated their weakness as moderate or severe. The scores for Centre P differ as the proportion with moderate or severe weakness was 83% and there were no patients who did not experience it.

Chart 6.3: Weakness & tiredness



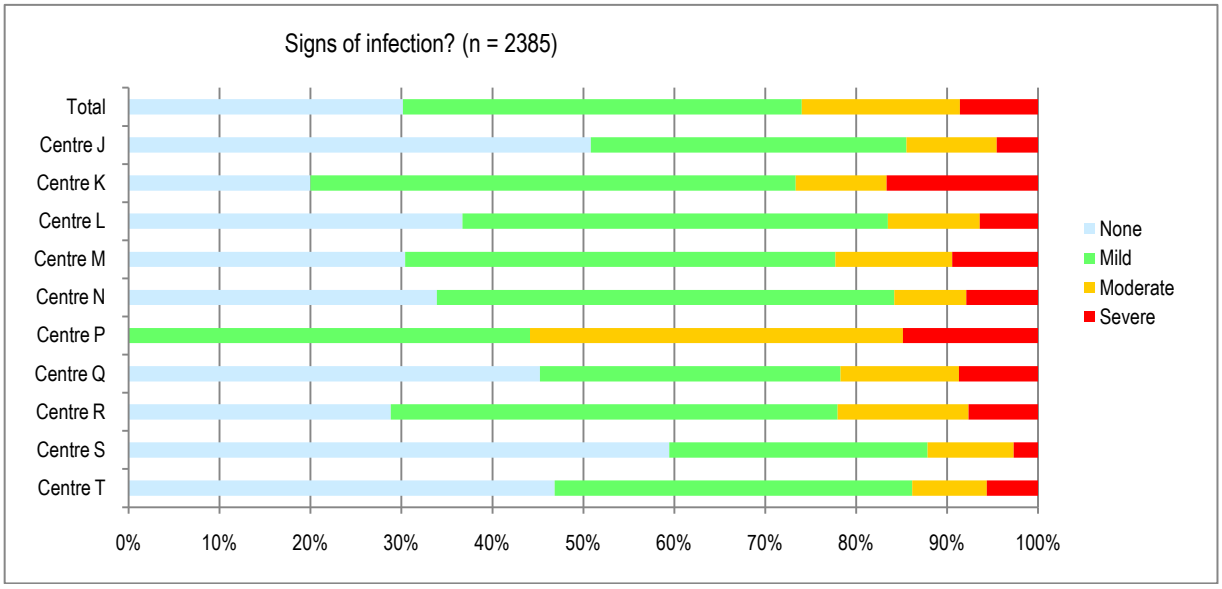
Across the whole sample 41% of respondents reported experiencing moderate or severe feelings of being low in mood or depressed (see Chart 6.4). There was variability between centres particularly in relation to the reporting of severe problems, for which the proportion ranged from 0% (Centre K) to 18% (Centre P). Results for Centre P differ from the other centres as more respondents reported feeling moderately low or depressed (52%) and there was no one who said they did not experience this symptom at all.

Chart 6.4: **Low or depressed**



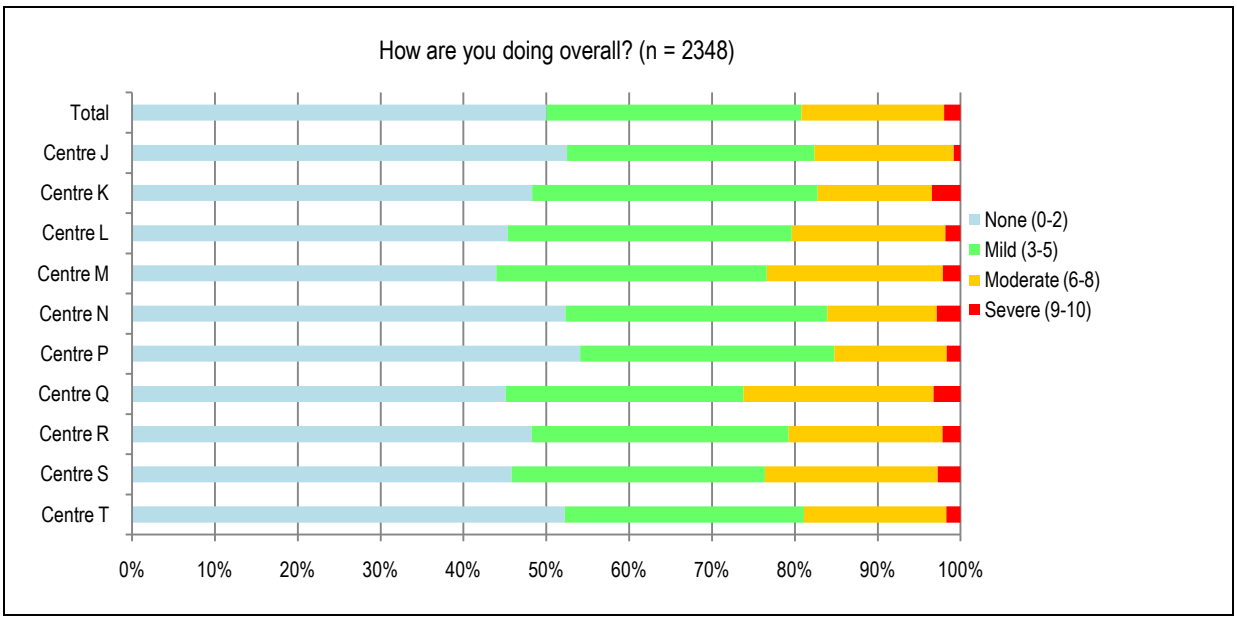
The proportion reporting they experienced moderate or severe signs of infection (see Chart 6.5) was over 10% in all centres (K and P). Rates varied from 12% in Centre S to 56% in Centre P. At Centre P there were no respondents who did not experience this symptom at all.

Chart 6.5: **Signs of infection**



Results of the "distress thermometer", designed to indicate global distress (see Chart 6.6) suggest it is not measuring the same construct as that assessed by the feeling low or depressed item as there is a smaller proportion (19%) who report moderate or severe distress (0-2). There is less between centre variability on this item.

Chart 6.6: Distress thermometer



6.1.3 Risk adjusted symptoms

Direct comparison between centres requires the assumption that like is being compared with like. However, variation in patient characteristics, case mix and drugs used will affect the symptoms experienced, irrespective of the quality of care delivered.

Regression-based models were used to adjust for case mix. We calculated a standardised symptom ratio (SSR) for nausea, vomiting, mouth problems and overall distress. This is analogous to the widely reported 'Hospital Standardised Mortality Ratios' used by Dr Foster to compare hospital death rates, and a similar methodology was used. The standardised symptom ratio is the ratio of the number of people reporting moderate or severe symptoms to the number predicted for that centre from a regression model. For overall distress, the proportion scoring above the 75th centile (≥5) was modelled.

The predictive variables in Box 6.1 were entered as dependants in a logistic regression analysis and the sum of predicted probabilities was used to calculate the expected number of cases. In order to make use of all the data, missing values on the following key predictor variables were imputed using multiple imputation techniques in SPSS: method of administering treatment, method of receiving treatment, sex, age, diagnosis and ethnicity. 99% confidence intervals (99% CI) were estimated using Byar's approximation to the Poisson distribution.

Box 6.1: Variables used to calculate the standardised symptom ratio

Demographics:
- Age (18-30, 31-40,41-50, 51-60, 61-70, 71+)
- Sex (male, female)
- Ethnicity (White UK, all other categories)

Clinical
- Diagnosis (Colorectal, breast, lung, gynaecological, haematology, other cancers)

Treatment
- Emetogenic treatments
- Inflammitant treatments
- Exfoliant treatments
- Vesicant treatments
- Treatment cycle (1, 2-5, 6-7, 7+)

A standardised symptom ratio of more than 100% indicates that more patients than would be expected were experiencing symptoms, based on the clinical, demographic and treatment characteristics of the patients treated. Each centre was ranked according to raw scores and SSR for moderate or severe symptoms (rank 1 = highest standardised symptom ratio). For each item the centres unadjusted rank order was compared to the adjusted ranking using correlation: the closer the correlation coefficient to 1 the greater the similarity between the unadjusted and adjusted rankings.

Overall, risk adjustment made relatively little difference to the 'ranking' of centres in terms of proportion of patients experiencing severe or moderate symptoms. Correlations between adjusted and unadjusted ranking were high across all items - see Table 6.4. A traffic light colouring system has been applied to the ranks, with green indicating lower scores and red higher scores.

Table 6.4: Standardised and unstandardised symptom rates

Centre	Rate per 100 patients	Rank	SSR	Rank	Lower CI	Upper CI	Correlation of un-standardised rank and SSR rank
Nausea							
J	25	10	67%	9	46%	93%	0.90
K	41	3	82%	5	33%	165%	
L	26	9	60%	10	35%	96%	
M	39	4	82%	4	57%	115%	
N	33	6	74%	8	51%	103%	
P	73	1	160%	1	139%	184%	
Q	38	5	89%	3	57%	131%	
R	43	2	103%	2	88%	119%	
S	32	7	77%	6	42%	129%	
T	29	8	75%	7	56%	97%	
Vomiting							
J	11	5	57%	5	32%	94%	.99
K	3	10	14%	10	0%	101%	
L	10	7	48%	6	19%	99%	
M	16	3	68%	3	37%	114%	
N	9	8	40%	8	18%	76%	
P	54	1	233%	1	197%	274%	
Q	10	6	47%	7	18%	98%	
R	17	2	83%	2	64%	105%	
S	7	9	33%	9	7%	94%	
T	14	4	66%	4	43%	96%	
Mouth problems							
J	28	9	77%	6	55%	105%	.88
K	34	6	71%	9	26%	151%	
L	44	3	106%	3	71%	153%	
M	47	2	107%	2	76%	145%	
N	27	10	65%	10	43%	94%	
P	69	1	156%	1	134%	180%	
Q	29	7	72%	8	43%	112%	
R	37	5	92%	5	77%	108%	
S	40	4	97%	4	57%	154%	
T	28	8	75%	7	56%	98%	
Distress							
J	26	10	86%	10	61%	119%	.98
K	28	8	88%	9	28%	204%	
L	31	5	97%	4	59%	150%	
M	38	1	117%	1	79%	165%	
N	30	6	96%	6	65%	135%	
P	28	9	90%	8	71%	112%	
Q	34	2	111%	2	72%	163%	
R	33	3	109%	3	91%	129%	
S	29	7	93%	7	49%	159%	
T	32	4	97%	5	73%	126%	

Only one centre (P) was a clear outlier, with the standardised symptom ratio being significantly above 100% for all symptoms except overall distress, indicating that investigation into the cause of the difference between this centre and others is warranted. However, two notes of caution should be issued here, prior to further discussion of this issue. The relative lack of change in ranks after this procedure suggests that the differences observed may not be simply a matter of differences in case mix on the variables that we measured. However, the information used to produce the risk adjustment model was incomplete and this does not by any means represent the ideal model. Further, since centre P returned a large amount of data compared to most others, the fact that most other SSRs are below 100% should not give undue reassurance as this really only reflects performance relative to that in Centre P. The relative, as opposed to absolute, SSR is probably the best indicator.

6.1.4 Support to manage symptoms

These items assess patient's perceptions of what nurses do in response to symptoms they experience (see Charts 6.7- 6.8). Across the whole sample the majority of patients report that the chemotherapy nurses ask about their symptoms (90%), are aware of symptom severity (85%), provide useful information (87%) and practical advice for symptom management (87%). However, a significant number did not fully agree with these statements and there was large variation between centres. Most respondents said they felt confident about managing their symptoms (85%).

Although respondents from Centre P consistently reported more moderate or severe symptoms, ratings for the process of symptom management were comparable to the other centres. Conversely, whilst the proportion of those with moderate or severe symptoms at Centre J was average or below average, respondents rated the nurses lower than other centres on the process of symptom management. However, overall and despite the small sample size (10) there was some modest evidence of correlation between a centre's performance on support to manage symptoms and symptom control (see Table 6.5). In particular, centres where more patients believed that nurses were aware of symptoms and provided information tended to have patients with better symptom control for vomiting and mouth problems and fewer reporting pain at their infusion site. However global distress did not show a similar relationship.

Chart 6.7: Support to manage symptoms (1)

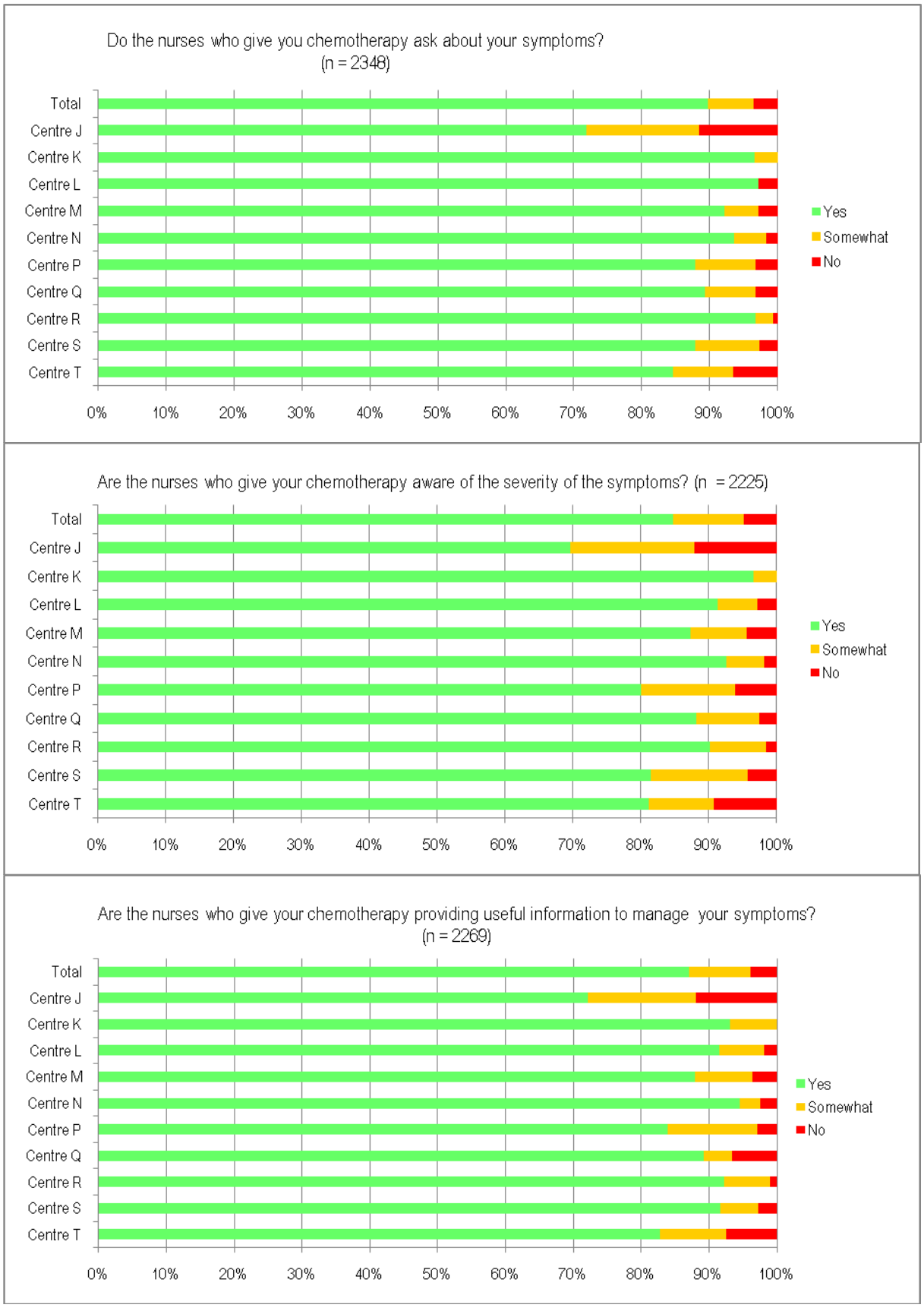


Chart 6.8: Support to manage symptoms (2)

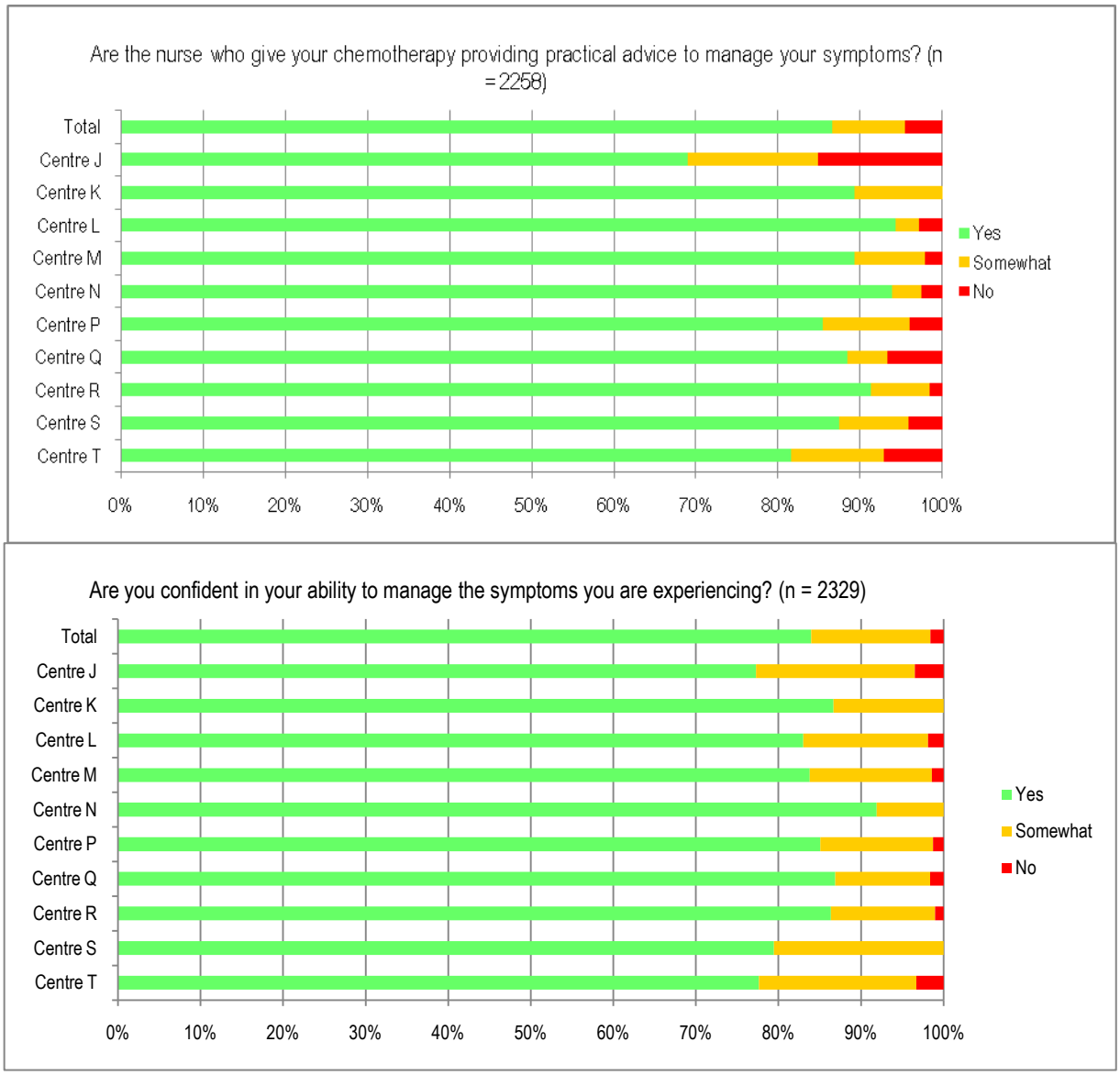


Table 6.5: Correlations between support and symptoms (centre level n=10)

	Nausea	Vomiting	Pain at infusion site	Mouth problems	Overall distress
Nurses ask about symptoms	.006	.200	.297	.067	-.406
Nurses aware of symptoms	.091	.527*	.624**	.479*	-.236
Nurses give useful information	-.030	.552**	.673**	.430	-.079
Nurses give practical advice	.109	.207	.340	.097	-.456*
Confidence in self care ability	.333	.842***	.527*	.212	.079

*** Correlation is significant at the 0.01 level (1-tailed)
** Correlation is significant at the 0.05 level (1-tailed)
* Correlation is significant at the 0.10 level (1-tailed)

6.1.5 Relationship with 2010 National Patient Experience Survey

Although it is not focussed on nursing the 2010 National Cancer Patient Experience Survey (NPES) [5] asks specific questions of those who have been treated with chemotherapy (see Box 6.2). We explored the correlation between symptom experience and support data from our nurse-sensitive indicators (adjusted ranks for symptoms) with 2010 national survey results for the centres in the study (see Table 6.6). We correlated the proportion of patients endorsing each item in the 2010 national survey (rank score) with the rank of the centre on our indicators.

Box 6.2: 2010 National Patient Experience Survey chemotherapy specific questions [5]

Q56: Did hospital staff do everything possible to control the side effects of chemotherapy?

Q57: While you were being treated as an out-patient or day case, did the hospital staff do everything they could to control your pain?

Q58: While you were being treated as an out-patient or day case, were you given enough emotional support from the hospital staff?

There was a high correlation between national survey scores on some aspects of symptom experience (nausea, vomiting, IV pain and oral problems) and the 2010 NPES questions [5]. However the relationship with the nursing support questions was small or non-existent.

Table 6.6: Correlations with 2010 National Patient Experience Survey items [5]

	National Patient Experience Survey		
Nurse Sensitive Indicators	Side effects (Q56)	Pain (Q57)	Emotional support (Q58)
Nausea	-.247	-.602**	-.586**
Vomiting	-.570*	-.347	-.682**
IV pain	-.383	-.694***	-.630**
Distress	-.741**	-.529*	-.769***
Ask about symptoms	-.630**	-.091	-.638**
Aware of symptom severity	.434	-.110	.035
Useful information	.017	-.329	-.297
Practical advice	.017	-.274	-.280
Confidence in self-care	.427	-.257	-.009

*** Correlation is significant at the 0.01 level (1-tailed)
** Correlation is significant at the 0.05 level (1-tailed)
* Correlation is significant at the 0.10 level (1-tailed)

6.1.6 Patient experience

Patients were asked to complete additional items regarding their experience of the process of the chemotherapy administration process and informational support once during the data collection period. This was a pragmatic decision aimed at reducing the burden on respondents who were being asked to complete the outcome measure repeatedly during the data collection period. The rationale for this was because responses on these items were generally summative of the entire experience and unlikely likely to change much, unlike those assessing chemotherapy-related symptoms and the process of symptom management.

Unfortunately the longer version of the outcome measure was inconsistently administered between sites due to distribution problems. Thus, small numbers (<50) were returned by most sites and three sites (Centres J, P, S) did not return any. Centre T was an exception and returned almost 200 completed questionnaires. Despite the small number available for analysis, scores demonstrated some variability between sites and between items (see Chart 6.9-6.10). Of 132 respondents taking oral chemotherapy 11% felt that they had not received a comprehensible explanation of what it involves. The proportion was higher at Centre N (34%). The majority (87%) of patients who had needed to contact a chemotherapy nurses about a problem reported the nurse had dealt with to their satisfaction. At Centres T and Q 7% and 8% respectively felt that the nurses did not sort out their problem and at Centre T 11% did not know who to contact. The numbers, however, are very small, and so estimates should be treated with some caution.

Chart 6.9: Information from chemotherapy nurses before treatment

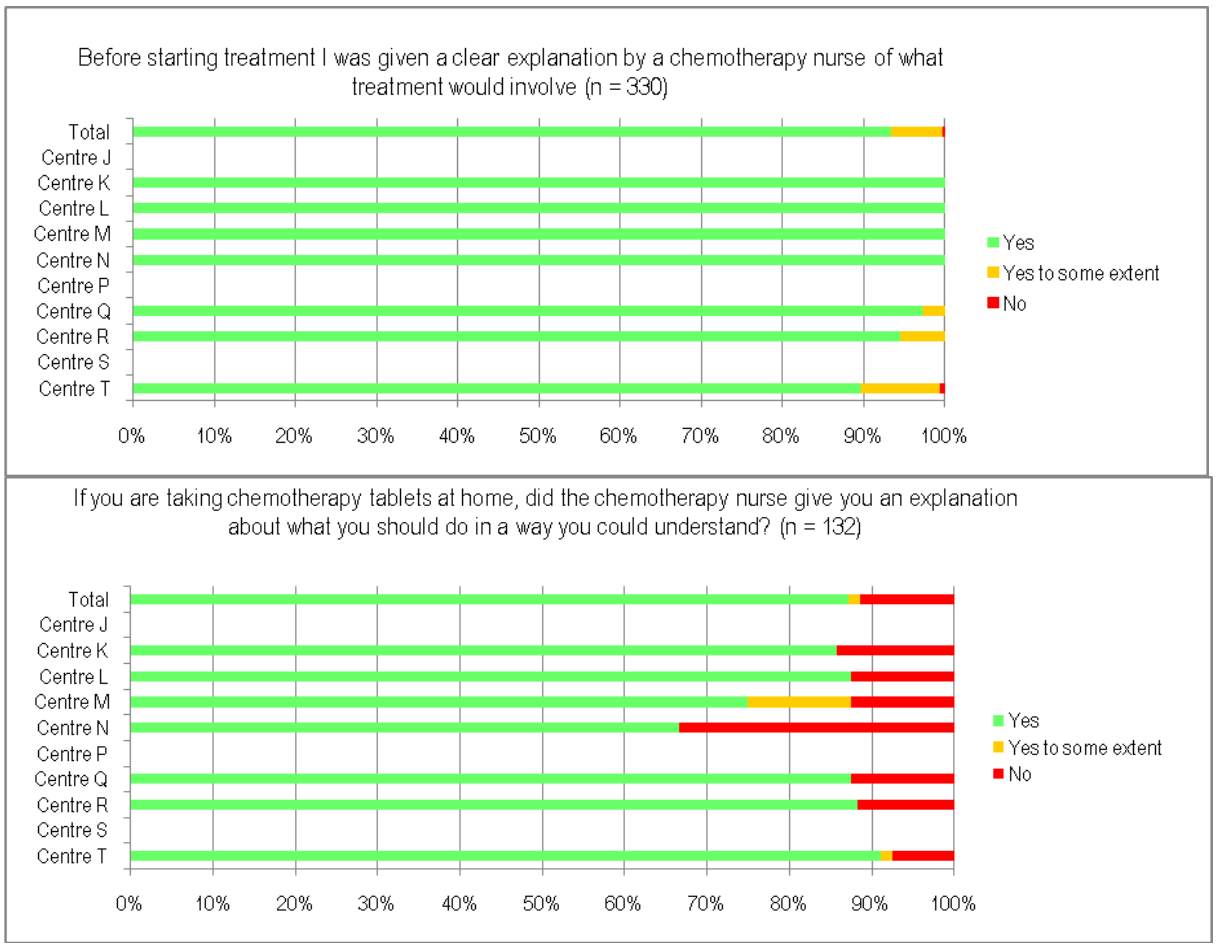
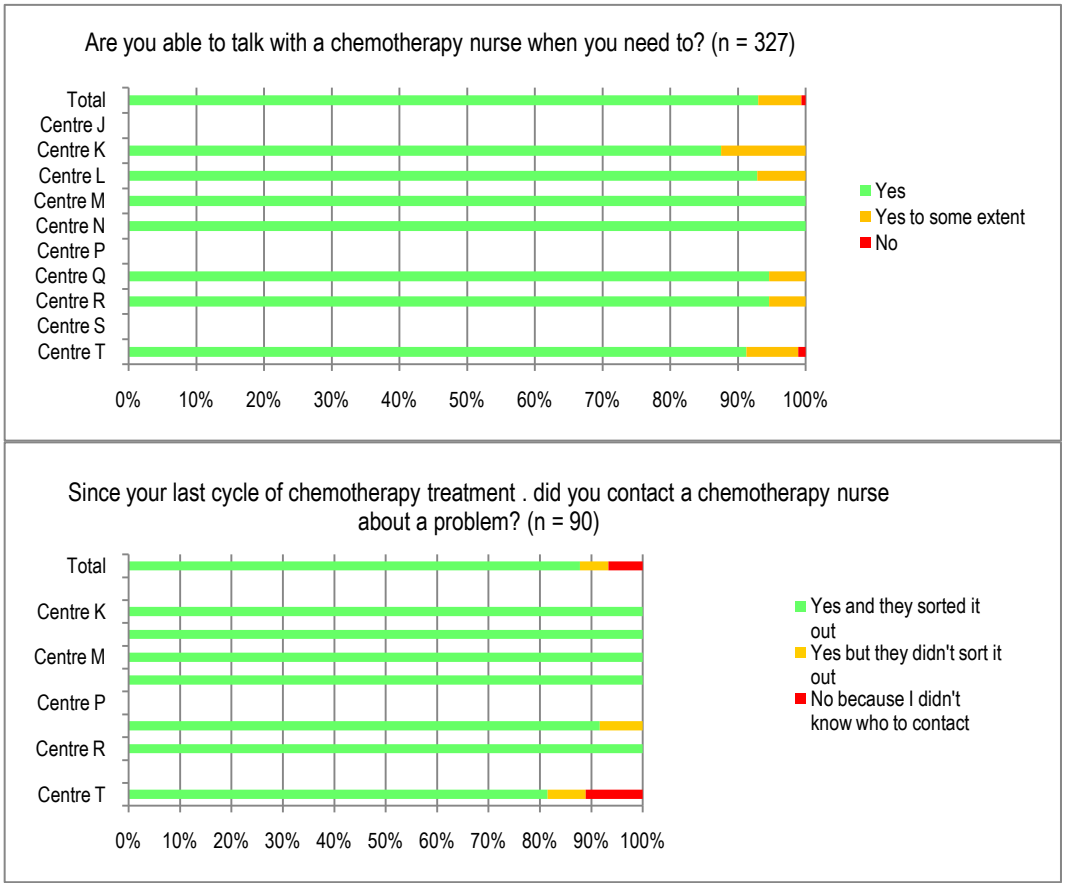
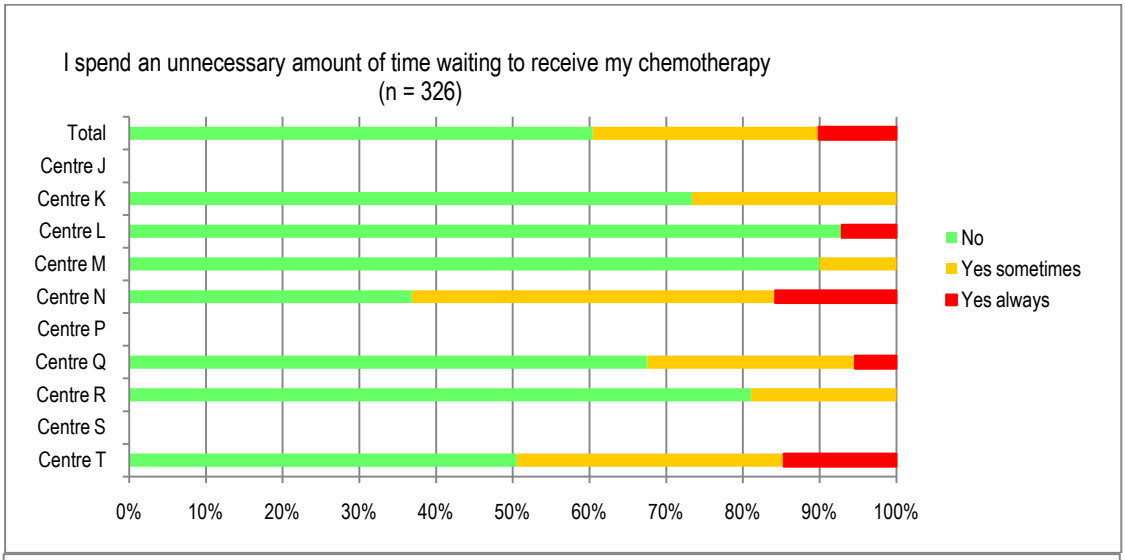


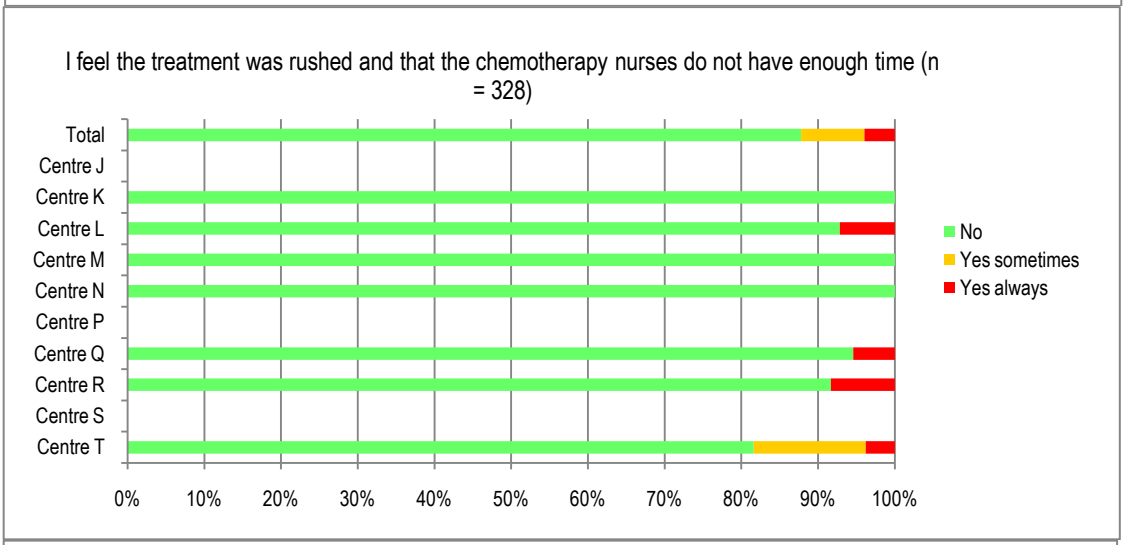
Chart 6.10: Availability of advice and support during treatment

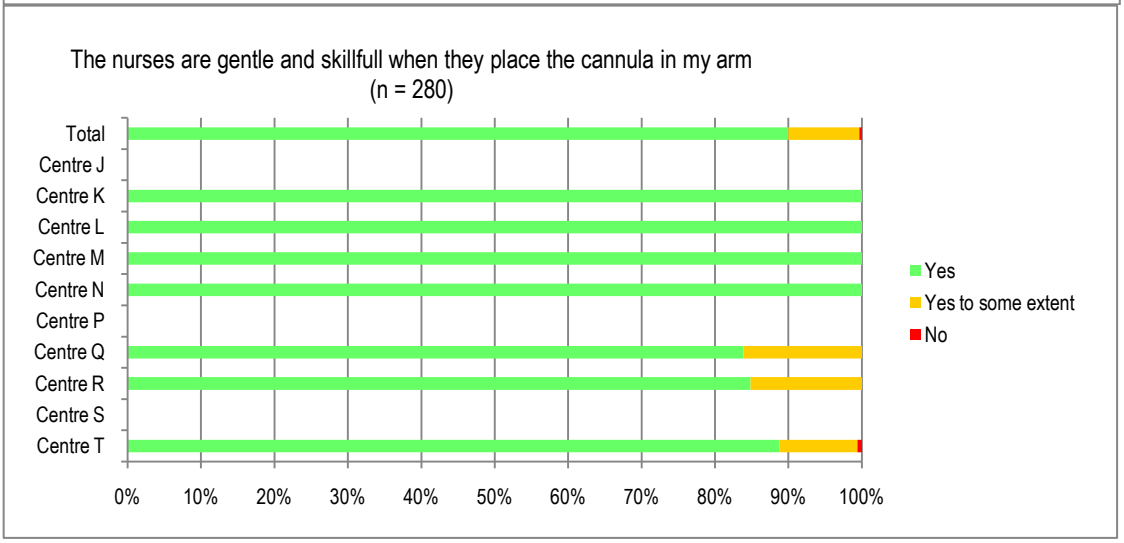


Although nurses cannot always influence whether patients receive their treatment in a timely fashion (e.g. pharmacy delays) waiting an unnecessary amount of time for chemotherapy and feeling treatment is rushed can adversely colour patient's experience of receiving treatment. However, if a service is managed by nurses, managing the problem is potentially a nursing accountability issue. As a consequence these items were retained in the outcome measure. From Chart 6.11 it can be seen that up to 15% at Centres L, N, Q and T said they always experience unnecessary waiting time. Across all the centres 29% reported sometimes experiencing unnecessary waiting time. In terms of whether patients felt that their treatment was rushed the majority (88%) said they never felt their treatment was rushed. However, at Centres L, Q R and T 4-8 % said their treatment was always rushed and at Centre T a further 20% said that it was sometimes rushed. At Centres Q, R & T 10-14% felt chemotherapy nurses were not always gentle or skilful at cannulation.

Chart 6.11: Experience of the administration process







6.1.7 Safety of drug administration

Table 6.7 shows the number of extravasations or suspected extravasations that occurred during the data collection period. The rate for the whole sample was 0.7 per 1000 chemotherapy regimen administered, though this varied between centres. No incidents of ulceration as a result of extravasation were reported during the period of data collection.

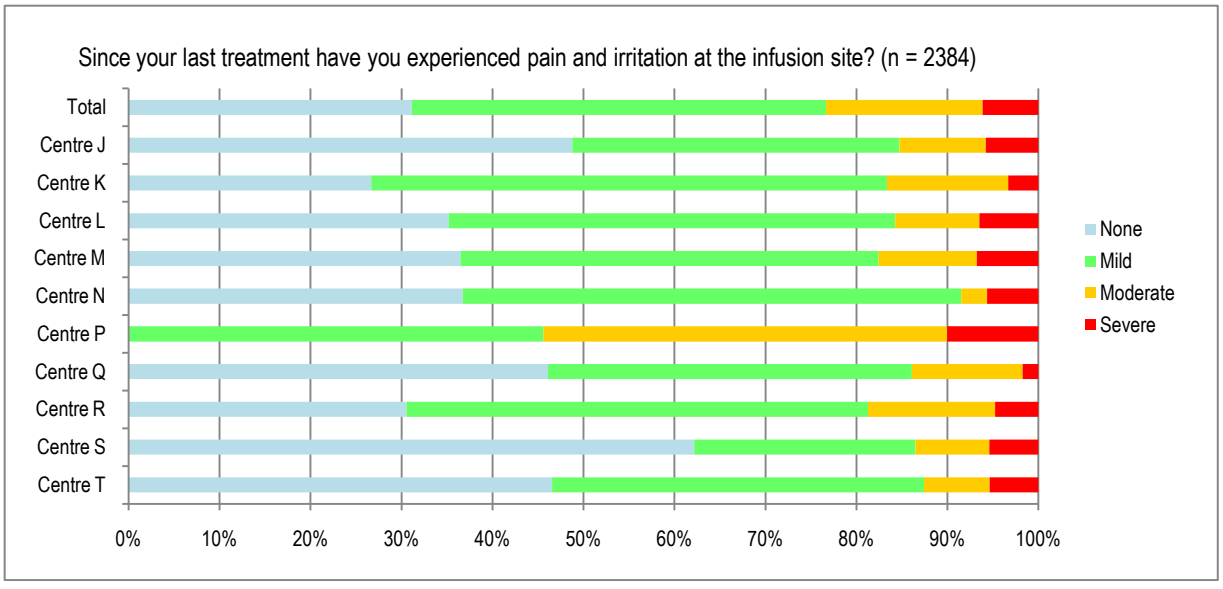
Table 6.7: Rate of extravasation

Centre	J	K	L	M	N†	P	Q	R	S*	T
Data collection (weeks)	12	10	6	6	-	8	6	10	*	9
Number	3	0	0	0	-	0	0	1	*	1
Number regimens administered	2464	140	244	187	-	593	706	487	*	2109
Rate/1000 regimens administered	1.2	0	0	0	-	0	0	2.1	*	0.46

† = not available * = combined with Centre T

Pain and irritation at the chemotherapy infusion site can be a symptom of extravasation as well as being caused by certain chemotherapy drugs. One way to reduce this symptom is to slow the rate at which the drugs are administered. Twenty three percent of patients reported this as a moderate or severe problem (See Chart 5.12). At nine centres the proportion was less than 20% and the percentage saying they had experienced any problems ranged between 27% - 62%. At Centre P, however, 54% reported moderate or severe pain at the infusion site and none said this had not been a problem.

Chart 6.12: Pain and irritation at the infusion site



As this symptom is likely to be influenced by the drug regimens used we used the method of risk adjustment described earlier to take this into account (see Table 6.8). Pain and irritation at the infusion site remained high at Centre P after adjustment was made to take account of drug regimens used.

Table 6.8: Pain and irritation at IV site

Centre	Rate per 100 patients	Rank	SSR	Rank	Lower CI	Upper CI	Correlation of un-standardised rank and SSR rank
T	13	9	60%	7	38%	89%	.75
J	16	5	79%	3	49%	119%	
K	17	4	56%	9	12%	158%	
L	16	6	67%	6	32%	121%	
M	18	3	82%	2	46%	133%	
N	9	10	40%	10	19%	76%	
P	55	1	210%	1	178%	246%	
Q	15	7	71%	5	34%	131%	
R	19	2	79%	4	62%	98%	
S	14	8	58%	8	21%	124%	

6.2. Stakeholder feedback

We conducted telephone interviews with the local project leads at eight participating centres to explore their perceptions of the project, the challenges and benefits of participating and to identify any improvements they thought should be made. Interviews were anonymised and each person assigned a code that corresponds to the centre at which they are employed (for example M1 represents a person working at Centre M). All centres were able to identify benefits from the data supplied by the indicators and many highlighted that it provided information that was otherwise unavailable to them. Several described specific plans to implement change and to use the indicators in future (see Table 6.9).

Whilst not all stakeholders were clear at the outset what the aim of the project was, by the end most articulated that it was about '*assessing whether patients are getting the support they need whilst undergoing chemotherapy to manage side effects'* (M1). One felt that it would '*highlight any areas in which the unit is falling short and we could do something about it'* (R1). Two others identified that a component of checking the quality of care is seeing '*where it [centre] stood in comparison with other sites'* (Q1) or benchmarking. When asked why they decided to participate most stakeholders clearly stated how they were keen to get feedback on patients perception of the care nurses delivered and one was particularly keen to establish '*that nurses do make a difference to patients experience'* (M1). One of the difficulties previously had been that it was not possible to make comparisons between centres in terms of chemotherapy services due lack of data. This was a key selling point for some stakeholders.

Without exception the stakeholders had found participating in the project valuable, despite the inherent challenges of data collection. They particularly appreciated having data on their performance and being able to judge how well they were doing by comparing themselves to other centres. One commented:

> *'Information that was returned from the audit; the NCAG, NCPOD reports and the issues these highlight have to be brought to the attention of nurses, that the same exists in their unit, i.e. the issues aren't just remote. It ties national documents to the local experience.'* (T1)

Another commented that the data provides another part of the informational jigsaw, and can help make sense of other data, such as that from the National Cancer Patient Experience Survey [5]. Some of the results were similar to those from this project, but the former results were not specific to chemotherapy

nurses. Thus the data from the nurse sensitive outcomes indicators provided some of the detail that may, to some extent, explain the patient survey results. It '*puts some meat on the bone'* (J1)

Having the data was seen as beneficial, even if the results were less encouraging than they had hoped for:

> '*Finding out there seemed to be a lot more patients experiencing symptoms than we had anticipated'* (Q1)
>
> *'I was shocked by interim report data suggesting 10% of patients reporting pain and irritation at the site'* (P1)

Nevertheless P1 then goes onto say that participating was a valuable experience as '*data about symptom management would not have been collected otherwise*'.
The majority felt that the way the interim results were presented was helpful. One person commented '*Happy with format of information. Charts using the mean deviation, as used in the NHS outpatient experience report is a confrontational way of presenting data. NHS managers focus on getting above this mean.*' (S1)

Most planned to use the information to make changes to care delivery, as illustrated by the following examples:

> '*The unit has changed anti-emetic treatments recently, but when the final results are available we will definitely look at the treatments again'* (Q1)
>
> '*I took it to a staff meeting and flagged up the extent of lethargy and fatigue which should not be underplayed. Also I want to look at what can be done regarding nausea and vomiting, but hope that this will improve as we are going to enforce some nausea and toxicity scoring in the clinic as part of NCAG. Nurses don't see patients in clinic, so are wanting to know what patients are saying to doctor and if doctor is picking up on what the patient is saying. I think that this action will make things better and will be in place soon.*' (P1)
>
> '*We have decided to make changes to practice in response to the finding about whether chemotherapy nurses are asking about symptoms. On the pre-assessment before patients start chemotherapy, we will start telling patients that they will be asked about certain problems, so they know it's going to happen and it's in their mind. Because at the moment although it is documented that nurses ask about symptoms, maybe patients don't realise that we're scoring the toxicities by asking them. Tell the patients that we're asking them for a reason and so they don't just think its general chit chat. It also brought to light the number of patients who didn't know what drugs they were on despite being given a hand-held diary with the drugs written in it.'* (R1)

The majority of the stakeholders interviewed said that they would use the nurse-sensitive indicators routinely in practice. However, they stressed that they felt that it would be more beneficial to use it intermittently, such as 3 or 6 monthly, and over a shorter data collection period, 3-8 weeks, to overcome some of the difficulties outlined above. Whilst one person felt that it would be useful to use it with patients at the midpoint in their course of treatment as by then many would be symptomatic, they recognised that identifying all eligible patients may make data collection more problematic. Another was considering using the measure at the end of treatment when patients would be able to review their experiences.

Table 6.9: Local implication of results identified by stakeholders

Centre	Implications of results	Future plans
J	Need to be more proactive about side effects Review current patient information booklets Explanations for symptom severity questions 1. nurses not systematically asking patients 2. nurses have insufficient knowledge base	
K	See what is working well and ways to improve	
L	Can compare experience of those having chemotherapy with other more general local audits of patient experience	
M		Would include NSI in future audits
N	No other audits conducted in unit therefore useful to have results	
P	What measures or improvements can be made to patients experience of pain and irritation at IV site – more proactive assessment and explanation to patients Increased awareness of fatigue and lethargy and impact made on patients experience What measures or improvements can be made to improve experience of nausea and vomiting	Use NSI into end of treatment assessment – pilot and adapt NSI to explore if and at which point patients were given relevant information and whether symptoms were managed appropriately Review anti-emetic protocol and use NSI again to identify drugs causing the most emesis problems. Introduce nausea and vomiting toxicity assessment by nurses
Q	More than anticipate patients experiencing symptoms	Anti emetic protocol recently changed will review in light of NSI results
R	What can be done to improve patients perceptions of nurse assessment of symptoms Large number of patients do not know what chemotherapy drugs they were receiving despite being recorded on patient-held diary What can be done to reduce the unexpectedly large number experiencing nausea	At pre-assessment will inform patients that symptoms will be systematically assessed at each treatment cycle Review anti-emetic protocol so medication started the day before chemotherapy administered. Use NSI to monitor whether it results in improvements
T*	NSI is an excellent method for assessing nursing service Ties national documents (NCAG, NCEPOD, NPES) to local experience Need formal assessment of treatment toxicities by nurses Nurses need to improve recording of assessment	Introduce multidisciplinary (nurses, doctors, pharmacists) pre-treatment consultation particularly for oral chemotherapy Introduce multidisciplinary (nurses, doctors, pharmacists) clinic for on-treatment patients

NSI = Nurse sensitive indicators * = Centre S combined with Centre T

A number of issues were raised about the process of data collection and these are as follows:

- data collection was seen as being arduous and time consuming and if it was to be done properly it needed to be supervised by the local project lead
- Nursing staff need to buy into the project rather than relying on reception staff to run the project
- The contextual data was difficult to collect as it was not readily available in management systems
- Many patients experienced questionnaire fatigue and chose not to complete the measure on multiple occasions. Some centres noted that this could be overcome if nurses were more involved and explained the rationale for completing it more than once

This feedback along with information collected during data collection has been used to revise the toolkit for centres using the self-report/self-assessment questionnaire (See Appendix J).

Some reported that the questionnaire was overly 'clinical' and this was reinforced by the long list of chemotherapy drugs at the beginning. The list was not felt to be comprehensive and it may be more useful to collect information on what regimen people were receiving rather than focusing on the specific drugs. The extensive instructions at the beginning were seen as being somewhat off-putting. One centre preferred the long version of the measure (incorporating additional experience items) as it provided more information.

7. Discussion

This project has successfully developed and tested a suite of nurse-sensitive indicators that could contribute to the effective monitoring of chemotherapy services. The indicators cover

- ***severity of subjective symptoms*** resulting from treatment, across a range of domains, including those that we identified as most sensitive to the quality of nursing services (nausea, vomiting, oral problems)
- perceptions of assessment, information and ***support to manage symptoms*** offered to patients by nurses who administer chemotherapy (support for self-care)
- ***safety of drug administration*** (extravasation and pain at infusion site) and
- ***patient experience*** of the administration process and informational support.

7.1 Severity of subjective symptoms

Our results show that substantial numbers of patients are experiencing distressing symptoms and there is variability between the centres that we studied in both perceived support from nurses and patients' subjective symptom severity. While the most prevalent symptoms (weakness and tiredness) were not ones which our review [6] had clearly supported as sensitive to the quality of nursing, there were substantial numbers of patients experiencing the symptoms which were most likely to be nursing sensitive and substantial variation between centres. For example, overall, 43% of patients experienced moderate or severe nausea but the figure varied across centres, from 24% to 73%. When we adjusted for case mix, large amounts of variation remained, although only one centre was clearly an 'outlier', with significantly higher numbers of patients reporting moderate or severe symptoms than would be expected, based on our statistical models.

Symptoms are largely a product of the chemotherapy regimen administered, the supportive care provided and individual variation. In the analysis here, we were able to explore the effect of diagnosis, chemotherapy cycle and drugs used, which should be helpful in allowing units to benchmark their performance. The low number of outliers (albeit in a small sample of centres) provides some evidence that the indicators are valid measures of quality. Any indicator system which yields a large number of outliers may simply be reflecting inadequate risk adjustment or an indicator which is not sufficiently sensitive to quality to be useful [18]. However, although the results give some confidence, our risk adjustment model was, of necessity, limited. There remains the possibility that the variation in response rate was an important contributor to the differences between centres. There was little evidence of positive correlations between the levels of adverse symptoms and response rates from centres, as would be found if response was biased toward patients who were experiencing less distressing symptoms. However the small sample size and the absence of a precisely defined sampling frame in the pilot sites makes further exploration of this issue difficult.

Despite some encouraging findings, based on the validation work undertaken so far, it is difficult to use direct comparisons between centres to make judgements about relative quality of services. Further work is needed in order to adjust levels of reported symptom severity for differences between regimens and, if necessary, characteristics of the individual patients. Collecting the information required for this from individual patients at each attendance was burdensome. To make further progress with this, fuller linkage to patient records, including full demographic details and precise chemotherapy regimen, which was beyond the scope of this project, is required. We believe this data will be available in the national chemotherapy minimum dataset. This raises significant issues about how the information should be gathered from patients and used in practice, to which we will return to later.

We initially intended to pilot indicators derived from those symptoms and issues that our review had given us most confidence their about sensitivity to nursing. During development we added a number of symptoms to our initial short list, as their absence made the self-assessment questionnaire seem incomplete and, implicitly, appeared to be disregarding other important symptoms. The addition of these symptoms seemed feasible and patients had the opportunity to add others on completing the self-report instrument. However, we remain unsure as to whether these symptoms, derived from the widely used Chemotherapy Symptom Assessment Scale [13] (tiredness, weakness, fatigue and signs of infection) are ideal candidates as nurse sensitive outcome indicators because of the limited evidence available for effective interventions[6]. The extremely high rates of "signs of infection" (100%) in one centre raises questions about this as an indicator of 'symptom experience'. Responses to this could be influenced by successful education about likely signs of infection while actual symptoms experienced were similar and ultimately, the presence or absence of infection is not a subjective experience.

7.2 Support to manage symptoms

In addition to the variation in symptoms, perceived support from chemotherapy nurses to manage symptoms was also variable. For example while overall 90% of patients answered 'yes' to the question 'do nurses ask you about your symptoms' the range was from 97% to as low as 72%. Similarly the numbers answering 'yes' to the question about nurses providing practical advice varied from 69% to 94%. This variation in support reflects the results of the National Cancer Patient Experience Survey [5]. The national survey showed that, in some trusts, as few as 60% of patients felt that staff did everything possible to control side effects of chemotherapy (compared to 95% in the best).

There were strong correlations between results from the national patient experience survey and symptom severity in our ten centres. This applied particularly to those symptoms that we had identified as having strongest evidence of sensitivity to nursing and gives a clear indication that there may be validity in the results. For the items most strongly associated with nursing (nausea, vomiting, IV pain and oral problems) we also found some evidence of an association with perceived support from chemotherapy nurses, although it was weaker than the evidence for association with the National Cancer Patient Experience Survey [5] results. Although there were some associations between the results of the national survey and our specific items about nursing awareness and support, the correlations observed in this small sample were not significant and were typically negligible. No clear pattern appeared suggesting that the items are largely independent of one another. Because of the small samples involved we are wary of speculating too much on the specific pattern of results, but broadly these associations give some support to the validity of the indicators as being nurse sensitive, while indicating clearly that much more data is required to come to firm conclusions.

There is evidence from the NHS annual inpatient survey and other similar surveys that there are systematic differences in response patterns between different patient groups (for example by age, sex, educational level and severity of illness). This means that comparisons between services may still need to be adjusted to ensure that results reflect differences between services provided, not just differences in the people who use them [19, 20]. The NHS National patient survey programme standardises results for demographic (age, sex) differences between trusts [15]. However since the views of an individual reflect their own experiences, such issues are secondary when identifying areas for improvement and issues experienced by patients actually using a service. Therefore we did not attempt to standardise data in this project. However it may be that further work is required if a direct measure of relative

performance is required and the fact that we did not standardise responses may account (in part) for the absence of *any* real evidence of correlation with the national survey results.

7.3 Safety of drug administration

We collected two indicators of safe drug administration. A large number (23%) reported moderate to severe pain or irritation at the infusion site with rates varying by site from 8% to 54%. Adjustment for the effect of diagnosis, chemotherapy cycle and drugs used showed one centre with a higher than expected ratio of observed to expected symptoms, suggesting that the differences are not simply a product of differences in regimens. However the cautions noted above about risk adjustment models apply here. We gathered data about extravasation rates from nine of our ten centres, suggesting that monitoring is feasible but we were unable to determine if there was any association with the patient reported indicator of pain and irritation. The number of incidents is low, and considerably more data would be required for any conclusion to be drawn. The rate of suspected / actual extravasations was such that none were reported in most centres. This indicator is also potentially biased by variation in surveillance and the index of suspicion used. No incidents of ulceration due to extravasation were reported and it is likely that this will be a sufficiently rare event to not prove useful as a routine indicator for comparison purposes, although clearly *any* incident warrants investigation.

7.4 Patient experience

We explored additional aspects of patient experience in a format designed to be administered at a single point during treatment. The items selected were all endorsed widely by our advisory groups and the service users we interviewed. Items related to experience of the administration process and information support offered prior to and during therapy. We strove to avoid overlap and repetition of items in the national experience survey and so focussed on specific items about the process of care in ambulatory chemotherapy. Because of the intermittent nature of distribution of the questionnaire (once during the survey period), and logistical problems experienced in the centres, the number of responses we received to this was low and most centres returned too few to warrant meaningful comparisons.

However, the responses obtained suggest that these items do cover issues that are of concern with some indication of variability in the experience of patients. In particular large numbers of patients in most centres (40% overall) said they sometimes or always waited an unnecessary amount of time for their chemotherapy. Inclusion of this item was relatively controversial, as members of the clinical reference group pointed out that reasons for delay were often not directly responsible for delays. However, the issue was so strongly endorsed in our interviews with service users that we retained the item (dropping the more specific question about being treated within 30 minutes). If a clinic is managed by nurses, the organisation of services, management of patient flow and information about processes is a nursing accountability issue, even though the service is delivered by a multidisciplinary team.

7.5 Utility and feasibility

The majority of information was gathered through patient self-report at the point of chemotherapy delivery. This mechanism was shown to be feasible and acceptable to patients. High response rates can be achieved, but not all centres were able to do this. In order to gather information to permit adjustment of results for underlying risk (e.g. treatment regimen, diagnosis) we gathered information from patients.

However, repeated questioning on these issues did not seem to be acceptable and response rates were adversely affected. We briefly tested an abbreviated form of the self-report instrument which did not include the personal information. This appeared to increase responses in the short term and was certainly a simpler instrument to complete.

Centres found the feedback from the indicators a useful adjunct to more general feedback from the National Cancer Patient Experience Survey [5] and some have already developed plans to act on results and to continue using the Indicators. Managers of the services involved testified to the usefulness of having the information provided by the indicators available to them. They were able to articulate how it was useful in both confirming issues that they were aware of, but also highlighting things that they were not aware of (see Box 6.1). A number of centres have used results to identify problems, develop action plans including plans to repeat. Evidence from our reviews suggested that nursing may provide a solution to sub optimal symptom control in a number of areas, but it should not be assumed that the difference is necessarily the result of differences in the quality of nursing care. As an example, prescribing practices differ between centres and the availability of more expensive antiemetic agents, such as Aprepitant, is sometimes limited. Managers of services were aware of this issue and were keen to know more about other centres in order to pick the most appropriate benchmarks to compare themselves with and to learn from other centres. Our ability to gather useful and meaningful contextual data from centres was limited in this study. Centres were inconsistent in provision of staffing and some other contextual information.

While benchmarking is important, any unit has the ability to use these indicators to explore variation in their performance over time, as has been planned by some centres. The level of symptoms experienced by patients is a significant issue which warrants attention and investigation, as is the perception of patients that they are not being properly assessed and supported. The results of the indicators can prompt service managers and individual practitioners to question their own practice, seek explanations for any apparent deficits and, if appropriate, to identify and evaluate the effects of change. Comparisons between centres may usefully stimulate the question as to why they differ even where appropriate benchmarks are unclear. Risk adjusted (standardised) comparisons such as those we have presented can give further incentive to investigate underlying causes of difference.

Box 7.1: Using the indicators to gain insight

"We knew that we were not always formally assessing symptoms but we were surprised by the levels of nausea and vomiting reported. We also thought that the information that we were giving was good but it seems clear that something isn't working well for the patients. This sort of feedback is valuable because it is more specific and detailed than the national survey and, importantly, it relates to the particular unit that care was delivered in, not the trust as a whole." ***Quote service manager centre J***

7.6 Developments and next steps

We designed a system that collected data from patients as they attended for chemotherapy, which allows for data collection to be integrated into routine practice rather than as a separate survey undertaken intermittently. Feedback from stakeholders was supportive but tended to point toward intermittent data collection as opposed to routine use. In Box 6.2 we discus key options for future deployment.

As currently implemented the patient self- report element is administered in a paper and pencil 'form'. This delivers significant advantages for administration in terms of simplicity and flexibility and is optimal for piloting an instrument under development. However, it does little to facilitate data linkage, which is important for risk adjustment, or indeed data handling at all. Based on our early piloting we targeted reception staff as the key point of distribution, but this did little to facilitate integration into practice.

Our approach was manual data entry, which was contracted out to a specialised provider. This had the advantage of flexibility but was also cheaper, given the relatively high start-up costs for preparing paper questionnaires for machine reading. Automated input of questionnaires is not a panacea and a step change in efficiency can only occur with direct data input. Technology certainly exists that would allow direct input onto handheld / tablet PCs and this is routinely used in a number of settings. Again this is not without challenges. Nevertheless we acknowledge electronic data collection methods are preferable in the long run.

A sensible compromise, which would allow the integration of the indicator collection into routine care, may be for core outcome indicators to be inputted directly by nurses into electronic records or e-prescribing systems with other data collected intermittently (say every 3-6 months) to elucidate underlying processes and patient experiences. It would be preferable if data on risk factors (e.g. regimen and personal characteristics) were collected from records rather than relying on self-report as this does not seem compatible with integration into routine practice. However abbreviated risk factor information could be directly inputted by staff if the system were implemented in an electronic format. Whilst the scope for data linkage was limited for this project, it is likely that that this is more of a possibility if conducted as locally initiated projects.

However to realise the benefits of this system it is vital that there is genuine ownership by staff in the ambulatory chemotherapy settings. Our findings showed how commitment of staff is required and that patient understanding of the purpose of repeated measurement could increase when it was perceived to be owned by nurses. This is consistent with evidence on 'self-assessment' measures more generally which were seen as acceptable and valuable by patients primarily when it was seen as something that was an integral part of clinical care and supported by health professionals, not simply a burden passed from practitioners to patients[21].

The comparison to 'self-assessment' opens up the possibility that the process of gathering information to populate these indicators can feed directly into clinical care. There are already a number of assessment tools in use which allow patients to self-report the subjective severity of symptoms as opposed to the objective toxicities rated by systems such as the National Institute for Health's Common Toxicities Criteria. These include the Chemotherapy Symptom Assessment Scale [13] which is widely used and upon which we based our symptom assessment. Our experience in the implementation sites suggests that use of these tools at the point of delivery of chemotherapy is variable. Research in primary care suggests that giving the patients an opportunity to reflect on and record problems they are having prior to seeing a health care practitioner has the potential to improve the quality of interaction and perception of the quality of health care delivered [22]. Nevertheless the key to success is that clinicians respond to the problems identified.

Box 7.2: Options for the future

Option	Pros	Cons
Method of Administration		
Paper and pencil administration	Simplicity, start up cost, flexibility, opportunity to use in clinical practice	Data handling burdensome, lack of integration with practice, no automatic record linkage
Tablet PC or equivalent	Reduced data handling burden	Initial expense, logistical challenges, limited opportunity to 'share' results with nurses, no automatic record linkage, unlikely to accommodate all items, systems of care may be dictated by technology
E-Prescribing systems at the point of care	Potential direct impact on the care process, reduced data handling burden	May be removed from point of administration so limited ability systems of care may be dictated by technology, logistical challenges, loss of control over content
Timing		
Continuous	Potential for integration into routine practice and use to guide patient care, positive impact on care processes (assessment), potential for rapid feedback on performance	Resource intensive unless integrated with automated data gathering.
Intermittent (episodic)	Compatible with more options for administration. Less resource intensive	Unlikely to be worth the cost of integrating into e systems. Effort required is intermittent so some 'start up' costs are repeated. Requires flexible deployment of resource
Personnel		
Administrative staff	Can be integrated into other administrative tasks	Lack of ownership by patients and clinical staff, just collecting data
Chemotherapy nurses	Ownership and commitment by nurses and patients required and facilitated	Requires integration into routine practice to realise the benefit and significant change management, potentially burdensome
Other clinical staff (e.g. pre assessment)	Ownership by patients and clinical staff facilitated	Feedback to chemotherapy nurses may be reduced.

Discussion of implementing our indicators as part of (or deriving them from) a clinical intervention involving self-assessment is, perhaps, moving beyond our brief. In any event it is important that the end goal of collecting the data is not simply to possess it. If the information is not used it is hard to justify the effort and expense collecting it. Rather the point is to make use of it to benefit patient care. If the information collected is not seen to be used, the necessary commitment from both staff and patients is unlikely to be sustained.

We struggled to gather information on workforce characteristics and deployment that were identified as important contextual factors in our previous work and by our advisory groups. Additional and more structured information, for example standardised descriptions of workforce inputs and clinic organisation, should be developed. While some of this information may be available from the CQuINS peer review the organisation of this around tumour groups means that some cross cutting elements of the service, such as organisation and delivery of ambulatory chemotherapy administration, may well be relatively 'invisible' within such audits. However, this information is helpful in interpreting and explaining the results of the indicators but its absence does not undermine the results.

8. Conclusion

We would recommend the following adaptations to the content of the self-report instrument:

- A single version of the self-report instrument suitable for use at *any* point in the cycle of chemotherapy
- Therefore the summative patient experience items should be dropped and incorporated into intermittent local patient experience surveys with content determined by service users and local practitioners.
- For local (single centre) centre use the abbreviated version (without patient detail) [items B1-B4 only
- To permit benchmarking, detail on patient factors and drugs (sections A&C) are required but could be derived from other sources of data to deliver core information on:
    - Cycle number
    - Drug toxicities
    - Diagnosis
    - Mode of administration
    - Age
    - Sex
    - Ethnicity

Because the core symptom assessment were derived from the commonly used Chemotherapy Symptom Assessment Scale [13] the indicator can be derived from other data sources and assessments that might be routinely undertaken. We would recommend and encourage the development of a benchmarking database based on the results of these indicators. Data would need to be supplied to a defined standard and definition but local centres could make their own decisions on implementation.

The system that we have designed and reported here has real potential to be used now for local quality improvement efforts and for benchmarking between centres. We have shown substantial levels of adverse symptoms, large numbers of patients who perceive that support to manage symptoms could be better and unexplained variation between centres which all suggestion potential for improvement. Stakeholders in our pilot sites gave a clear indication of the potential to use these indicators to stimulate and evaluate quality improvement.

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