

## Clinical governance in action

# Implementation of national cancer guidance: the experience of a primary care trust

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### ABSTRACT

In 1999 national cancer guidance was circulated to primary care organisations and looked to build on the work undertaken through the Calman Hine programme. More recently, we have received NICE guidance on primary care referrals for patients with suspected cancer. Within NE Lincolnshire locality our approach has been to utilise the national cancer guidance as an opportunity to 'localise' or practically integrate the current evidence to develop locality guidelines within care pathways. The localisation of national cancer guidance has been implemented by a three stepped process by which we have looked to engage the local health community. Within the establishment of the care pathways we have looked to utilise a number of key characteristics for the various areas of cancer considered.

The guidelines were developed over 3–4 year period and we focused on the areas for which the development of referral guidelines would be most appropriate.

What has been the value of the work to date? – from audits, as well as anecdotal feedback, there is a high level of awareness and utilisation of locality guidelines. One practical reflection of this is the high level of utilisation of referral proformas where they have been developed. The work to date has also led to significant sharing of experiences and outcomes across practices within the primary care trust, facilitated by the Primary Health Care Team structure.

The above were desirable as we looked to reflect on the value of the implementation of locality guidelines. However, the most important factor is what positive impact there is on service delivery. A potential independent indicator is that of conversion rates of urgent two week wait (2WW) referrals to cancer.

The paper considers the potential impact of localisation on conversion rates. It then highlights the potential quality assurance framework for the development of effective care pathways.

## Introduction

In 2000, national cancer guidance was circulated to primary care organisations to build on the work undertaken through the Calman–Hine programme, strengthened more recently by National Institute for Clinical Excellence (NICE) guidance on primary care referral for patients with suspected cancer.<sup>1–3</sup>

Within North East Lincolnshire, our approach has been to see the national guidance as an opportunity to 'localise' or practically integrate current evidence in order to develop locality guidelines within care pathways. We have utilised a similar approach for the implementation of the National Service Frameworks, for example that for coronary heart disease. This

article describes the development and the positive impact of our approach.

North East Lincolnshire Primary Care Trust (PCT), established in 2001, has a population of approximately 165 000 with 34 local practices. The practices, to support development, sharing of good practice and communication, are aggregated together into populations of around 20 000 as seven primary healthcare teams; one practice is a double primary healthcare team. It is served by Diana Princess of Wales District Hospital which is part of Northern Lincolnshire and Goole Acute Trust.

## Box 1 Local framework for development of locality guidelines and care pathway

### Step 1

Establish the project team constituting clinicians from primary and secondary care with appropriate administrative and audit support.

Initial objectives of this group were to develop a draft:

- clinical value\*
- guideline
- referral proforma

\*An agreed local standard of care which reflects the current national and local perspective, and which looks to utilise primary and secondary care effectively and appropriately by the development of a shared care pathway.

### Step 2

Obtain initial feedback from the PCT clinical governance committee and other appropriate arenas including a lead managers meeting and the clinical governance forum. This provided an initial reference point and practical guidance as to whether the proposed objectives identified within the clinical value, and anticipated to be implemented by the suggested guideline and supporting proforma, were appropriate to be considered more widely to support the development of local cancer services.

### Step 3

Service review meeting

A joint meeting of local primary and secondary care health professionals, incorporating a mixture of clinical, administrative and audit experience and skills, supported by input from other groups as appropriate.

Local secondary care lead clinicians in the service area to act as the specialist resource within the meeting.

#### *Format of the meeting*

- Overview of guidance
- Current situation
- Draft proposals (developed by project team)
- Group work
- Feedback from above
- Achieve consensus view
- Action plan
- Agreed review date

#### *Objectives of the meeting*

- Communication of guidance/draft proposals
- Ownership of initiative
- Communication and implementation of action plan

## Engagement of the local health community

The 'localisation' of the National Cancer Guidance has been implemented by using a three-step process as detailed in Box 1.

## Key characteristics of the locality guidelines and care pathway

### User friendly

As a health community we wanted guidelines that were practical and relevant to day-to-day practice.

Therefore, the majority of the guidelines developed contained within a single sheet of A4 or, where linked to a referral proforma, the referral proforma is on one side of the sheet with the supporting guidelines on the flipside. As well as being available in paper form, they have been made available electronically to local practices. We anticipate that within the 'Choose & Book' initiative they will become integrated as part of the electronic referral pathway.

### Timely referral

The intention of the care pathway, as well as supporting appropriate local primary care practice, was to facilitate an effective system for timely referral for patients suspected of cancer. Both the guidelines and

the utilisation of referral proformas have been used to support this.

## Appropriate primary care management

In addition, the initiative also looked to support, as appropriate, ongoing primary care management. Guidelines were used to endorse the appropriate ‘wait and watch’ policy, perhaps best highlighted in the guidance relating to management of patients presenting with potential colorectal pathology. We also enhanced primary care access to diagnostics, including ultrasound, further supporting management within a primary care setting of patients such as those presenting with haematuria and proven urinary tract infection. Primary care access to transvaginal scanning has been facilitated by guidance on postmenopausal bleeding which is dependent on endometrial thickness.

## The health community approach

Development of the locality skin cancer care pathway provided an opportunity to integrate and further enhance the provision within primary care, provided by the longstanding general practitioner (GP) minor surgery group, with that provided by the specialist service. This care pathway facilitated the co-ordination of resources within the locality, maximising the benefits to patient services.

## Locality guidelines established

As a locality, we selected, over a 3–4-year period, to develop locality guidelines for the following cancer areas:

- breast
- lung
- upper and lower gastrointestinal (GI)
- skin
- gynaecological
- urological
- testicular
- head and neck.

Due to the small numbers and the range of presentations, it was decided not to develop locality guidelines (in addition to the national cancer guidance) for cancer affecting children, the brain or central nervous system, or sarcomas. We initially took the same approach for haematological cancers, but recently we have begun to develop guidelines for some haematological cancers, again looking at the practical management within a primary care setting.

## Referral proforma

For some cancers it has been deemed appropriate to develop referral proformas as a practical mechanism to support utilisation of locality guidelines as well as facilitating timely specialist referral. Referral proformas have been developed for breast, colorectal, and upper gastrointestinal cancers, as well as the primary care element of the skin cancer service. Although the referral proformas initially were optional, given their ease of use they have become the standard tool for referral.

## Clinical guidelines within developing care pathways

Clinical guidelines provide opportunities to maximise the management of patients in line with current evidence, and to co-ordinate healthcare resources. We used the opportunity of development of locality guidelines to highlight our local philosophy on guidelines as expressed by the Royal College of Radiologists in 1990, in their review of guidelines ‘a guideline does not place a constraint upon clinical practice, but rather promotes the concept of good practice against which the management of the individual patient can be considered’.<sup>4</sup>

## Implementation of locality guidelines

The guidelines were developed over a 3–4-year period beginning with breast and colorectal cancer, which represented conditions with the highest referral and diagnostic rate. Following the success of this approach, a similar process was adopted for other cancers. Following the introduction of the guidelines we have been keen, as a health community, to ensure that they do not sit on the shelf gathering dust but, as intended, are practically useful. We have looked to support audits both at the practice as well as PCT level to reflect three principal areas of review:

- the clarity and appropriateness of the current referral proforma and guidelines
- the effectiveness of the guideline in identifying patients with the relevant cancer
- utilisation of the guideline within the overall care pathway.

We have encouraged practices to review ‘conversion rates’ of urgent two-week-wait (2WW) referrals to cancer diagnoses,<sup>4</sup> and to use the significant event review programme as a positive way to reflect on non-2WW referrals that are later demonstrated to have cancer.

In 2004, in collaboration with our local acute trust, we undertook a prospective audit of the appropriateness

of urgent 2WW referrals for breast and gynaecological cancers. Over a three-month period, the receiving consultants for urgent 2WW referrals for breast and gynaecological services reviewed each referral and, where this appeared to fall outside locality guidelines, wrote to the GP highlighting it as a potential non-compliant referral and inviting a response. The referred patients were managed as usual. All but one GP replied promptly to the letter and provided feedback which highlighted a degree of misunderstanding with regard to the 2WW referrals and non-cancer urgent or 'soon' referrals. In the light of this, the referral proforma and guideline for the breast service were updated.

## Outcomes and value of locality guidelines

### Ownership and utilisation

Our intention has been to ensure professional ownership and confidence in locality guidelines which has led to a high level of utilisation. Practice-level local development initiatives, including practice cancer action plans, have further supported this. Most GPs have welcomed the referral proformas including the guideline and found them to be useful, in particular the concept of having the guideline on the flipside and therefore easily to hand. The layout of the referral proformas has been standardised, also improving uptake. However, one or two doctors have found this to be impersonal. Although retaining the facility to refer to a named consultant, the proformas have provided a pooled referral as an option and a practical way of addressing the two-week referral deadline.

The breast cancer referral pathway was launched at a service review meeting in 2000, and its implementation was reviewed 18 months later. Audits showed good adherence to the guideline, and feedback revealed strong support for the referral proforma. At the suggestion of those present it was accepted that rather than optional utilisation of the proforma it would be adopted as standard for referral to the breast service. Over the following years the guideline has been updated on a number of occasions, the current version is given in the Appendix.

### Collaboration

The work to date has led to significant sharing of experiences and outcomes across practices within the primary care trust. The establishment of project teams across primary and secondary care has provided the opportunity for close working and greater awareness of mutual objectives and challenges between clinical and managerial colleagues. The locality guidelines

would not have become a reality without the active and ongoing support of the lead specialist consultants.

## Indicators of added clinical value

If implementation of locality guidelines is to have added value, the most important consequence is their impact on service delivery to patients. A key indicator is that of conversion rates of urgent 2WW referrals to cancer. Conversion rates are not simply a result of guideline implementation in isolation, but rather reflect related issues such as awareness, access and professional relationships across the primary/secondary care interface.

Table 1 details the conversion rates of the cancer areas considered within the national cancer guidance. It provides the information for North East Lincolnshire PCT referrals within the calendar year 2004. In addition, on the right side of the table, additional data are provided, highlighting the range of conversion rates within Humber and Yorkshire Coast Cancer Network and the average conversion rate.

## Interpretation of conversion rates

Conversion rates are determined by the quality of the data entered into the Cancer Waiting Time database. For all cancer areas where a locality guideline has been developed, the conversion rate is above the average for the network. In five out of the eight cancers, the conversion rate achieved was the highest in the network.

Of the three areas where, given the small numbers and variation of presentations, a locality guideline was not developed, conversion rates were zero. However, it is important to qualify these results by considering the very small number of referrals involved, the range of presentations and the likelihood, as was our original consideration, that the introduction of a locality guideline may not have had an impact.

## What is the value of conversion rates?

Following discussions within and outside our cancer network, there appeared to be no national data showing conversion rates for each locality and cancer type, nor were we aware of any indicative targets.

The intention of developing locality care pathways was to raise the profile of the national cancer guidance, and provide a practical framework that would allow local primary care clinicians to target patients presenting with likely significant pathology. Conversion rates could be used as a measure of how sensitive such guidelines are, but high conversion rates may also reflect guidelines that tend to detect more advanced cancers. The objective of the guideline is to identify a

**Table 1** Conversion rates for 2WW referrals for first attendances between 1 January 2004 and 31 December 2004<sup>a</sup>

Suspected tumour site	NE Lincolnshire PCT referrals				Humber & Yorkshire Coast Cancer Network	
	Total no of referrals	Cancer	Not Cancer	% Cancer diagnosed	Conversion rate (%)	
					Range	Average
<i>Brain/CNS</i>	2	0	2	0.0		
<b>Breast</b>	522	66	456	12.6	9.2–18.4	12.0
<i>Children's</i>	11	0	11	0.0		
<b>Gynaecological</b>	105	15	90	14.3	7.6–18.4	13.5
<i>Haematological</i>	3	0	3	0.0		
<b>Head and neck</b>	83	8	75	9.6	0–9.6	3.4
<b>Lower GI tract</b>	308	41	267	13.3	6.3–15.2	12.1
<b>Lung</b>	60	32	28	53.3	20–53.3	26.7
<b>Skin</b>	108	25	83	23.1	6.3–23.1	10.1
<b>Testicular</b>	13	7	6	53.8	0–100.0	29.7
<b>Upper GI tract</b>	82	11	71	13.4	1.1–13.4	5.5
<b>Urological</b>	89	38	51	42.7	0–42.7	19.8
<b>Total</b>	1422	253	1169	17.8		

<sup>a</sup> Data provided from the Cancer Waiting Time live download database extracted in March 2006. Cancers with locality guidance are shown in bold, those without locality guidance are shown in italics.

cancer presentation within a primary care setting, at a stage that is most amenable to treatment. Therefore, although conversion rates can be a useful guide, other indicators need to be considered, which may include cancer diagnosis presenting outside the 2WW arrangements, and the outcome of cancer treatment, including survival rates.

### Benefit of the review of conversion rates

Conversion rates of 2WW referrals to cancer are one indicator that we can independently compare against other localities. From an NE Lincolnshire PCT perspective it has provided the opportunity for two key outcomes:

- positive feedback to local primary and secondary care clinicians with regard to the work they have jointly undertaken to date
- generating local discussion on what should be done next.

However, there is also an opportunity within our cancer network and beyond to generate discussion on the following:

- benefits of 'localisation' of national guidance and, as a consequence, a positive impact on local clinical engagement
- the added value of local guidelines:
  - what is the value of conversion rates?
  - is there an indicative target?
  - what should be the quality assurance framework to support the implementation of clinical guidelines within the emerging care pathways?

### The commissioning focus

The last five to six years have seen a significant investment in cancer services, particularly in secondary and tertiary care, following the introduction of *The NHS Cancer Plan*.<sup>5</sup> Within our cancer network there is an acknowledgement that, given the significant challenges faced by secondary and tertiary care, this focus has been appropriate. The introduction of

the 31/62-day cancer target promotes further development of specialist services. However, it also provides the opportunity to refresh the primary/secondary care interface and review the utility of referral guidelines to enable the achievement of the 31/62-day target.

We are currently in an organisational consultation period, following which it is anticipated that the majority of PCTs will reconfigure. We hope to utilise the change to refresh the primary care focus. It is essential that the future commissioning focus, as well as addressing the secondary and tertiary services, supports primary care management and the interface between primary and secondary care.

## Conclusion

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Locality guidelines have been used to support effective and appropriate primary care management, timely access to diagnostics and, where clinically appropriate, prompt referral within the 2WW arrangements. The process is one of ongoing review and refinement, for example, in recent months, following review of the colorectal care pathway, we are now piloting a 'straight to test' arrangement, further utilising skills within primary care, while reconfiguring the care pathway to target probable cancers, hence, maximising the benefit to our patients of the specialist service.

## REFERENCES

- 1 NHS Executive. *Cancer Referral Guidelines: referral guidelines for suspected cancer*. HSC 2000/013. London: NHS Executive, 2000.
- 2 Calman K and Hine D. *A Policy Framework for Commissioning Career Services*. London: Department of Health, 1995.
- 3 National Institute for Clinical Excellence. *Referral Guidelines for Suspected Cancer*. London: National Institute for Clinical Excellence, 2005.
- 4 Royal College of Radiologists. *Making the Best Use of a Department of Clinical Radiology*. London: Royal College of Radiologists, 1990.
- 5 Department of Health. *The NHS Cancer Plan: a plan for investment, a plan for reform*. London: Department of Health, 2000.

## CONFLICTS OF INTEREST

None.

## ADDRESS FOR CORRESPONDENCE

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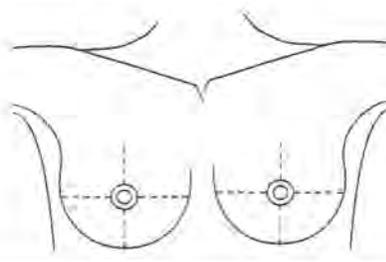
## Appendix: A South Bank Breast Service Referral Form

### Please see reverse of form for referral guidelines.

- All referrals should be sent by **FAX** to:
  - Urgent (2WW)** (01724 387704) for Scunthorpe patients/(01472 302450) for Grimsby patients
  - Non-urgent** (01724 387704) for Scunthorpe patients/(01472 875468) for Grimsby patients
- This form to be completed in full to comply with guidelines and regulations HSC 1998/242 and local guidelines for referral to the breast clinic. Local guidelines have been drawn up between the local PCTs and the secondary care Breast Service.

PLEASE ENSURE THAT THE PATIENT'S DETAILS, INCLUDING TELEPHONE NUMBER, ARE CORRECT

PATIENT DETAILS (please print legibly)		PRACTICE DETAILS (please print legibly)			
Hospital No.		Name of GP			
Title	Surname	Name of Practice			
First Names		Address			
Date of Birth .....					
Address		Post Code			
		Telephone No.			
Post Code		Practice Code			
Daytime Telephone No.		GP Referral Date .....			
Evening Contact No.		Please refer this patient to:- (Please tick appropriate box)			
Dates Patient Unavailable 1)		<b>NE Lines</b>	Mr LAD	Mr HJP	<b>EITHER</b>
2)		<b>N Lines</b>	Mr LAD		

CLINICAL DETAILS – Reasons for Referral (Please tick appropriate box)					
Breast lump – under 30					
Breast lump – over 30 (urgent)					
Blood stained nipple discharge					
Recent nipple retraction					
Peau d'orange/Eczema					
Thickening					
Breast pain					
Details, including Family History					
Significant Past Medical History:-					
None		Yes		Details	
Drug/Allergies:-					
None		Yes		Details	
Previous Mammography:-					
No		Yes		Year:-	Place:-
Fulfils the 2WW criteria (see guidelines overleaf)		YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
For Family History (Please see over)		Soon Referral	<input type="checkbox"/>	Non-Urgent	<input type="checkbox"/>

## **GUIDELINES FOR REFERRALS TO THE BREAST CLINIC<sup>1</sup>**

**This has been changed to facilitate differentiation between 2 week wait patients (i.e. a high risk of breast cancer), clinically soon and non-urgent referrals as is now defined by the Government.**

### **2 WEEK WAIT - TO BE SEEN WITHIN 2 WEEKS**

- Clinically suspicious new or discrete lump in lady over 30 years of age.
- Recent nipple inversion or eczema.
- Skin tethering.
- Peau d'orange.
- Suspicious skin ulceration.
- Blood-stained nipple discharge.

### **SOON REFERRAL - ANTICIPATED TO BE SEEN WITHIN 3 WEEKS**

- Not at high risk of cancer, but clinically indicated as soon referral e.g. abscess not resolving. If require clarification of priority of referral please contact the Breast Clinic for further advice.

### **NON-URGENT REFERRAL – TO BE SEEN WITHIN 8 WEEKS**

- Discrete lump in a woman under 30 years of age.
- Unilateral persistent pain in postmenopausal women.
- Intractable breast pain and not responding to reassurance, an appropriate bra and simple analgesics.
- Nipple discharge (**not blood stained**)
  - All women aged 50 years or over.
  - Persistent leakage from one nipple duct

### **Management of Family History**

- Women at or near population risk of developing breast cancer (i.e. a risk of <3% age 40–50 years and a lifetime risk of <17%) should be managed within primary care
- Women at moderate risk of developing breast (i.e. a risk of 3–8% age 40–50 years or a lifetime risk of ≥17%, but <30%) should be referred to secondary care for further management
- Women at high risk of developing breast cancer (i.e. a risk of >8% aged 40–50 years or a lifetime risk of ≥30%) should be referred to tertiary care (specialist genetic service) for further management. High risk also includes a ≥20% chance of a faulty BRCA1, BRCA2 or TP53G in the family.
- Risk should be assessed utilising the recently published NICE guidance (May 2004) for Breast Cancer – the Classification Care of Women at Risk of Familial Breast Cancer in Primary, Secondary and Tertiary Care. Copies are available from [www.nice.org.uk/CG014NICEguideline](http://www.nice.org.uk/CG014NICEguideline)

### ***Referral is not usually required for:-***

- *Pain in ladies under 35 years of age who have a low risk of underlying pathology.*
- *Ladies on HRT who often develop cyclical breast pain.*

**NOTE:- Mammography in isolation is no longer considered acceptable practice and patients requiring further assessment now require full triple assessment in the clinic.**

<sup>1</sup> Guideline developed in line with national guidance including Calman Hine Report, National Cancer Guidelines, the National Cancer Plan and also reflects local provision and referral frameworks.