What constitutes a histological confirmation of cancer? A survey of terminology interpretation in two English regions

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Abstract

Aims—To compare interpretation by cancer registries and histopathologists of phrases that might confirm a diagnosis of cancer.

Methods—One hundred and thirty one consultant pathologists were sent a questionnaire containing 37 phrases used in pathology reports, including those indicating cancer and those not. Pathologists were asked to indicate whether each phrase confirmed the disease, ruled it out, or was uncertain, together with a subjective estimate of how frequently they used the phrase.

Results—There was a 58% response rate with similar interpretation between regions. There were some differences in frequency of use. At least 50% of respondents considered 12 terms as confirmatory (for nine the lower 95% confidence limit was greater than 66%).

Conclusions—The registry should consider ignoring four of the 13 terms currently regarded as confirmatory. Terminology used in pathology reports should be standardised across registries. Registries and coding departments should use empirical evidence to assess which phrases confirm a diagnosis.

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Keywords: communication; cancer registration; medical records; terminology; surgical pathology

Some cancer registries receive registrations passively from clinical coding departments, as in the Trent NHS Region, whereas others employ their own staff to seek out and abstract case notes, as in East Anglia. In either type of registry, it is necessary to decide whether a case has been histologically confirmed. Because pathologists do not use standard descriptions, sometimes it is not clear whether the pathology report has confirmed the presence of malignancy or merely indicates suspicion. If the latter, it is not histologically confirmed, although there may be additional clinical, radiological, or laboratory evidence to support a diagnosis of cancer. In Trent, clinical coders are encouraged to notify the registry of all potential cases, and it is part of the registry's task to decide which cases should be weeded out, by querying those cases where the histological evidence appears insufficient and requesting further clinical details.

Typically, cancer registries will have a list of qualifiers to help interpretation—for example,

“diagnostic of . . .” confirms cancer, whereas “reminiscent of . . .” does not. However, such lists seem to lack empirical evidence for their validity. On the other hand, such evidence can be obtained, as in a previous study¹ on this topic, which examined the interpretation of 13 phrases by 20 pathologists in South Wales.

Methods

By pooling phrases used in Trent, East Anglia, and in the Irish Cancer Registry we produced a list of 37 qualifiers ranging from “rules out”, through “apparently”, to “diagnostic of”. All consultant histopathologists in Trent and East Anglia were sent a questionnaire listing the phrases in random order. The pathologists were asked to indicate whether each phrase confirmed a diagnosis, ruled it out, or was uncertain by circling the appropriate response. At the same time, we similarly obtained a subjective estimate of how frequently (often/rarely/never) the pathologists used each phrase.

If two adjacent terms were both indicated, the response was coded to the less certain one. For example, if “uncertain” and “yes” were both circled then the response was coded as “uncertain”. Six pathologists gave some responses of this type, covering 28 items.

If two adjacent terms were marked, but with an arrow leading from one to the other, the coded term was that to which the arrow pointed. For example, if “uncertain” was circled but an arrow pointed to “yes” then it was coded as “yes”. Three pathologists (including one of the above six) gave some responses of this type, covering 12 items.

The proportion of “confirm” responses was estimated for each phrase, and 95% confidence limits (CL) obtained by logistic transformation (to avoid values outside the range 0–1). For proportions of zero, an upper 95% CL was found using the “rule of three”².

Comparisons of the responses in each region were performed by trend χ^2 tests on the two 2×3 tables corresponding to each phrase. Data manipulation and analysis were performed in Excel³ and Systat.⁴ A second mailing was distributed to those who did not respond the first time.

Results

In Trent, 45 of 76 and in East Anglia 31 of 55 questionnaires were returned, giving an overall response rate of 58%.

Concerning the interpretation of the phrases there was little difference in the pattern of responses between East Anglia and Trent, with

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Table 1 Phrase and percentage of pathologists stating it confirms a diagnosis

Phrase	% "Confirm"	LCL	UCL	Number of respondents
Diagnostic of	98.7%	91%	100%	78
Characteristic of	96.1%	88%	99%	77
Represents	95.9%	88%	99%	74
Appearances of	94.9%	87%	98%	78
Typical of	90.9%	82%	96%	77
Indicates	90.5%	81%	95%	74
Indicative of	89.6%	80%	95%	77
That of	89.2%	80%	95%	74
Show	85.1%	75%	92%	74
Consistent with	70.5%	59%	80%	78
In keeping with	65.8%	54%	76%	76
Compatible with	62.2%	50%	73%	74
Most likely	32.9%	23%	45%	73
Rules out	31.5%	22%	43%	73
Appears to be	25.0%	16%	36%	72
Highly suspicious of	23.4%	15%	34%	77
Apparently	22.2%	14%	33%	72
Likely	20.3%	12%	31%	74
Suggestive of	18.4%	11%	29%	76
Favours	18.4%	11%	29%	76
Suggests	14.5%	8%	25%	76
Probable	12.0%	6%	22%	75
Seems to be	10.8%	5%	20%	74
Suspicious of	10.5%	5%	20%	76
Reminiscent of	8.5%	4%	18%	71
Presumed	6.8%	3%	15%	74
Appearances approaching	5.5%	2%	14%	73
Not ruled out	5.3%	2%	14%	75
Worrisome	4.0%	1%	12%	75
Questionable	3.9%	1%	12%	77
Suspects	2.8%	1%	11%	72
Risk of	1.4%	0%	10%	70
May be	1.4%	0%	9%	74
Possible	1.3%	0%	9%	75
Not excluded	0.0%	–	4%	74
Equivocal	0.0%	–	4%	76
Could be	0.0%	–	4%	74

Phrases in bold are regarded as definitive.

LCL, lower 95% confidence limit; UCL, upper 95% confidence limit.

Table 2 Frequency of use

Phrase	% "Often"	LCL	UCL	Number of respondents
Diagnostic of	72.4%	61%	81%	76
Characteristic of	52.6%	41%	64%	76
Represents	48.6%	38%	60%	74
Appearances of	76.6%	66%	85%	77
Typical of	50.6%	40%	62%	77
Indicates	43.4%	33%	55%	76
Indicative of	30.3%	21%	41%	76
That of	66.2%	55%	76%	74
Shows	78.1%	67%	86%	73
Consistent with	84.4%	75%	91%	77
In keeping with	53.2%	42%	64%	77
Compatible with	45.3%	34%	57%	75
Most likely	22.4%	14%	33%	76
Rules out	7.9%	4%	16%	76
Appears to be	13.0%	7%	22%	77
Highly suspicious of	48.1%	37%	59%	77
Apparently	6.6%	3%	15%	76
Likely	9.2%	4%	18%	76
Suggestive of	42.1%	32%	53%	76
Favours	37.7%	28%	49%	77
Suggests	39.5%	29%	51%	76
Probable	24.0%	16%	35%	75
Seems to be	2.6%	1%	10%	77
Suspicious of	57.1%	46%	68%	77
Reminiscent of	5.3%	2%	13%	76
Presumed	3.9%	1%	12%	76
Appearances approaching	5.3%	2%	13%	76
Not ruled out	7.9%	4%	16%	76
Worrisome	9.1%	4%	18%	77
Questionable	4.0%	1%	12%	75
Suspects	9.7%	5%	19%	72
Risk of	5.4%	2%	14%	74
May be	6.5%	3%	15%	77
Possible	21.1%	13%	32%	76
Not excluded	20.3%	13%	31%	74
Equivocal	15.8%	9%	26%	76
Could be	9.2%	4%	18%	76

Phrases in bold are regarded as definitive.

LCL, lower 95% confidence limit; UCL, upper 95% confidence limit.

$p < 0.05$ for only one of the 37 comparisons. For frequency of use, four of the 37 comparisons were significant (two with $0.04 < p < 0.05$ and two with $p < 0.005$). All were no longer significant after allowing for multiple comparisons, so for the remaining analyses the results for each region were pooled.

Table 1 displays, for each phrase, the proportion of pathologists regarding it as "confirming" a diagnosis, together with 95% CL and the denominator of the proportion. These vary slightly because some respondents omitted some items. For 12 phrases, at least 50% of pathologists regarded the expression as confirmatory, whereas for nine of these phrases the lower 95% CL was at least 66% (these are shown in bold), and they were therefore regarded as "definitive". Table 2 shows the reported frequency of use of each phrase.

Discussion

The aim of our study was not to provide a formal, comprehensive overview of this topic, but rather to draw attention to a real problem faced by cancer registries, and indicate possible solutions. Several papers have been published over the years dealing with issues such as the workload implied by an increasing overall information content of pathology reports⁵ and the value of checklists and standardised reports^{6,7} to achieve consistency in the content of clinically relevant information. Similar issues apply to radiological diagnosis.⁸ With regard to phraseology, the most pertinent comment⁹ described how ambiguous or misinterpreted terminology could have disastrous consequences, and yet be unappreciated by pathologists. However, the paper in question cited Attanoos and colleagues¹ as its prime source, thus emphasising the lack of primary data in this area—which of course will always be specific to particular languages. Gall¹⁰ also described the uncertainty of pathological diagnosis: "I think it is cancer but don't hold me to it", but only briefly and in an anecdotal way.

In brief, the principal findings of our study were that only a limited number of terms in a pathology report are regarded by pathologists as confirming a diagnosis of cancer. Our study used a much larger number of phrases than that of Attanoos *et al.*¹ and covered more than one health region. On the other hand, our response rate was only 58% compared with 100%. Nevertheless, it was encouraging that the pathologists in two regions were consistent in their interpretation, and that our results were similar to those found in Wales by Attanoos *et al.*: "diagnostic of", "characteristic of", "represents", "indicative of", "that of", and "shows" were definitive in both studies, although our definitive terms included two that were non-definitive in the Welsh study, plus four that were not used at all.

We were puzzled by one apparent paradox: 11% regarded "highly suspicious of" as confirmatory compared with 23% who regarded "suspicious of" as confirmatory. In addition, at first we were slightly surprised that "rules out" was considered to exclude a

diagnosis by only 59% of pathologists, but on reflection it is clear that the pathologist can only give an opinion on the specimen and not the patient.

In terms of frequency of use, our pathologists used "diagnostic of" more often, "that of" and "in keeping with" less often, and "consistent with" at about the same frequency as in the Welsh study. These are of course self reported figures. However, we reviewed 548 reports from East Anglia and 400 from Trent (restricted to the four laboratories that report to the Trent Cancer Registry) and found a rank correlation of 0.68 between the frequency with which terms appeared in the report and the proportion of pathologists who claimed they "frequently" used the terms. Although this is encouraging, it is not definitive because there is a large subjective element when analysing the text of reports, and our results are not entirely representative.

We were relieved to find that the changes we might want to make were relatively small. We need not change the terms that we currently regard as not being confirmatory, and of the 13 "confirm" terms currently used, we might drop four, namely:

- "Probable"
- "Likely"
- "Most likely"
- "Appears to be".

We now have an empirically justified list of phrases that, when used in pathology reports, can be taken to confirm the presence of cancer. Moreover, in Trent we can reduce our workload by only querying those notifications from coding departments that use non-confirmatory terms.

In the future, pathologists and clinical coders in our regions need to be educated to describe what has been done. The advent of a standard format for pathology reports might help, but not all pathologists like ticking boxes, and not all anatomical sites will as yet have a standard format for reporting. Advocates of automated pathology coding will also need to incorporate the uncertainties of terminology in their algorithms.^{11 12} Meanwhile, there should perhaps be moves at the national level (through the UK Association of Cancer Registries, The National Centre for Coding and Classification, and the Royal College of Pathologists) towards a standard terminology.

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