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# Perceptions of Ductal Carcinoma in Situ (DCIS) among UK health professionals

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## Abstract

Ductal carcinoma in situ (DCIS) is a complex medical entity which presents challenges for the health professionals who manage the treatment and support of the increasing numbers of women diagnosed with the condition. Health professionals' perceptions and experiences of working with DCIS have rarely been explored, which this study sought to address. Two hundred and ninety-six UK health professionals involved with the treatment of DCIS patients were surveyed. Respondents had diverse perceptions of the condition. Explaining DCIS to patients was challenging for many respondents, and the terminology used varied considerably. This exploratory study highlights the substantial diversity in the perceptions and communication of DCIS among UK health professionals. The nature and implication of these variations and the professional challenges presented by DCIS warrant further exploration and debate in order to inform the provision of appropriate care, support and information to patients.

*Keywords: Ductal carcinoma in situ (DCIS); health professionals; perception; communication.*

# Introduction

Diagnoses of ductal carcinoma in situ (DCIS) have risen dramatically since the National Health Service Breast Screening Programme (NHSBSP) was established and it now represents 20% of screen-detected breast cancers in the UK.[1] DCIS is a non-invasive condition, where cancer cells are confined to the ducts of the breast.[2] Whilst these cells are contained the condition is not life-threatening, and following treatment most patients have an excellent prognosis.[3] However, despite this positive outlook, when compared to invasive breast cancer (IBC) patients 'different' psychosocial problems may occur,[4] which may be due to the asymptomatic nature of the condition,[5] patients' lack of prior awareness of DCIS,[6-7] the uncertainty of the natural history of the condition,[8] and the treatment paradox it presents (e.g. extensive treatment, including mastectomy, to treat non-invasive/early disease).[9]

Recent research suggests that DCIS is a challenging and confusing diagnosis for patients, because of the complexity of the condition,[6, 10-13] and that treatment recommendations and the terminology used to communicate DCIS may contribute to their uncertainty.[14] Furthermore, women diagnosed with DCIS have expressed diverse perceptions of the nature of the condition ranging from breast cancer to pre-cancer, which may impact on their feelings and experiences of treatment, support and adjustment.[10] This diversity amongst patients may be due in part to the varied opinions about the condition, styles of communication and preferred terminology among health professionals, which has been reported anecdotally and in recent research.[10, 15-16] Furthermore, debate about the most appropriate treatment for DCIS is ongoing;[17] among radiation oncologists management of DCIS varied according to geographical region

(North America versus Europe) and academic status, [18] and a recent study with clinicians highlighted the difficulty of DCIS treatment decision-making.[19]

The inherent complexity of DCIS and the increasing evidence collated among patients, suggest that professionals' own attitudes and perceptions about the condition are important. To date, only one study has explored this area. Partridge et al. (2008) found considerable differences in professionals' perceptions, communication and management of DCIS;[19] however, this study was conducted in the United States and may not necessarily translate to UK practices. Furthermore, the authors did not specifically explore similarities and differences across different professional groups, with the focus generally limited to surgeons and medical oncologists. They did not include professionals who in the UK play a vital role in communicating with patients, such as specialist breast care nurses (BCNs).[20-21] Therefore, the current exploratory study aimed to investigate the terminology, perception and experiences of DCIS among UK health professionals, and to compare responses across a variety of professional groups.

## Materials and methods

### *Design and materials*

A brief survey was developed, piloted and made available for completion online, via email or post. In addition to demographic (age, gender, profession, personal experience of DCIS) and practice details (years in profession/breast speciality, number of new cases of 'pure DCIS' seen per year), the survey explored 2 main areas: 1) *Terminology in DCIS* was explored with two separate open-ended questions that asked participants to explain how they described low and high grade DCIS to patients, and 2) *Attitudes towards DCIS*, which incorporated the following four concepts: a) *perception of DCIS,* which was explored using a single item based on three verbatim quotes ("breast cancer", "fall between normal and cancer" or "not cancer, pre-cancer") derived from a recent study involving DCIS patients;[10] b) *general risk* for patients' long-term health (measured using a 5-point scale: low to high risk); c) *explaining*, including the perceived difficulty of describing DCIS generally (5-point scale: not difficult at all to very difficult), and in comparison to the difficulty of explaining invasive breast cancer (IBC) (less, same as or more difficult); and d) *challenges of DCIS* which asked participants to state the three greatest challenges facing patients and health professional themselves (ranked according to difficulty, e.g. 1 = most challenging).

*Recruitment and participants*

Ethical approval was sought from the Faculty of Health and Life Sciences Ethics Committee at the University of the West of England, Bristol. Additionally, as the target population was NHS staff, advice was sought from the Central Office for Research Ethics Committee (COREC). COREC confirmed that NHS ethical approval was not required because the proposed recruitment strategies via professional bodies and conferences did not involve recruiting directly through the NHS.

UK health professionals involved with DCIS were informed and directed to the survey via various professional bodies, organisations and conferences aimed at a variety of professions including specialist BCNs, surgeons, physicians, radiologists, radiographers, oncologists and pathologists. All participants gave informed consent and were notified that their responses were strictly confidential and could be entirely anonymous. Contact details were only required if participants wished to enter a prize draw, receive feedback on the results or participate in further research.

### *Statistical analysis*

All quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) version 13. Descriptive statistics explored frequency responses and chi-square analysis was undertaken to compare the professional groups. Some questions were specifically aimed towards professionals who have direct patient contact (e.g. BCNs and surgeons who explain DCIS to patients and must choose their terminology), as opposed to those with little face-to-face patient contact (e.g. pathologists). On review of the responses to these questions it was clear that those with little patient contact did not find these questions relevant and their responses were subsequently excluded from the analysis of these items. Binary logistic regression explored the factors associated with health professionals' views of the long-term risk of DCIS. Qualitative data provided in response to the open-ended questions were analysed using content analysis.

## Results

Two hundred and ninety-six health professionals participated, the majority of whom were surgeons (n = 90), breast care nurses (n = 51), pathologists (n = 47) or radiologists (n = 40). Demographic details by professional group are presented in Table 1. The mean age of all participants was 47.2 years, 56.1% were female and 12.2% indicated having a personal experience of DCIS (e.g. self, family). The number of new cases of 'pure DCIS' seen each year was most frequently in the range of 11-20 (35.1%).

*Table 1 about here*

*Terminology*

Two questions explored how professionals described DCIS to patients according to whether it was low or high grade. Excluding pathologists, almost one-third described low grade DCIS as a type of ‘cancer’, and an additional 20% described it as ‘cancerous’, ‘malignant’ ‘cells’ or ‘changes’ (see Table 2). In contrast, 21.8% explained it as a ‘pre-cancer(ous) condition’ or ‘pre-cancer(ous) cells’ and 17.2% as an ‘abnormality’, ‘abnormal cells’ or ‘cell changes’, in which there was no mention of cancer or malignancy. When these four main terms were dichotomised into two response groups (cancer or not cancer – see Table 2 for details), oncologists were significantly less likely to use the terms that mentioned cancer or malignancy: $\chi^2 = 14.98$, df = 5, p = 0.01.

Many professionals described the additional information they offered to patients, such as the ‘risk of progression’ (n = 112), the ‘contained’ (n = 106) and ‘early’ (n = 55) nature of the condition. The main differences in responses to the high grade scenario were: higher risk of progression (n = 131), the necessity/increased urgency of treatment (n = 50), less positive language (n = 42), uncertainty of the diagnosis/possibility of invasive disease (n = 27), and the faster timescale for progression (n = 23).

**Table 2 about here**

*Attitudes towards DCIS*

a) Perceptions of DCIS

Professionals held diverse perceptions of DCIS; 35.1% perceived it as ‘breast cancer’, whilst the remainder considered it to be ‘not cancer, pre-cancer’ (43.9%) or a ‘stage between normal and cancer’ (16.9%). Twelve professionals did not respond to this item (4.1%). When dichotomised into two response groups (breast cancer; not breast cancer, i.e. ‘fall between’ and ‘pre-cancer’), oncologists were also significantly less likely than other professions to view DCIS as breast cancer: $\chi^2 = 14.60$, df = 6, $p = 0.024$ (Figure 1).

**Figure 1 about here**

b) Perceived risk of DCIS

The perceived risk of pure DCIS for patients’ long-term health was rated as low (43.3%), medium (41.6%) or high (15%) and responses significantly differed by profession: $\chi^2 = 32.4$, df = 6, $p < 0.001$. Mann-Whitney U with Holms-Stepdown procedure[22] to adjust for inflated type I error rate confirmed that BCNs perceived a lower risk than pathologists, and that surgeons and oncologists perceived a lower risk than radiologists, radiographers and pathologists. Similar to the analysis of Partridge et al, [19] logistic regression identified factors associated with perceiving a higher risk of DCIS (dichotomised into low-medium vs. high). The factors entered were age, gender, number of years in profession, personal experience, number of new DCIS patients seen per year (deviation coding, comparing to mean), perception (breast cancer or not), and difficulty explaining DCIS compared to IBC. Unfortunately, professional group could not be entered as a predictor because none of the oncologists viewed DCIS as a high risk, and this empty cell biased the regression coefficients and resulted in non-convergence. Therefore, excluding profession, the model found that those who saw in excess of 40 new DCIS patients per year were over 3 times more likely to view DCIS as a higher risk (odds ratio 3.05, CI 1.38 – 6.73, p = 0.006). Reporting more difficulty explaining DCIS compared to IBC, a 'breast cancer' perception and older age of health professional were also significant predictors of a higher perceived risk for patients' long-term health (see Table 3).

**Table 3 about here**

c) Explaining DCIS to patients

Of the 246 responses (excluding pathologists who did not have direct patient contact), 54 professionals (22%) found it somewhat or very difficult to explain DCIS to patients, whereas 46.7% indicated it was not difficult, and the remaining 31.3% were undecided (neither option). However, in contrast and surprisingly given the previous agreement of low-medium perceived risk, 51.4% found DCIS more difficult to explain to patients than IBC (only 9% found DCIS easier to explain). Responses to open-ended questions revealed that the uncertainty of progression, treatment paradox, and discrepancies in terminology and professional opinion were perceived as reasons for this difficulty.

Chi-square analysis revealed a significant difference between the professional groups in the difficulty explaining DCIS compared to IBC (dichotomised as more difficult vs. same or easier): $\chi^2 = 15.2$, df = 5, p = 0.009. Further partitioned chi-square analysis revealed that: 1) surgeons and oncologists reported more difficulty than physicians, and

2) surgeons, oncologists, BCNs and radiologists reported more difficulty than radiographers. The percentages within each category can be viewed in Table 4.

**Table 4 about here**

d) Challenges of DCIS

The challenge of DCIS for patients that was most frequently reported by professionals was ‘understanding the condition’; cited 134 times across all responses, and this was also viewed as the most challenging by 103 participants (e.g. ranked as the number 1 challenge). Ninety-seven responses emphasised the ‘treatment paradox’ (ranked as the number 1 by 46), particularly in relation to recommending a mastectomy to treat a non-invasive/early disease. The ‘long-term risk’ (n = 97), ‘treatment decisions’ (n = 81) and ‘distress/psychosocial issues’ (n = 63) were also viewed as challenges for patients.

Whilst there were similarities between professional groups in their perceptions of the challenges faced by patients, there was less concordance in participants’ reports of the DCIS-related challenges they themselves faced, possibly due to the variety of interactions that different professions have with the condition (e.g. explaining it to patients, diagnosing the condition). For example, pathologists identified technical difficulties associated with assessing excision specimens, whilst the remaining professions described their most frequent challenge as ‘explaining’ DCIS to patients (cited 95 times across all responses and ranked as number 1 by 68). This further demonstrates the difficulty of communicating DCIS to patients. Seventy-six responses emphasised ‘professional issues’, which incorporated fear of overdiagnosis, uncertainty, and the lack of research/evidence base of the natural history of DCIS. ‘Communication of treatment' (cited by 70), 'treatment decisions' (cited by 69) and 'disease/diagnosis-related issues' (cited by 64) such as estimating the extent (especially among radiologists and radiographers), were also frequently reported challenges.

## Discussion

The findings from this exploratory study highlight the substantial variation in the perceptions and communication of DCIS among UK health professionals, and support recent findings in the United States.[19] The current study also validates the diverse terminology and difficulty of communicating DCIS emphasised in a recent study involving patients,[10] which confirms that these may influence patients' perceptions and experiences. In addition, the findings highlight that DCIS can be a challenging diagnosis for professionals to manage, especially in relation to the uncertainty surrounding the condition and communicating with patients.

There was considerable diversity in perceptions of DCIS both within and between professional groups. However, in each group a small majority viewed it as not being breast cancer (identifying instead with the 'pre-cancer' or 'fall between' options), and it was noticeable that oncologists were less likely to perceive DCIS as breast cancer than other professionals. This may be because the majority of patients are treated by surgery alone. Consequently, the oncologists in this study saw fewer new cases of 'pure DCIS' each year than other professional groups (see Table 1). However, it should be noted that there were fewer oncologists in this study than the numbers of respondents from other professional groups (e.g. surgeons, specialist BCNs). Further research is required to explore the experiences of different professionals groups in more detail.

In general, DCIS was viewed as a low or medium risk to patients' long-term health, reflecting prevailing medical knowledge concerning the condition. However, it was interesting to find that oncologists and surgeons perceived DCIS to be a lower risk than did pathologists, radiologists and radiographers, and that BCNs viewed it as less risky than pathologists did. In addition, those who saw a larger number of new DCIS cases each year (which may also be influenced by their profession) perceived it as having a greater long-term health risk for patients. Perceptions of higher risk were also associated with more difficulty explaining DCIS than IBC and with perceiving DCIS as 'breast cancer'. These associations do not infer causality and cannot necessarily be generalised, but they do suggest that the diversity of professionals' own views about DCIS influence how they perceive concepts such as risk, which in turn are likely to impact on their management of the condition and communication with patients.

The terms health professionals used to describe DCIS to patients varied considerably.[19] Over 40% of professionals described the condition as abnormal cells, an abnormality or a pre-cancer(ous) condition or cells, all of which could be seen as minimising the impact of the diagnosis. In contrast, 53.1% reported using terms that emphasised a type of cancer (albeit non-invasive, early or pre-invasive) or cancerous cells or changes, which could be interpreted as overstating the risks of the condition. The precursory terms 'early' or 'non-invasive' might act to lessen the seriousness of the diagnosis if they are understood and acknowledged by patients. However, anecdotal evidence suggests that many patients focus on the term 'carcinoma' or 'cancer' when they are diagnosed with DCIS,[14-15] both of which are associated with metastatic disease and mortality.[15] The general inconsistency in language and terms used in DCIS has been reported to leave patients confused.[6, 10] From a patient-centred perspective it is imperative that the language health professionals use to explain DCIS is understandable, coherent and consistent,[23, 6] so that patients can clearly comprehend the condition and the rationale for the recommended treatment.

Furthermore, explaining DCIS was reported to be a particular challenge for many professionals, with a substantial number reporting that this was the most difficult aspect of the condition for them. Over half found DCIS more complex to explain to patients than IBC. This finding is intriguing and warrants further research. The difficulty may stem from the inherent uncertainty and paradoxical nature of the condition. This study indicates that efforts to enhance professionals' ability to confidently and consistently explain the condition to patients would offer benefits both for them and for patients affected by DCIS. Communication advice and training in this area is currently under development in Australia.[13]

It is important to acknowledge the limitations of the method undertaken in this study. In particular, respondents were predominantly from four professions: surgeons, breast care nurses, radiologists and pathologists, and therefore some professional groups had less representation in the sample. Furthermore, the method of distributing the survey precluded the calculation of a total population size or response rate. The survey was presented as an exploration of health professionals' views rather than specifically about the challenges of DCIS, although it is possible that it attracted those professionals who were particularly interested in the challenges of DCIS. Therefore, the findings should be viewed in light of these caveats.

## Conclusion

It is evident that DCIS can be a complex and challenging diagnosis for health professionals to deliver to patients. The challenges inherent in explaining the condition reflect the uncertainty, complexity, ongoing debates about the condition and a lack of clarity about optimum treatment. Research findings from the UK Sloane Project,[24] a national audit of screen-detected DCIS, will hopefully ameliorate some of the difficulties and challenges for professionals in clinical practice. In the meantime, it would be beneficial for professionals to consider the impact of their own views, and the diversity of views within the health care professions, on patients' experiences of being diagnosed and treated for DCIS.

In view of this diversity of views it would be useful to debate the appropriate terminology and the most suitable information to offer women diagnosed with DCIS. It would seem logical to suggest that information should be consistent across different information sources (e.g. verbal, leaflets, internet). However, given the variety of views and terminology currently used, and the extensive research literature which emphasises the benefits of individualised communication and information provision,[25] future research should address whether greater consistency in the messages given to patients about a complex condition such as DCIS is possible or even desirable.

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## Conflict of interest statement

The authors have no conflict of interest to declare.

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*Table 1 – Demographic characteristics of the sample (n = 296)*

| | **Specialist BCN**<br>**n=50** | **Physician**<br>**n=16** | **Surgeon**<br>**n=90** | **Radiographer**<br>**n=25** | **Radiologist**<br>**n=40** | **Oncologist**<br>**n=27** | **Pathologist**<br>**n=47** | **Overall**<br>**n=296** |
|---|---|---|---|---|---|---|---|---|
| *Age (years)* | 46.0 | 48.1 | 47.4 | 52.0 | 49.7 | 42.3 | 46.1 | 47.2 |
| *Gender - male/female* | 0/50 | 7/9 | 60/29 | 0/25 | 20/20 | 16/11 | 26/21 | 129/166 |
| *Years in:* | | | | | | | | |
| - profession (general) | 16.7 | 14.9 | 15.4 | 24.0 | 20.4 | 13.7 | 20.2 | 17.6 |
| - breast speciality | 9.4 | 11.2 | 10.3 | 12.7 | 14.9 | 10.1 | 14.3 | 12.2 |
| *Personal experience %* | 11.8% | 18.8% | 6.7% | 28% | 10% | 7.4% | 17% | 12.2% |
| *No. of new cases of 'pure DCIS':* # | | | | | | | | |
| - less than 10 | 12% | 6.3% | 11.1% | 21.7% | 10.3% | 40.7% | 15.2% | 15.1% |
| - 11-20 | 24% | 43.8% | 47.8% | 21.7% | 17.9% | 25.9% | 45.7% | 35.1% |
| - 21-30 | 32% | 18.8% | 23.3% | 21.7% | 20.5% | 22.2% | 8.7% | 21.6% |
| - 31-40 | 8% | 18.8% | 8.9% | 13% | 20.5% | 7.4% | 4.3% | 10.3% |
| - 41+ | 24% | 12.5% | 8.9% | 21.7% | 30.8% | 3.7% | 26.1% | 17.9% |

*# per year*

*Table 2 – Terms used by participants to describe DCIS to patients*

| **Term used** | **Number (%) of responses** |
|---|---|
| *Cancer*$ | 127 (53.1%) |
| - form of cancer/breast cancer | - 45 (18.8%) |
| - non-invasive/in situ cancer | - 21 (8.8%) |
| - pre-malignant/pre-invasive cancer | - 12 (5%) |
| - cancerous or malignant cells/change | - 49 (20.5%) |
| *Not cancer*$ | 93 (38.9%) |
| Abnormality/abnormal cells/cell changes | 41 (17.2%) |
| Pre-cancer(ous) cells or condition | 52 (21.8%) |
| DCIS/ductal carcinoma in situ # | 7 (2.4%) |
| Other* | 12 (5%) |

* Other terms included: a warning sign/first step, risk/lesion, not a true cancer, unstable/unhealthy tissue

# It is uncertain from the data whether those who use 'DCIS' further described the components of the diagnosis to their patients

$ The top 2 rows were used in the chi-square analysis on the main terms utilised ('DCIS' and 'Other' were excluded due to small numbers and lack of clarity whether the emphasis was on cancer or not)

*Figure 1 – Perception of DCIS according to professional group (n = 284)*

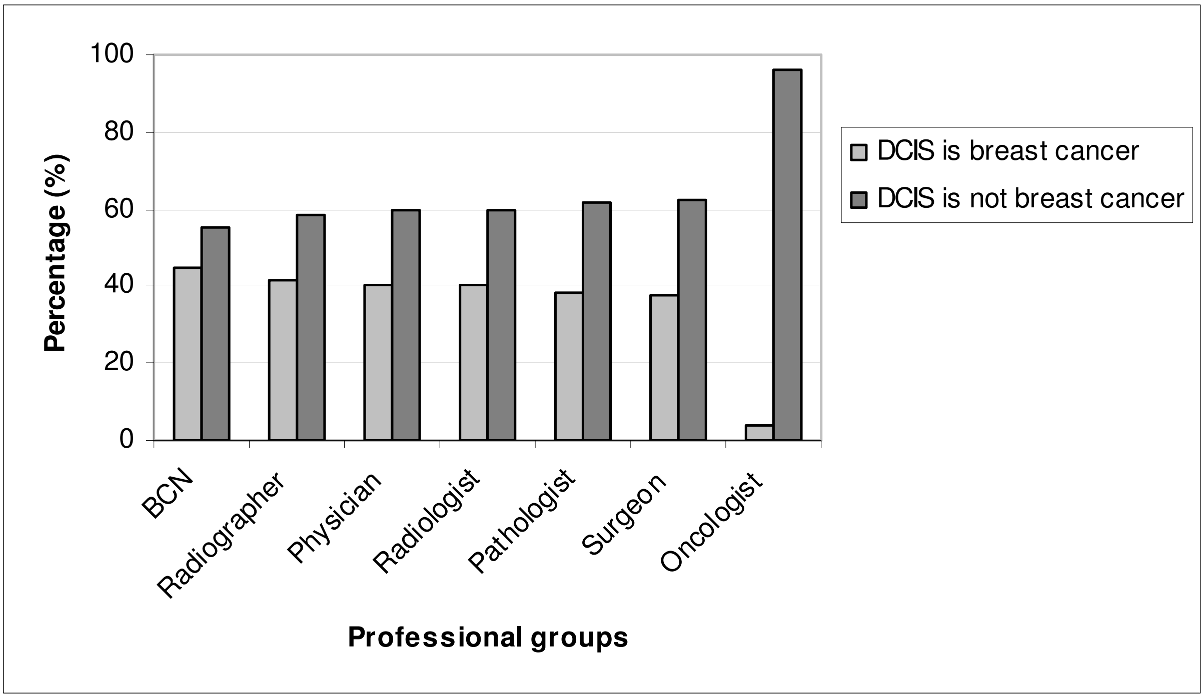

*Table 3 – Factors associated with higher perceived risk of DCIS*

| **Higher perceived risk of DCIS** | *B (SE)* | p | Exp *b* (OR) | **95% CI for Exp *b*** |
|---|---|---|---|---|
| Constant | -6.79 (2.12) | 0.001 | 0.001 | |
| | | | | |
| 41+ cases of DCIS (per year) | 1.11 (0.40) | 0.006 | 3.05 | 1.38-6.73 |
| More difficulty explaining (IBC) | 0.99 (0.46) | 0.029 | 2.71 | 1.11-6.66 |
| Breast cancer perception | -0.81 (0.42) | 0.052 | 0.44 | 0.20-1.01 |
| Older age | 0.07 (0.04) | 0.054 | 1.08 | 1.00-1.16 |

Non-significant factors were gender, years in profession, personal experience.

*Table 4 – Difficulty explaining DCIS compared to IBC, according to profession*

| | **% Same or less difficult** | **% More difficult** |
|---|---|---|
| BCN (n = 51) | 47.1 | 52.9 |
| Physician (n = 16) | 75 | 25 |
| Surgeon (n = 90) | 41.1 | 58.9 |
| Radiographer (n = 22) | 77.3 | 22.7 |
| Radiologist (n = 39) | 48.7 | 51.3 |
| Oncologist (n = 27) | 37 | 63 |