Dear [name of the medical professional you are approaching. This may be your Breast Surgeon, Oncologist or a Consultant Radiologist]

Firstly, I want thank you and your team for the excellent treatment that I have received, since my diagnosis of lobular breast cancer. This letter in no way changes my appreciation of this. However, I do have concerns about how I will be monitored moving forward, largely due to the distinctiveness of the disease.

Following my [insert whatever treatment you have had here e.g. lumpectomy, mastectomy], I would like to raise the issue of having an annual MRI scan as follow up, rather than a mammogram.

Research has demonstrated that “the detection of ILC on mammography is notoriously difficult, largely due to the growth pattern with which this tumour infiltrates the breast tissue.” (Johnson et al.) growing in single cell lines rather than forming a solid tumour.

The sensitivity of mammogram for breast cancer drops significantly for lobular breast cancer, especially if an individual has dense breasts.

* 63% - 98% for detection of all types of invasive breast carcinomas;
* 57% and 81% for lobular breast cancer;
* 11% for detection of lobular in people with dense breasts. (see reference below)

As a result lobular breast cancer is often diagnosed at a later stage with resultant larger tumour and possibility of spread to the lymph nodes or beyond.

 My own results and diagnosis reflect research referenced below, which recommend MRI as the gold standard for monitoring for lobular breast cancer.

Between [insert date] and my mastectomy in [insert date], I had [insert number of mammograms] mammograms, that did not identify a tumour/identified a tumour of [insert size of tumour or tumours in cm]. Pathology following surgery found the tumour to be [insert size of tumour(s) in cm] cm.

These results demonstrate that [insert number]% of my tumour(s) was/were missed on mammogram. This means they had to be [add number] cm before they were seen on current imaging methods.

Is it appropriate to be left feeling that, if I have a recurrence in the future, I have to potentially wait until any tumours reach such a size again before they are identified on mammogram?

We are frequently told that early detection is key for treating breast cancer, but people with lobular are more likely to be diagnosed later at Stages 3 or 4.

Stress is a known factor in the development of cancer. I am concerned that the protocol that is now meant to be keeping me safe is actually increasing that stress due to my lack of confidence in its effectiveness. I am being asked to trust a mammogram to find any recurrence when it did not find my primary tumour/identified only a proportion of my primary tumour, [Delete which is most appropriate] and is not the most appropriate and medically evidenced method of monitoring lobular breast cancer.

I am aware that the majority of treatment plans are based on research conducted for ductal breast cancer rather than lobular, a very distinctive and separate disease in its initial growth, presentation and potential spread. I am aware that many clinical decisions are guided by NICE (for England, Wales and Northern Ireland)/SIGN (Scotland) and local Trust guidelines. Current guidelines do not take into account the most up-to-date and increasing evidence that lobular breast cancer and Ductal breast cancer/No Specific Type are distinctive diseases and should be treated differently in terms of diagnosis, treatment and follow-up.

I therefore ask you to consider the most current relevant medical evidence and request a MRI scan rather than mammogram as follow-up.

Should you disagree with my request, can you please provide me with your evidence-based rationale for denying an MRI?

I look forward to hearing from you, thank you.

Yours sincerely

[Your Name]

**Key points and References**

*‘There has been increasing awareness that ILC and IDC are distinct, but this large multi-center study provides compelling evidence that these are two different diseases that require different management,’*

Oesterreich, S. et al. **Clinicopathological Features and Outcomes Comparing Patients With Invasive Ductal and Lobular Breast Cancer**. Journal of the National Cancer Institute (2022) https://academic.oup.com/jnci/advance-article-abstract/doi/10.1093/jnci/djac157/6758318?login=false

*‘Due in part to the histopathologic features of ILC described above, the sensitivity of mammography in detecting ILC is lower, ranging between 57 and 81 % [13–15]. When breast tissue is described as heterogeneous or extremely dense, the sensitivity of mammography for the detection of invasive tumours can be as low as 30 to 48 % [16, 17]. Berg et al. [18] specifically examined the performance of mammography as a function of both tumor type and breast density. Mammographic sensitivity was 81 % for IDC compared with 34 % for ILC; when only those patients with dense breast tissue were considered, sensitivities decreased dramatically to 60% and 11 %, respectively. Due to these diagnostic challenges, it is crucial for breast imaging radiologists to be aware of the atypical and subtle mammographic patterns of ILC.*

‘*Studies have repeatedly shown that MRI is superior to conventional imaging, not only in terms of its increased sensitivity for detecting ILC, but also for the detection of ipsilateral and contralateral disease….*

Johnson, K., Sarma, D. & Hwang, E.S. **Lobular breast cancer series: imaging**. *Breast Cancer Res* **17,** 94 (2015). https://doi.org/10.1186/s13058-015-0605-0

**‘***Mammograms are less sensitive for the detection of ILC than for invasive ductal carcinoma (IDC): up to 30% of ILCs are not visualized at mammography’*

Porter AJ, Evans EB, Foxcroft LM, Simpson PT, Lakhani SR. **Mammographic and ultrasound features of invasive lobular carcinoma of the breast.** *J Med Imaging Radiat Oncol* 2014; 58: 1–10. doi: <https://doi.org/10.1111/1754-9485.12080>

Copied to: Dr .......[your Gp]