



Response to:

RESHAPING BREAST ASSESSMENT SERVICES

Proposals for the Future Model of Breast Assessment Services for
the Population of Northern Ireland

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Prepared by:-

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Introduction

HERE NI (previously LASI), established in 2000, is a regional organisation that works across all areas of Northern Ireland and the boarder counties to support lesbian and bisexual (LB) women and their families.

We advocate for and support LB women and their families and improve the lives of LB women across Northern Ireland. We do this in lots of different ways; through providing information; peer support; facilitating training; lobbying government and agencies on; offering a community space for meeting and much more.

Here NI is the only women focused organisation within the NI LGBT+ sector.

While there are no conclusive figures around the number of people who identify as Lesbian, Gay, Bisexual and Transgender (LGB&T) it is broadly recognised that LGB&T people make up between 6-10% of our population. If this is accurate, the LGB&T sector is one of the largest minority communities in Northern Ireland and accounts for 108,100 – 181,000 of the population. As LGB&T people become increasingly visible within our society so will their needs – and the needs of their families.

Of the numerous issues impacting on the health and wellbeing of LGB&T people in Northern Ireland, visibility remains of paramount importance. This impacts both directly and indirectly on this group and helps sustain the homophobic and heterosexist bias that exists within society.

We welcome the opportunity to engage with the Department of Health's Reshaping Breast Assessment Services consultation. This consultation response is the result of engagement with service users, the Belfast Public Consultation event and a literature review of research on the particular experiences of LB women in relation to breast cancer.

We would take this opportunity to note that our service users were largely unaware of the proposals until we brought it to their attention. Here NI attended the Belfast public consultation, which was in a venue outside of the city centre with limited public transport links. The Department should consider how it can better publicise consultations and ensure it engages with those who are vulnerable and marginalised, for example due to living rurally or on a lower income.

We recommend that the Department review the WRDA guidance for public authorities on consulting with women¹ to ensure consultation documents are accessible, as well as the process generally. The WRDA guidance on public consultations² also states “the binary ‘agree/disagree’ nature of many questions hides the complexity of how people feel about different issues”. In our opinion the yes/no answers should be given less weight than the accompanying text responses from participant.

Research carried out in Northern Ireland identified that LGB&T people are substantially more likely than the Northern Ireland population to use drugs and are nearly three times more likely to have taken an illegal drug in their lifetime (62% v 22%). The use of drugs and alcohol had been a factor in 15% of LGB people and 36% of transgender people self-harming. Drugs and alcohol contributed to 30% of LGB&T people thinking about suicide (suicidal ideation) and 13% attempting suicide. Given the health dangers associated with the use of drugs, alcohol and cigarettes, higher than average use of these substances is likely to expose LGB&T people to greater risk of a range of physical conditions including cancer, heart disease, liver disease, and high blood pressure.² Smoking increases the risk of a range of illnesses including heart disease, pulmonary disease and various cancers, including breast cancer. Research carried out in Northern Ireland identified that LGB&T people are more likely than the Northern Ireland population to smoke tobacco. A total of 44% of LGB&T people smoke cigarettes compared to 24% of the Northern Ireland population as a whole.³

¹ Women at the Heart of Public Consultation, A guide for Public Authorities and Women’s Organisations, WRDA, November 2017
https://wrda.net/wp-content/uploads/2018/10/WRDA_WomenAtTheHeartOfPublicConsultation.pdf

² Women at the Heart of Public Consultation, A guide for Public Authorities and Women’s Organisations, WRDA, November 2017
https://wrda.net/wp-content/uploads/2018/10/WRDA_WomenAtTheHeartOfPublicConsultation.pdf

³ Statistics drawn from ‘All Partied Out – Substance use in Northern Ireland’s lesbian, gay, bisexual and transgender community, ‘The Rainbow Project, E.Rooney

LB women experience significant barriers to accessing health services. They:

- Are reluctant to disclose their sexual orientation for fear of discrimination by health professionals;
- Lack awareness and knowledge of health risks;
- Access health services less often than other women;
- Delay treatment and follow-up;
- Generally prefer a more holistic approach to healthcare;
- Have a preference for female service providers;
- Are at risk of psychological distress, damaged self-esteem and reluctance to access preventive care if they do not have access to an LGB community;
- Have a high uptake of counselling services;
- Are up to 2-3 times more likely to attempt suicide and have higher levels of self-harm than their heterosexual counterparts.⁴

⁴ This section draws on Quiery, M. (2007). A review on the impact of discrimination and social exclusion on lesbian and bisexual women's health in Northern Ireland. (LASI/HERE NI publication).

Question 1 – Do you agree that a breast assessment network should be established as part of the future service delivery model?

A Breast Service Delivery Model must include representation from service users, with attention paid to differences amongst service users for example with regards to age, location and sexual orientation. Any engagement with such a network must be meaningful. It was clear from the public engagement event that service users were knowledgeable about their own care and had many practical suggestions.

Question 2 – Do you agree that breast assessment services should be provided in no more than three locations?

No, we do not agree that breast assessment services should be provided in no more than three locations. It is not clear from the Department of Health information why the three site model was the preferred option, when it scored less than the four site model in the Department's assessment. The statistics provided by the Department on wait times and do not appear to reflect the current status.

It is important that the health service is sustainable. Reducing services to three locations would likely put extra pressure on the staff within those locations. As our population continues to age it is likely that even more people will need to access these services, so the service should be broadened rather than restricted. Existing services should be improved. At the Belfast public consultation event a former staff member of Belfast City Hospital breast assessment unit made suggestions to increase efficiency of the service for example targeted clinics, staff views on best practice should be sought in an attempt to improve the service.

Question 3 – Do you agree with the proposal to consolidate service delivery at the three stated locations (Altnagelvin, Antrim and Dundonald)?

There should be access across the province, so the suggestion of services in different Trusts is welcome, however there are significant areas with no provisions in the South and South West. .

We are surprised at the suggestion that the Belfast City Hospital specialist unit will be closed. As well as being a site accessible by public transport its proximity to research facilities and Macmillan facility were noted by service users at the Belfast public event. It was also raised that the service in Craigavon is performing to target currently, although this is not reflected in the out-dated information from the Department.

Question 4 – Do you agree that patient referrals to breast assessment services should be managed through a central booking system?

A central booking system may improve the efficacy of the service; however there still must be an option of choosing where treatment is delivered.

Question 5 – Are any of the options set out in the consultation document likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the 1998 Act?

Yes, there are a number of Section 75 groups who are likely to be adversely impacted by the options set out in the consultation document:

Sexual Orientation – Over one in twelve lesbian and bisexual women aged between 50 and 79 have been diagnosed with breast cancer compared to one in twenty of women in general.⁵ Research suggests that lesbians may have an increased risk of developing breast cancer because of a ‘cluster of risk factors’⁶, which are linked to attempts to manage the stress of living with homophobia and discrimination. Lesbian and bisexual women as a combined group have higher rates of smoking, drinking alcohol and recreational drug use than the general population.⁷ Lesbians are less likely to have been pregnant which is a factor in reducing the risk of breast cancer.⁸ Aside from these risk factors lesbian and bisexual women are less likely to seek help if they find a lump. A 2010 UK cancer awareness measure survey of 600 lesbian and bisexual women found that among older women (40+), 75% of lesbians said they would present to a doctor within a week of finding a lump compared to 68% of bisexual women and 80% of heterosexual women.⁹

⁵ Prescription for Change, Lesbian and bisexual women’s health check 2008, Ruth Hunt and Dr Julie Fish

https://lgbt.ie/wp-content/uploads/2018/06/attachment_233_prescription_for_change_1.pdf

⁶ What do we know about lesbians and breast cancer? Not enough!, Dr Susan Love Research Foundation, Liz Margolies

https://www.drSusanLoveResearch.org/pdfs/Great_Reads_lesbianscancer.pdf

⁷ Prescription for Change, Lesbian and bisexual women’s health check 2008, Ruth Hunt and Dr Julie Fish

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⁸ What do we know about lesbians and breast cancer? Not enough!, Dr Susan Love Research Foundation, Liz Margolies

https://www.drSusanLoveResearch.org/pdfs/Great_Reads_lesbianscancer.pdf

⁹ The Emerging Picture LGBT people with cancer, Macmillan Cancer Support, September 2014

<http://be.macmillan.org.uk/Downloads/CancerInformation/RichPicture/RP-LGBT-people-with-cancer.pdf>

Gender - While there are some men who are diagnosed with breast cancer the numbers are relatively small. Women predominantly use breast assessment services so these proposals are likely to have a substantial adverse impact on women. The particular needs of trans people must also be considered, we recommend engagement with Transgender NI for specialist advice.

Dependants – Women are more likely to have caring responsibilities than men. This can impact a person’s availability to travel for healthcare.

Age – Older women are likely to be adversely impacted by these proposals. Breast cancer risk is strongly related to age with 81% of cases occurring in females over the age of 50 years and incidence rates greatest among women aged 80-89.¹⁰

Racial Group – There must be consideration of the particular needs of Black, Asian and Minority Ethnic women who are often marginalised from service provision as well as on lower incomes. Migrant women who live in the Southern Trust Area are likely to suffer adverse impacts if the proposal to close breast assessment services in Craigavon Area Hospital proceeds.

Question 6 – Are you aware of any indication or evidence – qualitative or quantitative – that any of the options set out in the consultation document may have an adverse impact on equality of opportunity or on good relations?

Yes, this is set out in detail in response to Question 5. There will be particular impacts on rural women, older women, and women with a lower income related to travel, as well as exacerbated barriers for BAME and LGBT+ service users.

It would be advantageous to gather data on hard to reach communities, like for example LB women or LGB&T people. It is important that the Department realises the benefits of using relevant current data, and that it also acknowledges the need to collect data that does not exist, particularly on sexual orientation. There must be the development and implementation of data on aspects of LB women’s lives.

¹⁰ Breast Cancer Factsheet, Northern Ireland Cancer Registry
<https://www.qub.ac.uk/research-centres/nicr/FileStore/OfficialStats2017/Factsheets2017/Fileupload,896072,en.pdf>

Question 7 – Is there an opportunity to better promote equality of opportunity or good relations?

Retaining breast assessment services at the existing five sites provides the best opportunity to promote equality of opportunity.

Question 8 – Are there any aspects of the proposals in the consultation where potential human rights violations may occur?

Yes.

The human right to health is recognised in several international human rights documents and conventions including the Universal Declaration of Human Rights the International Covenant on Economic, Social and Cultural Rights ('ICESCR'). While not the main focus the following also refer to the provision of healthcare; the Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and the revised European Social Charter.

The department must carefully consider their obligation to provide available, accessible, acceptable and good quality healthcare.

Question 9 – Are the actions/proposals set out in this consultation document likely to have an adverse impact on rural areas?

Yes.

The proposed three site model leaves those in the South and South West of Northern Ireland without a local service.

The poor transport infrastructure, including public transport, in rural areas would present a barrier to people in those areas accessing care.

Conclusion

We welcome this consultation process, and the attempts made by the Department to maximise engagement. The Northern Ireland Sexual Orientation Strategy and Action Plan (SOSAP) was originally proposed by OFMdFM during direct rule in 2005. However, upon devolution this draft strategy was shelved until 2012 when it was announced through the draft 'Strategy for Cohesion Sharing and Integration' that a new strategy would be developed. To date, this has not been implemented. With no legislative agenda, strategy or follow through on many commitments by central government on LGB&T issues, this community remains largely invisible at the heart of government and politics in Northern Ireland. We hope that the diverse views of respondents are taken into account and that particular attention is given to the additional barriers which some groups experience, some of which are highlighted in our own consultation response.

We are also hopeful that an efficient service which meets the needs of patients, staff and the community is achievable

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