Consortium for the Regional Support for Women in Disadvantaged and Rural Areas

Response to: Reshaping Breast Assessment Services

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Women's Centre Derry
ACCESS & EMPOWERMENT

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Enabling women into non-traditional employment

Foyle Women's
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Women's Regional Consortium: Working to Support Women in Rural Communities and Disadvantaged Urban Areas

1. Introduction

1.1 This response has been undertaken collaboratively by the members of the Consortium for the Regional Support for Women in Disadvantaged and Rural Areas (hereafter, either the Women's Regional Consortium or simply the Consortium), which is funded by the Department for Communities and the Department of Agriculture, Environment and Rural Affairs.

1.2 The Women's Regional Consortium consists of seven established women's sector organisations that are committed to working in partnership with each other, government, statutory organisations and women's organisations, centres and groups in disadvantaged and rural areas, to ensure that organisations working for women are given the best possible support in the work they do in tackling disadvantage and social exclusion.[1] The seven groups are as follows:

- Training for Women Network (TWN) – Project lead
- Women's Resource and Development Agency (WRDA)
- Women's Support Network (WSN)
- Northern Ireland's Rural Women's Network (NIRWN)
- Women's TEC
- Women's Centre Derry
- Foyle Women's Information Network (FWIN)

1.3 The Consortium is the established link and strategic partner between government and statutory agencies and women in disadvantaged and rural areas, including all groups, centres and organisations delivering essential frontline services, advice and support. The Consortium ensures that there is a

[1] Sections 1.2-1.3 represent the official description of the Consortium's work, as agreed and authored by its seven partner organisation

continuous two-way flow of information between government and the sector. It also ensures that organisations/centres and groups are made aware of consultations, government planning and policy implementation. In turn, the Consortium ascertains the views, needs and aspirations of women in disadvantaged and rural areas and takes these views forward to influence policy development and future government planning, which ultimately results in the empowerment of local women in disadvantaged and rurally isolated communities.

1.4 The Consortium works to advance the interests and enhance the wellbeing of disadvantaged, marginalised women in some of the most deprived areas of Northern Ireland.

1.5 The Women's Regional Consortium appreciates the opportunity to respond to the Department of Health's Reshaping Breast Assessment Services consultation. Women's views were gathered during a series of focus group engagements in local women's centres, with Consortium partners and by individual telephone interviews with individual women (service users).

2. General comments

2.1 We welcome the extensions to the consultation deadline to enable us to more fully canvas the views and experiences of women across Northern Ireland on this important subject. There is no doubt the strength of feeling among women about the proposals in this consultation document. We believe that it is of the utmost importance that these views are shared with the Department with a view to reshaping these proposals to the benefit of existing and future users of these services, their families and friends.

2.2 In our focus group engagement with local women we found a widespread lack of knowledge about this consultation and the proposals contained therein. Despite the call by the Permanent Secretary, Richard Pengelly to *"encourage as many people as possible to read this consultation and make their voices*

heard" [2] it seems that many local women were unaware of this consultation. We would therefore ask the Department to consider and evaluate how it reaches out to people about consultations on issues of such importance.

2.3 It is important for the Department to consider how it might best reach those who are the most vulnerable and marginalised and whose views must be reflected in a consultation of this nature as they are likely to be significantly and disproportionately more affected by increases in travel times/costs.

2.4 We would also suggest that online-only means are insufficient to reach many people particularly those who are the most isolated and vulnerable. Since 2010, government policy has assumed the majority of consumer interactions with government services will be carried out online. However there are issues with broadband access (particularly in rural areas) and cost with some of the most disadvantaged unable to afford the extra costs associated with internet use.

2.5 The provision of internet access is not enough on its own and many people need support to use digital services. Marginalised citizens are least able to make effective use of e-Government services. They are least likely to be connected, to be aware of services, or have the necessary digital literacy to make meaningful use of such services. As government services become "digital by default" there is growing evidence that the most marginalised are being left behind.[3]

2.6 We welcome the fact that the Department held a number of public consultation events to gauge opinion from the public on these proposals. However once again we question how well these events were publicised. Many of the women we spoke to at our own focus group events had not heard about

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[2] Reshaping Breast Assessment Services, Public Consultation Document, Department of Health, March 2019
https://www.health-ni.gov.uk/sites/default/files/consultations/health/updated-bas-consultation-document.pdf

[3] Leaving No One Behind in a Digital World, Hernandez and Roberts, K4D Emerging Issues Report, Institute of Development Studies, November 2018
https://assets.publishing.service.gov.uk/media/5c178371ed915d0b8a31a404/Emerging_Issues_LNOBDW_final.pdf#page16

the Department's public consultation events. Some of these events were therefore very poorly attended. For example, approximately 40 people attended the Belfast event. This is despite the fact that there is strong opposition to one of the proposals within this consultation to relocate breast assessment services from the Belfast City Hospital. Questions must be asked about the low turnout to this event. The Department must consider its venue choice and the level/type of publicity about these events in order to reach the widest possible audience. Perhaps a more central venue (city-centre) and more widespread publicity using different methods of communication would have resulted in a more realistic turnout to this event?

2.7 A number of the public consultation events were very well attended and this was primarily due to local campaign groups who spread the word and galvanised local people to attend. This was particularly the case in Enniskillen and Craigavon, both these areas are likely to be considerably affected if these proposals go ahead.

Accessibility of Consultation Document

2.8 Despite the focus on plain language and accessibility many public consultation documents contain jargon and policy terms which mean very little to ordinary people. WRDA guidance for public authorities on consulting with women[4] says that: *"the terminology can create a language barrier or make the respondent feel like they don't know enough to take part."* Unfortunately this is the experience of some of the women we spoke to about the format of this consultation. There was a sense that it was too "*high level*" for them and they did not feel it was something that they would be able to respond to.

2.9 The language used in the document is often complex containing technical health service terminology. While we understand it may be difficult to avoid the use of more complex language in a consultation of this nature we believe that the document does not meet the guidelines set out for consultations in terms of

[4] 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

simplicity. The consultation guidelines state that when government consults it must: *"make sure the document is as simple and concise as possible"* [5] and we believe that this has not been achieved in this instance. Unfortunately this has led to a situation where some women have not responded to this consultation because they feel it is not for them. This is to the detriment of this process.

2.10 We welcome that at the public consultation event (Riddel Hall, Belfast) the Chief Medical Officer assured attendees that responses will be taken in any shape, form or way that responders wish to submit them. However many women will not have heard this if they have not attended a public consultation event and will feel excluded from this process due to a lack of understanding.

> "Do they know that some of the people that read this won't understand it? That makes you feel inadequate."
>
> - Participant at Consultation Event

> "Do they word things this way to put people off?"
>
> - Participant at Consultation Event

> "Language/lingo used in the consultation is too Department focused. I look forward to plain talking and true co-production language.
>
> - Participant at Consultation Event

> "If this is a true consultation for everyone in Northern Ireland then it needs to be reviewed as some people don't understand this consultation document."
>
> - Participant at Consultation Event

[5] nidirect https://www.nidirect.gov.uk/articles/public-consultations

Format of the Consultation Questionnaire

2.11 The Consortium has concerns about the format of the consultation questionnaire. It asks nine questions each of which has a 'yes/no' format followed by a space to expand the answer. As WRDA guidance on public consultations[6] states: *"the binary 'agree/disagree' nature of many questions hides the complexity of how people feel about different issues."* We would urge extreme caution on using statistics on responses to these binary questions as the basis for making conclusions on the proposals. The answer to these 'yes/no' questions needs careful analysis alongside the accompanying text.

2.12 Careful consideration must be given to the fact that many people will give an answer of 'yes' but clarify this in the space below. They may have several qualifications to their 'yes' answer which could be negated if these issues are not properly addressed. The results from the 'yes/no' answers must not be considered in isolation or presented in such a way that they paint a misleading picture of responses. We would encourage the Department not to use results from these binary questions as the basis for any decision making. If they are to be used they should not be used in isolation from any clarification given within the accompanying text.

Co-Production

2.13 The Bengoa Report [7] details the *"increasing acceptance that people who use services and have healthcare needs will have views on how they should be treated as individuals and as groups who have interests in services. It is now recognised that people should be treated with respect and listened to and that major changes to services should be consulted upon."* Bengoa describes a co-production approach which recognises *"people who use services as assets with unique skills."*

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[6] 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

[7] Systems, Not Structures: Changing Health & Social Care, Expert Panel Report, October 2016
https://www.health-ni.gov.uk/sites/default/files/publications/health/expert-panel-full-report.pdf

2.14 There is clearly much to learn from users of breast assessment services and this is an issue that was raised very passionately at the Belfast public consultation event (25/06/19 in Riddel Hall). True co-production as described by Bengoa recognises: "*a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities."* Bengoa makes clear the difference between co-production and participation. Participation means being consulted while co-production means being equal partners and co-creators. *"The benefits of adopting co-production include delivering change that is owned by service users rather than being resisted by them and designing services that reflect the knowledge and expertise that comes from using services."*

2.15 The Consortium has concerns that genuine co-production has not taken place with regards to formulating the proposals in this consultation. While the Department has consulted on the proposals and made attempts to encourage participation in the consultation there is less evidence about true co-production in the development of the proposals. We urge the Department to employ genuine co-production in this consultation process and in the implementation of any resulting proposals.

2.16 While Annex B to the consultation cites: *"The Project Board recognised the need for co-production in assessing the relevant issues and agreeing a preferred option for a future service model"* there were only three patient/user representatives as members. There is no further detail about the circumstances or location of these members and it is therefore difficult to determine how representative they were and whether this was done in the true spirit of co-production.

2.17 At the public consultation event in Belfast questions were asked about the make up of the Project Board. Attendees felt that there needed to be much more service user involvement in this group in order to properly reflect the needs and experiences of patients.

"Women who have been diagnosed with cancer have a strong voice and need to be heard."

- Participant at Consultation Event

"In keeping with co-production guidelines have service users scrutinised this?"

- Participant at Consultation Event

"It is a money saving exercise. It is not people-centred. This is about cutting costs."

- Participant at Consultation Event

Cancer Statistics in Northern Ireland

2.18 Cancer is the leading cause of death in Northern Ireland with breast cancer being one of the most common types of cancer diagnosed.[8]

2.19 Among women incidence rates are projected to continue to increase, with a 7% rise by 2020 and a 13% rise by 2035 expected. The number of cancer cases diagnosed is projected to rise by 63% for women by 2035. By 2035 the most common cancers are expected to remain breast, colorectal, lung and prostate cancer, with the number of breast cancers expected to reach 2,000 cases per year.[9]

2.20 Over the last ten years the number of breast cancers cases in women has increased. After accounting for the increasing number of older people in the Northern Ireland population, breast cancer incidence rates in women have

[8] Cancer: Northern Ireland, Research and Information Service Research Paper (NIAR 64-17), Northern Ireland Assembly, June 2017 http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2017/health/3217.pdf

[9] Cancer Incidence Trends 1993 – 2013 with Projections to 2035, NI Cancer Registry http://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/NIrelandReports/Filetoupload,532183,en.pdf

increased during 1993-2017 by an average of 1.3% per year. 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]

2.21 Given the increasing incidence of breast cancer, coupled with an ageing population and the fact that it is one of the most common types of cancer diagnosed it seems incongruous with these proposals. This was very much reflected in discussions with local women who were surprised about decisions to potentially reduce these services at a time of increasing demand.

> "If they are already struggling to cope with five venues I don't see how this can work – how will reducing services work when demand is going to increase?"
>
> - Participant at Consultation Event

> "It is hard to justify these cuts when demand is increasing so much."
>
> - Participant at Consultation Event

> "If demand is increasing why cut services?"
>
> - Participant at Consultation Event

> "The population is getting bigger and services are getting smaller, it doesn't make sense."
>
> - Participant at Consultation Event

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

> “Statistics on the increase in cancer are phenomenal. How can they close centres when demand is increasing for appointments? The projections are horrendous so how can they reduce services? They should be investing in staffing, services, infrastructure instead of pulling back.”
>
> - Participant at Consultation Event

> “They need to keep all the assessment units open to facilitate local women and men in local communities. If the numbers increase there is going to be the demand for it.”
>
> - Participant at Consultation Event

Lack of local Assembly

2.22 We welcome the fact that the Department has announced that it will commission a new Cancer Strategy for Northern Ireland. Given the fact that cancer is the leading cause of death in Northern Ireland and incidences of cancer are on the rise it is imperative that Northern Ireland has an up to date Cancer Strategy which is focused and adequately resourced.

2.23 While we welcome that work has begun on developing a new Cancer Strategy for Northern Ireland we are conscious that decisions on the implementation of any new Cancer Strategy would be for a future Health Minister. This is concerning given there has been no functioning local Assembly in Northern Ireland for over two years. We do not wish to see any new Strategy ‘gathering dust’ and we remain disappointed about the lack of a functioning local Assembly in Northern Ireland which is holding up progress on a whole range of women’s issues.

2.24 At local focus group sessions women have been expressing frustration at the lack of a local Assembly in Northern Ireland. This means that these changes are being proposed without scrutiny by locally elected representatives and without access to a locally elected Health Minister. These are important

decisions for Northern Ireland and for the future health and wellbeing of citizens here which are likely to have a major impact for many years to come. We are concerned that the lack of local Assembly results in a democratic deficit for the people of Northern Ireland. The current situation where unelected civil servants are proposing and potentially implementing changes on issues of such major significance is concerning and it is no substitute for democratically elected Ministers.

> "There is no Health Minister to talk to about these issues. I feel like these changes are just being brought in without access to Ministers to advocate on people's behalf."
>
> - Participant at Consultation Event

> "There is no Government to make decisions – everything is stretched everywhere. They are trying to cut back everywhere."
>
> - Participant at Consultation Event

> "I'm frustrated there's no Government, nothing is changing here, we're just being left behind."
>
> - Participant at Consultation Event

> "It would help if we had a government at Stormont to make better decisions."
>
> - Participant at Consultation Event

Totality of Service

2.25 This consultation is clear that it relates to breast assessment services only and does not propose any changes to breast screening or delivery of breast treatment services. We believe it is impossible to look at the issue of breast assessment in isolation. There is a need to look at the service in its totality

rather than in separate services because those services are so interconnected. Decisions which will have an impact on breast assessment services will undoubtedly impact on cancer treatment services.

2.26 Many of the women we spoke to were convinced that decisions made about breast assessment services were a precursor to decisions on breast cancer treatment. This was reinforced by the statement that *"the Department will commence a review of breast treatment services in the near future, with the objective of developing proposals to improve resilience and best meet the needs of patients across Northern Ireland."*

2.27 The Consortium believes the Department is not being entirely open about the likely full impact of these proposals. At the public consultation event in Belfast there was a discussion around the rationale for moving breast assessment services to Dundonald and one of the reasons given was that there was more theatre space available in Dundonald. This is suggestive that decisions about cancer treatment will follow any decisions about breast assessment services. This adds a whole new dimension to this consultation. Issues around location and travel times are considerably more important when it comes to cancer treatment as that involves repeated visits over a longer period of time and usually the involvement of more people than simply the service user, ie, family members/friends.

Continuity of Care

2.28 The consultation document addresses how critical continuity of care is. Annex B to the consultation document makes a number of statements about continuity of care:

"The Project Board agreed that any future model should preserve continuity of care…….The clinical view within the Project Board was that continuity of care could be optimised by having aspects of care most notably, assessment, diagnosis and surgical services physically co located in the same centre."

“Project Board members acknowledge that if co-location of services represents the optimum service model, then the consolidation of breast assessment services, which is essential to improve sustainability, would mean a consolidation of other breast services. Specifically, this may mean that breast cancer surgery, currently provided by five Trusts, would be provided by fewer Trusts.”

“Continuity of care is considered critical in providing high quality patient centred holistic care.”

2.29 The critical importance of continuity of care was also mentioned in all of the focus group engagement with local women on these proposals. Many stressed the absolute importance of receiving a cancer diagnosis from the same consultant who was involved in their treatment. It was vitally important that these women were seen as individuals and not just notes on a screen. They spoke about the importance of the medical professionals involved in their care knowing their name, their circumstances and their case history.

2.30 Continuity of care will clearly be affected by the decisions made through this consultation process and that is why the two services cannot be looked at in isolation from each other. You cannot have continuity of care if you reduce the number of locations for breast assessment services. We are therefore very concerned that if these proposals are implemented the importance of continuity of care will drive a reduction in locations for breast treatment services also. As previously stated this requires much greater consideration as location/travel times are considerably more relevant to cancer treatment.

> “I am very wary about this. At the minute they are talking about moving breast assessments but through time everything will be moved to these locations including treatment if these proposals go ahead.”
>
> - Participant at Consultation Event

“Is this the start of changes to treatment services in the future?”

- Participant at Consultation Event

“Once assessment goes everything else will follow. Once one thing goes they’ll all go.”

- Participant at Consultation Event

“When you walk in they know your name. You are treated as a human being. The same nurse sees you after your operation that was at your assessment. You know the nurse and you can lift the phone to them. You are not just a number.”

- Participant at Consultation Event

“If you give a wee bit, then another wee bit then before you know it the whole thing is gone. Once breast assessment is moved, then treatment will move then it’s all gone.”

- Participant at Consultation Event

“The best pill I was ever given was continuity of care. I was given my diagnosis by the consultation who performed my surgery and I was able to put my trust fully in him.”

- Participant at Consultation Event

“I was never in a room with unfamiliar faces – they were always familiar to me. This made such as horrendous experience liveable and acceptable. It wasn’t just a doctor reading notes off a screen – they know you as a person and know your case and your history.”

- Participant at Consultation Event

> “Continuity of care will be affected by the reduction in locations.”
>
> - Participant at Consultation Event

> “Continuity of care is very important between assessment and treatment. The fact that you are dealing with people who have cancer at a very emotional time. People put their trust in people – it is not helpful seeing people you don’t know or who don’t understand your situation. Seeing the same people is very important.”
>
> - Participant at Consultation Event

> “I was diagnosed on the same day as my assessment. The same consultant who gave me my diagnosis operated on me. He knew me and he knew my situation. He wasn’t just reading notes off a screen, I was able to talk to him about my treatment and I didn’t have to keep repeating my story.”
>
> - Participant at Consultation Event

Wider Impact

2.31 Discussions about attending breast cancer assessment appointments with women highlighted a number of wider issues which impact on these appointments and these merit consideration within these proposals. The women discussed attending their assessment appointment (and subsequent treatment appointments) with many describing the wider impact it had on them personally, their families, work and home lives.

2.32 Women talked about how increasing travel times to appointments would have an impact as well as the associated cost implications. They would not only have to travel further but pay increased costs for transport and in some cases they may also need to pay extra costs for childcare.

2.33 Women discussed the fact that attending a breast cancer assessment appointment was naturally a very stressful experience and anything that can relieve the stress of this should be avoided.

> "Anything which makes what is an already horrible experience worse should be avoided at a time when you are feeling at your most vulnerable."
>
> - Participant at Consultation Event

> "Women are already stressed because of what they are travelling there for and this is only going to add to this stress."
>
> - Participant at Consultation Event

2.34 Those women who worked explained the issues they had taking time off work. Some explained the fact that having a more local service allowed them to take a shorter time off work than would be necessary if they had to travel a longer distance to access their assessment appointment.

> "Increasing the travel time adds to the amount of time you need to take off work and this only adds to the overall impact."
>
> - Participant at Consultation Event

> "Employers are often reluctant to give time off. If I had to travel to Dundonald instead of Craigavon I would have to take the whole day off whereas in Craigavon I only needed to take a couple of hours off."
>
> - Participant at Consultation Event

> "I had to take time off and I am lucky I have a supportive boss. In my previous job there is no way my old boss would have been as understanding about having time off for appointments."
>
> - Participant at Consultation Event

> "There are lots of smaller employers here and that means it is sometimes difficult to get time off for appointments."
>
> - Participant at Consultation Event

2.35 Attending appointments does not just affect the woman concerned. Many of the women talked about their need to have someone with them at their appointment or the need to have someone to drive them to the appointment. Those who had children spoke about arranging childcare or having to arrange collections to and from school while they were at their appointment.

> "I found it difficult to juggle who would take me to hospital with who would take the kids to school."
>
> - Participant at Consultation Event

> "There is a lot to organise for getting to appointments. You need to get someone to bring you and you also need to organise someone to drop off and collect your kids from school."
>
> - Participant at Consultation Event

> "If it takes an extra two hours to get to an assessment appointment that's an extra two hours for the person who is driving you and for those who have to pick up your caring responsibilities for kids, etc."
>
> - Participant at Consultation Event

> "My mum is 70 and she had to take me to my appointment as my husband was working. She is not used to driving in the City. Older people don't have the confidence to do this and this only adds to the stress – the stress you don't need at a time when you are already under pressure."
>
> - Participant at Consultation Event

> "I'm not married so I had to find someone to bring me to my appointment. If you have young children you would have to get them looked after too."
>
> - Participant at Consultation Event

3. Consultation Questions

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

3.1 In discussions with women there was little opposition to the establishment of a breast assessment network. However the caveat was that this must include **adequate** representation from female service users. Women were clear that this network must be representative of service user's views and have province-wide representation to reflect views across Northern Ireland including in rural areas.

3.2 This service user involvement must be central to this process and not just "token" involvement. Many service users can provide expert opinion as part of this network as they have lived experience of these services and a unique contribution to make.

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

3.3 No, we do not agree that breast assessment services should be provided in no more than three locations. Women were conscious of the issues around resourcing of the health service but the majority expressed concern that these proposals suggest a reduction in services at a time when demand is increasing and likely to continue to increase in the years ahead.

3.4 Statistics on the incidence of breast cancer in Northern Ireland previously referred to (see paras 2.18 – 2.20) indicate an increase in demand for these services particularly given an ageing population. It is therefore hard for women to understand why at a time of increasing demand proposals are being made to reduce these services.

3.5 Most of focus groups reported that there was insufficient information in the consultation and the Supplementary Information document to convince them that the 3-site model was the best option. There was a general feeling that the consultation document and Supplementary Information had not provided good enough reasons for the proposals put forward by the Department. Therefore women were left questioning the real reasons behind these proposals.

> "You just worry that deals are being done in the background about these decisions."
>
> - Participant at Consultation Event

> "Are these proposals actually going to give better care?"
>
> - Participant at Consultation Event

“These proposals are downplaying the importance of women’s health – reducing services is not good for women.”

- Participant at Consultation Event

“I can’t understand the logic of these decisions.”

- Participant at Consultation Event

“The supplementary document provides no evidence that a 3-site model would help.”

- Participant at Consultation Event

3.6 Annex B to the Consultation document outlines the criteria for the assessment/scoring of service options. Section 5.2 of this document contains detailed information about how the assessment of service options were carried out: *“The Project Board formed a multidisciplinary subgroup (criteria subgroup), which included service user representatives, to specifically develop criteria for assessing service options, propose criteria weighting and subsequent option scoring. All of the proposals developed by the subgroup were discussed in detail at the Project Board and subsequently approved by the Project Board.”* The document goes on to say: *“Throughout this process it was recognised that the process of appraising and scoring each potential option against agreed criteria provided a valuable quantitative tool by which it was possible to identify preferred options.”*

3.7 Given the amount of effort involved in developing these criteria it is difficult to understand why the Project Board did not recommend the 4-site model which scored the highest (scoring 755/1000) and instead chose to recommend the 3-site model (scoring 715/1000).

3.8 In explaining this decision Annex B states: *“the decision on the number of sites to be recommended was subject to further discussion at the Project*

Board and took account, in particular, of the population needs and likely longer term sustainability associated with four or a three services model." However the document gives no further information on these discussions or any data on which they were based. At the outset of this document the actions and methodology of the Project Board was set out: *"An open, transparent and collaborative approach was considered central to the work of the Project Board."* We do not consider the arrival at these proposals to be open and transparent.

3.9 In focus group sessions women discussed how a reduction to 3-sites would place even more demand on the chosen locations. They were concerned that this would impact on existing quality of service and the ability to provide personalised care. There were also discussions around how costly it would be to restructure assessment units. Women questioned whether it would be better and cheaper to invest in the existing breast assessment units and staff rather than to continue with these proposals.

> "If more and more pressure is put on a smaller number of units the staff will not have time to provide the level of service they have been providing. Putting pressure on services means that it less of a pleasant experience – there is less time for patients and no room for people to sit, etc."
>
> - Participant at Consultation Event

> "How will they guarantee the quality of care if these changes are brought in?"
>
> - Participant at Consultation Event

> "If everything is going to one place – can they cope with demand?"
>
> - Participant at Consultation Event

“If it is a more stretched/crowded environment then you start to lose the personal connection which is very important.”

- Participant at Consultation Event

“The administration costs in reducing from five sites to three will be hugely costly. Would it not be better to put investment into staffing at the existing five sites? Bring staff in and cover the gaps – surely that would be cheaper in the long run?”

- Participant at Consultation Event

“Investment in this service is for long-term reward – if the government are under pressure to see results immediately to take the heat off them then they won’t think long-term. It is all about saving money now there is no long-term thinking.”

- Participant at Consultation Event

“I don’t understand how the 4-site model was discounted. In the next number of years the number of patients will increase and in the long term surely that would provide a more resilient service?”

- Participant at Consultation Event

“It would be cheaper to recruit extra radiographers than move a whole unit out to Dundonald.”

- Participant at Consultation Event

“If they are not meeting the targets in one place surely moving it to somewhere else will just create bigger waiting lists there?”

- Participant at Consultation Event

Statistics

3.10 The figures provided in the Supplementary Information document around HSC NI Performance Statistics could be viewed as misleading. We refer to the figures provided in **Table 1: Number of patients seen by a breast cancer specialist following an urgent referral for suspected breast cancer across all HSC Trusts in Northern Ireland**. These figures are given over a period of 57 months meaning that some of the statistics are now five years old. It is clear from the table that waiting times have improved steadily from their worst period in April 2015 to March 2016. The most recent data shows a gradual upward trend in relation to target times with the latest 9-month data showing that 91.6% of patients seen by a breast cancer specialist following an urgent referral for suspected breast cancer. While we recognise that this means that 985 people were not seen within the target times we would like to see more information on how much longer these people had to wait in order to be seen.

3.11 It is our understanding that waiting times in the City Hospital and Craigavon have improved and there are currently no major issues with waiting times at these locations. It would have been useful for the Department to provide the most recent statistics broken down by location so that a genuine debate could have taken place over waiting times.

3.12 Presenting statistics in this way is disingenuous. Decisions must be based on the most recent data and figures should not be presented in such a way as to paint a picture which is no longer the case. This could be viewed as a scare tactic used to encourage respondents to respond in a particular way. Few people facing a potential cancer diagnosis want to wait longer than necessary and using figures in this way plays on people’s fears.

3.13 We would like to see the situation where no-one has to wait longer than the target times but we feel that the way the statistics are presented in this consultation give an outdated picture of target times and therefore is not the basis on which to make these important decisions.

> “They are using statistics for their own gain – they think we are stupid.”
>
> - Participant at Consultation Event

> “The consultation is shabby around some of the details and research.”
>
> - Participant at Consultation Event

3.14 In Consortium focus group engagement with women some acknowledged that waiting would cause stress and that they would be prepared to travel further to be seen quicker. However this was in light of breast assessment only (in most cases this would involve one single journey). In further discussions around this issue the women were concerned that if breast treatment services were to follow and be reduced to 3-sites this reduction in locations would have a bigger impact and people would be less willing to travel further even if it meant getting treatment earlier.

> “If this was properly explained to people that reducing to three locations would mean people would be seen within the time limits then it may be accepted better but it needs properly and honestly explained to people. If the changes will ensure that people get seen within the target times then they may be happy to travel further?”
>
> - Participant at Consultation Event

> “If reducing to three venues would ensure that everyone was seen within the target times then I can’t see many people disagreeing with this but is that going to happen in reality? Each of these three locations will have to see a lot more people. How will this help with staffing?”
>
> - Participant at Consultation Event

Service User Engagement

3.15 We welcome the fact that the Project Board undertook a range of service user and public engagement exercises in the development of these proposals but we would have liked to see a wider engagement given the importance of these proposals. In particular we would question whether the feedback from the Service User Focus Groups is properly representative and accurately reflects the views of service users and carers with enough breadth and depth. Each Trust was asked to write to 60 service users to invite them to attend these focus groups. However only 41 (33 patients and 8 carers) attended these.

Travel Times

3.16 The Supplementary Information document provides Travel Time Analysis for the existing 5-site model and the proposed change to a 3-site model. Given that travel times were one of a number of factors used to make decisions around these proposals it is vital that the data on which these travel times are based is accurate and representative of real life circumstances. We are concerned that this is not the case.

3.17 The travel times were modelled using journey data from the Google Maps Time-Distance API based on a start time of 9am by private transport in average traffic conditions. This data does not paint an accurate picture of travel times as it makes too many assumptions. It assumes that these journeys are by private car and does not take into account travelling by public transport or adverse weather/traffic conditions. It is simply not realistic to provide travel times as the basis for making decisions when these do not take into account access by public transport. Therefore these figures do not paint an accurate picture of the travel times involved especially for those relying on public transport.

3.18 Under the 3-site model travel times will increase significantly for many women relying on public transport to access breast assessment services. We are particularly concerned about the impact that increased travel times will have

on those who are more vulnerable and marginalised and who are likely to be more adversely impacted by these proposals.

> "A lot of people use public transport instead of a private car."
>
> - Participant at Consultation Event

> "A lot of people can't afford the costs of public transport for these appointments."
>
> - Participant at Consultation Event

> "It is not just physical miles (distance) it's the length of time with traffic etc, it takes you to get there. Once you get near Sprucefield it's a total car park. You have to allow an extra hour or more to your journey."
>
> - Participant at Consultation Event

> "Travel times are given door to door – this is not the reality. What about public transport? The longest journey time is from Newtownbutler to Antrim but where's the public transport there and how much longer would that journey take?"
>
> - Participant at Consultation Event

> "The travel times do not reflect peak times and have not factored in traffic or cost issues."
>
> - Participant at Consultation Event

> "I personally don't mind how far I travel as long as I was getting seen. For the worry you would travel further. But I can drive and have access to a car."
>
> - Participant at Consultation Event

"If they are looking to centralise services how are they going to facilitate people's access to these services? In some cases there are not even Translink services available."

- Participant at Consultation Event

"The travel time figures are just a nonsense. You need to have access to a car, afford the fuel, take someone with you, be able to park, etc."

- Participant at Consultation Event

"It is unbelievable that the figures don't include public transport times."

- Participant at Consultation Event

"I am a public transport user. I am concerned that some people may put off their breast assessment because of this especially if you are a working mother and busy with children, etc."

- Participant at Consultation Event

"They need to look at the transport infrastructure when making these decisions. If you are going to Belfast it is easier because the infrastructure is there. Public transport is a huge issue."

- Participant at Consultation Event

"The travel times are misleading. They are not times for public transport and do not take into account traffic, etc."

- Participant at Consultation Event

"Travel is a huge issue and the cost of travel is a big factor."

- Participant at Consultation Event

> "If you are older and don't drive how will you get there? How long will it take you to get there? This is all likely to cause anxiety."
>
> - Participant at Consultation Event

> "For some people it does matter how far you have to go – the impact on you – not everyone can take time out and some will struggle with the cost element and there is no help with this."
>
> - Participant at Consultation Event

Staffing

3.19 At focus group sessions women discussed how staff might feel about these proposals. It was suggested that as they are experts on how the service works they should have been asked to contribute to these proposals before they were put out to consultation.

3.20 Some staff are likely to be substantially impacted by these proposals and may be required to travel longer distances to work if the site they currently work in faces closure. This could contribute to making the job less attractive and as a result the service could risk losing experienced staff.

3.21 Women talked about how increased demand and staff shortages make it difficult for existing staff to work within the demands of the service and equally how difficult this makes it to attract staff. There was concern among the women that rationalising services to fewer sites would just put more demands on the staff who work in those sites which could ultimately impact on service delivery. Women were concerned that this would make the experience of attending an assessment centre less supportive of service users and in danger of losing the "personal touch" as staff would be under increased pressure.

"Poor management has led to staffing shortages – it is not the fault of the assessment units. Management are culpable for that."

- Participant at Consultation Event

"The Health Service needs looked at and needs investment – doctors and nurses are needed. Shortages make it an unattractive job and that makes the situation even worse."

- Participant at Consultation Event

"You are going to end up with an unhappy workforce if you change things and make people travel further. It doesn't make for a good workforce they will be looking for other jobs."

- Participant at Consultation Event

"Money is not being invested in staff – they are under huge pressure."

- Participant at Consultation Event

"The focus should be on how they are recruiting and investing in staffing. They should be investing in their own infrastructure."

- Participant at Consultation Event

"If there aren't sufficient staff to accommodate more people then it just won't work."

- Participant at Consultation Event

"The consultation assumes that staff will move. Would they want to move to Antrim or Dundonald? Will this be feasible for staff – they just can't lift their whole life and move it."

- Participant at Consultation Event

> "They need to think of the working environment and how to attract people into it. It is not very attractive at the minute due to burnout and stress. It is not attracting people as they see it as very pressurised."
>
> - Participant at Consultation Event

> "Staff are experts they should have been asked their views at an earlier stage."
>
> - Participant at Consultation Event

> "How will this help? There are still going to be the same staffing needs even with reduced locations to cope with increasing demand? Current radiographers will be even more in demand? How will this help this issue?"
>
> - Participant at Consultation Event

Simple Changes

3.22 The Chief Medical Officer Michael McBride acknowledged at the Belfast Public Engagement event that any change in services would require significant investment. Women talked about the costs involved in implementing these proposals and questioned would it not be cheaper and more effective in the long run to make some simple changes and invest in existing services/staff than continue with these proposals?

3.23 A former staff member of Belfast City Hospital breast assessment unit spoke at the public consultation event in Belfast about simple changes which had been made within the Belfast City Hospital to make things more efficient. Some of these changes were not that expensive, for example, having separate clinics for under 30s, breast pain, family/genetics, etc thus freeing up space/staff for urgent symptomatic referrals.

> “Need to look at simple things that could be improved first before considering closing sites.”
>
> - Participant at Consultation Event

> “Why don’t they look at improving the existing services?”
>
> - Participant at Consultation Event

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

3.24 As part of the review the Project Board developed a set of guiding principles which should underpin future models of care. One of these guiding principles is that: *“Service users should have equitable access to the breast assessment service.”* We fail to see how these proposals allow service users in Northern Ireland to have equitable access to breast assessment services. There is no doubt with the 3-site model proposal that those service users in the South and South West of Northern Ireland will no longer have equitable access to these services.

3.25 Women at focus group sessions expressed their complete incredulity that there was a proposal to remove breast assessment services from the Belfast City Hospital site. There was a consensus that assessment services at this site were excellent and that it did not make any sense to relocate these services away from what was originally set up to be a centre of excellence for cancer. Women questioned why you would want to relocate breast assessment services from the Belfast City Hospital site when it was next to Queen’s University, the medical school with research facilities and the BRCA clinic dealing with hereditary breast cancer?

3.26 In addition to the Belfast City Hospital site's connectivity to other facilities/research there are existing and well established transport links to this site. It is well served by the existing public transport infrastructure and is a central venue for the Greater Belfast Area that a great majority of people know and are familiar with.

3.27 The proposal to relocate breast assessment services to the Ulster Hospital in Dundonald as an alternative to Belfast City Hospital was met with disbelief by many of the women at focus group sessions. They simply could not understand this proposal. Many of the women felt that Dundonald was "*out of the way*" and "*not accessible*". They felt that Dundonald did not have the same transport infrastructure as the City Hospital site meaning that it was a much less desirable location for these services.

> "The City Hospital was set up to be the Cancer Centre and a centre of excellence – why the decision to move it?"
>
> - Participant at Consultation Event

> "Dundonald is just not accessible."
>
> - Participant at Consultation Event

> "How much can Dundonald take on? The parking there is already horrendous."
>
> - Participant at Consultation Event

> "There is just no rationale for the move to Dundonald."
>
> - Participant at Consultation Event

> "The Centre for Cancer Research and Cell Biology is located at the City Hospital – the location of the Cancer Centre makes for excellent co-working."
>
> - Participant at Consultation Event

"The journey to Dundonald involves going into Belfast then out again or going by the back roads. It is not just the distance but also the traffic and waiting times. There is no parking at Dundonald – there is nothing to cope with the demand if it gets these services."

- Participant at Consultation Event

"There is a perfect service at the City Hospital. It doesn't make sense to move it from where the Cancer Centre is. It is a clockwork service."

- Participant at Consultation Event

"There is a fantastic unit at Belfast City Hospital. Fragmentation of these services does not make sense. Why move it?"

- Participant at Consultation Event

"I appeal to you not to treat Belfast City Hospital in this shabby way. I knew my outcome within three hours of walking through the door. It is joined-up, excellent care which I'm sure has saved my life not only physically but mentally. You feel the confidence of the great structure, administration, surgeon, breast care nurses, etc. I appeal to you to reconsider these proposals."

- Participant at Consultation Event

"It goes without saying that the City should be part of the picture – Dundonald should never have been part of the picture – where is the evidence for that?"

- Participant at Consultation Event

"The move from Belfast City to Dundonald will require huge amounts of money – how many radiographers could you buy for that?"

- Participant at Consultation Event

"Some patients will not want to go to Dundonald – they may not want to travel to East Belfast – it may not be seen as a neutral venue?"

- Participant at Consultation Event

"There is an established and successful specialised Unit in the City Hospital – why change this? It is a neutral venue and easy to access."

- Participant at Consultation Event

"There is no train service to Dundonald. The Glider is not the answer to access – how will standing on a Glider help someone in this situation? If someone has no experience of the Glider (and may of those travelling will not have) it is not easy to understand."

- Participant at Consultation Event

"If someone is dealing with cancer symptoms and anxious about their assessment the last thing they want to be thinking about is trying to get the Glider out to Dundonald."

- Participant at Consultation Event

"How did they choose these options? How did they choose Dundonald over the City which is a centre for excellence for cancer?"

- Participant at Consultation Event

"Belfast City Hospital is much more accessible – the transport infrastructure already exists there and that means that it is cheaper to get to."

- Participant at Consultation Event

"There is a Cancer Centre at the City Hospital anyway – why not keep it there?"

- Participant at Consultation Event

3.28 There was little opposition to the location of breast assessment services in Altnagelvin with most of the women acknowledging that it is reasonable to continue to provide breast assessment services in the Western Trust area. However a suggestion was made that consideration should have been given to the location of breast assessment services in the South West Acute Hospital in Enniskillen to spread these services more equitably across Northern Ireland.

> "In terms of location it is not hard to get from Antrim to Belfast. Would having a service in Enniskillen not make more sense? Then it would be like a triangle of services across Northern Ireland and everyone would be closer to at least one of them."
>
> - Participant at Consultation Event

3.29 There was also great resistance from local women about the proposal to relocate breast assessment services from Craigavon Area Hospital. It was generally felt that this proposal would significantly disadvantage those who live in rural areas. Women who were local to the Craigavon area felt that Craigavon was a very successful unit and held it in very high regard. They felt that basing these decisions on meeting target times (over 57 months as detailed in the consultation document) was misleading as Craigavon is now performing well against target times.

> "I was so lucky to have Craigavon on my doorstep. There has to be something this side of the Province. No one will question Altnagelvin as a location and there has to be a location in Belfast but they need to look at a fair option for the third location. I want to know what their decision was based on? I want it to be evidence-based and they just don't have the evidence."
>
> - Participant at Consultation Event

"The Southern Trust has the greatest percentage of the female population and the greatest number of migrants – how are they going to be able to afford to travel the distance they need to travel to access these services. These proposals have huge implications for rural people."

- Participant at Consultation Event

"Craigavon has an excellent breast unit."

- Participant at Consultation Event

"There is no rationale to remove these services from the City Hospital and Craigavon if both are performing well."

- Participant at Consultation Event

"When I was going to Craigavon I just had to take a couple of hours off work but if I had to go to Belfast I would have to take the whole day off."

- Participant at Consultation Event

"Craigavon is a one-stop shop. I went in at 5pm and was diagnosed at 7pm. I had all three assessments done within 2 hours and had my diagnosis."

- Participant at Consultation Event

"There is a purpose-built fantastic facility in Craigavon with chemo and breast suite side by side and there is a beautiful atmosphere there. Your life falls apart and is in pieces and you come into the building and you are wrapped in cotton wool, they wrap cotton wool around you throughout the process. The staff are fantastic and there is such a beautiful atmosphere there while people are going through such a terrible experience."

- Participant at Consultation Event

3.30 Those women who had used Antrim Area Hospital also spoke very highly of their experiences at this site. However some of the women expressed their concern about increasing capacity at this site which is already very busy.

3.31 There were discussions at focus group sessions around the choice of Antrim as the third location given its proximity to Belfast with some women suggesting that the third site may be better in a location which is further away from Belfast allowing for greater equity in service provision across Northern Ireland.

"Why put everything in one area of Northern Ireland? It does not make sense when Antrim is so close to Belfast."

- Participant at Consultation Event

"It is already busy in Antrim, there are signs up saying only one visitor is allowed with you – it's already busy and there's nowhere to sit. How will they cope with the extra workload?"

- Participant at Consultation Event

"The service in Antrim is second to none. It is excellent. If all the assessment services are going to a smaller number of places the question is would you able to get the same level of service that you get now? In Antrim there is nowhere for people to sit – are they going to build a bigger building?"

- Participant at Consultation Event

"Antrim has a great service and my experience was very positive."

- Participant at Consultation Event

"These proposals will be difficult for people in the West, they have lost so much in the West."

- Participant at Consultation Event

Population Characteristics

3.32 The consultation document outlined that one of the reasons for the choice of Antrim Area Hospital as the third location was that 25% of the population of Northern Ireland reside in the Northern Trust area which represents the largest proportion of all the Trust areas. While this may be the case there are a number of population characteristics within the Southern Health and Social Care Trust that must also be given due consideration as part of these proposals.

3.33 Population projections for Northern Ireland for mid-2026 indicate that Armagh City, Banbridge and Craigavon Local Government District will be one of the areas with the greatest percentage population growth (8.9%). These results are illustrated in the table below[11] and show that the Local Government Districts with some of the highest figures for projected population growth are served by Craigavon Area Hospital. While these results are not gendered they are indicative of potential increasing demand due to increases in the size of the overall population.

[11] Population Projections for areas within Northern Ireland: 2016-based, NISRA Statistical Bulletin, April 2018
https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/SNPP16-Bulletin.pdf

Table 1: Projected Population growth by Local Government District (mid-2016 to mid-2026)

Area (ordered by percentage growth)	Estimated population mid-2016	Projected population mid-2026	mid-2016 to mid-2026	
			Growth	% Growth
Derry City & Strabane	150,100	150,300	200	0.1
Causeway Coast & Glens	143,500	145,400	1,900	1.3
elfast	339,600	346,200	6,600	1.9
Ards & North Down	159,600	163,500	3,900	2.5
Mid & East Antrim	137,800	141,400	3,600	2.6
Antrim & Newtownabbey	141,000	145,100	4,100	2.9
Fermanagh & Omagh	115,800	119,200	3,400	3.0
Newry, Mourne & Down	177,800	188,800	11,000	6.2
Mid Ulster	145,400	157,200	11,900	8.2
Armagh City, Banbridge & Craigavon	210,300	228,900	18,600	8.9
Lisburn & Castlereagh	141,200	153,700	12,500	8.9
Northern Ireland	**1,862,100**	**1,939,700**	**77,600**	**4.2**

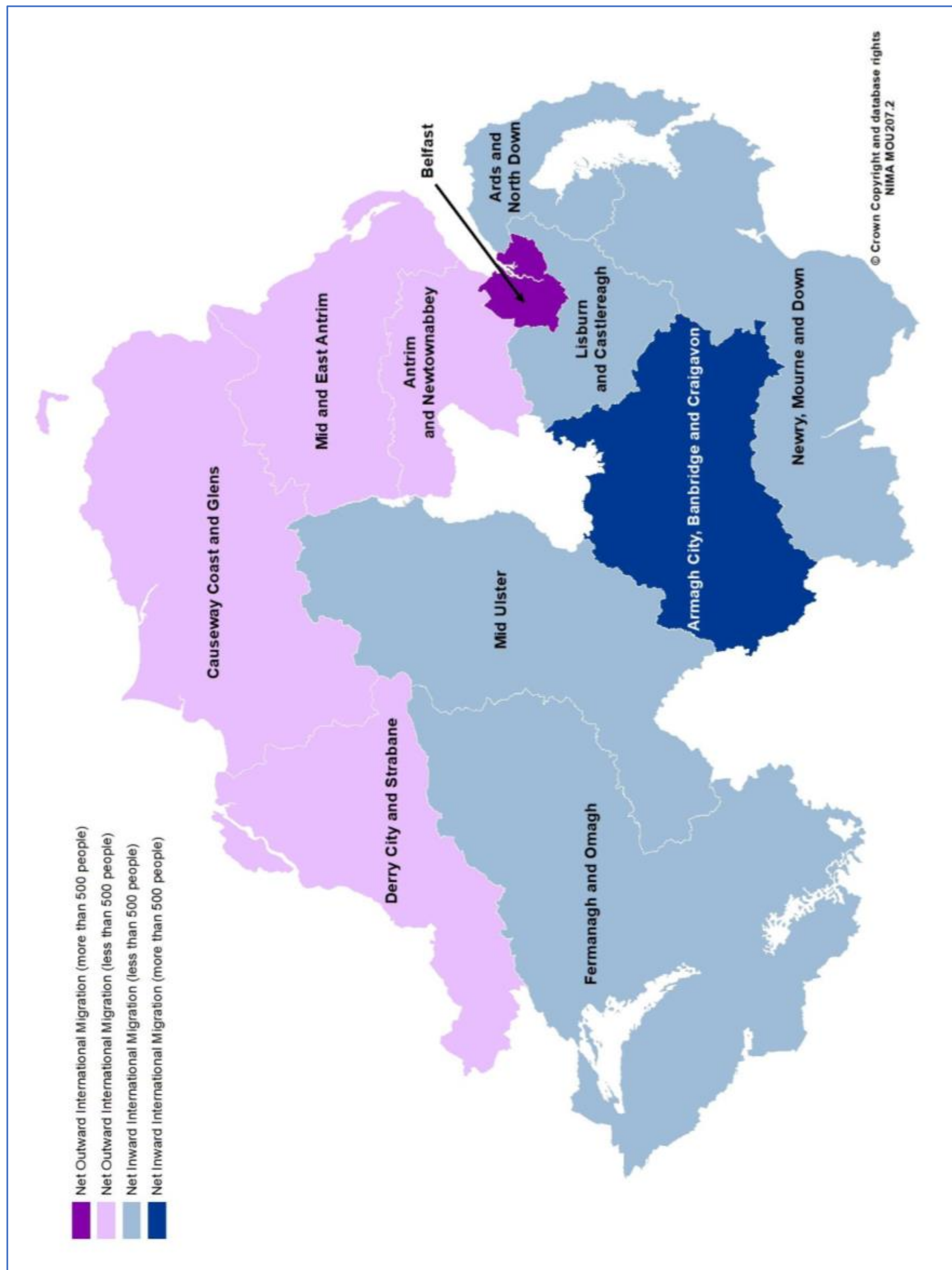
3.34 In addition to increased population growth for the areas served by Craigavon Area Hospital this area also has the largest number of net international migration by Local Government District as shown in the map below.[12] Outside of Belfast, Craigavon District has the largest migrant population in Northern Ireland. In terms of the size of the population born outside of the UK and the Republic of Ireland, Belfast was followed by Craigavon, with 6,712 residents in the area in 2011, and Dungannon with 5,998. In fact, in terms of the population share, it is the local government district of Dungannon that comes out first, with 10.4% of the local population born outside of the UK or the Republic of Ireland in 2011.[13]

3.35 Consideration must be given to the needs of migrant communities within this consultation. It is well documented that BME and migrant communities are amongst the most socially excluded groups in society and are at greater risk of

[12] Long-term International Migration Statistics for Northern Ireland (2017), NISRA Statistical Bulletin, September 2018
https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/Mig1617-Bulletin.pdf
[13] Northern Ireland: Census Profile, The Migration Observatory
https://migrationobservatory.ox.ac.uk/resources/briefings/northern-ireland-census-profile/

multiple deprivation. Increasing barriers to healthcare in terms of limiting access to services can have greater consequences for these communities as they are more likely to live in low-income households and face additional barriers in accessing public services. Given the concentration of migrant communities within the Southern Health and Social Care Trust this must be given careful consideration by the Department as they are likely to be more adversely impacted by these proposals and may suffer poorer health outcomes as a result.

Map 1: Net International Migration by Local Government District (year ending mid-2017)



3.36 Statistics from the Southern Health and Social Care Trust[14] show the population issues that impact on this Trust Area and are predictors of likely demand in the future:

- We have the second largest resident population compared to other Trusts in Northern Ireland at 365,712 (20% of population)
- We have seen 18.9% growth in population between 2000 and 2013, compared to NI average of 8.7% with projected growth of a further 25% by 2023, compared to NI average of 10%
- We had the largest increase in births since 2001 at 17%, compared to NI average of 10%. An 11.3% growth in 0-17 population is expected between 2012 and 2037, compared to a decrease in NI of -3.3%
- We have the highest projected growth in the over 65 population between 2012 and 2037 of 95%, compared to NI average of 79%
- Central & Eastern European migration accounts for 4.2% of the Trust population, compared to the NI average of 2.2%.

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

3.37 Focus group engagement with women showed no opposition to this proposal. The women agreed it was good practice to optimise efficiency in the system. However this must be patient-led and give users the right to choose. If a woman wishes not to travel further for an earlier appointment then they should have the right to wait for an appointment at a location which suits them and their circumstances better if that is their choice.

[14] http://www.southerntrust.hscni.net/3404.htm

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?

3.38 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:

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.

These proposals will also have an impact on transgender communities. Breast cancer is a highly gendered healthcare intervention because of the inherent demographics of the people who access it. However this presents psychological, physical and social barriers to trans people and other gender non-conforming people who need to access these services. Issues relating to transgender healthcare are poorly understood and poorly addressed within medical and healthcare organisations and among healthcare professionals. It is often the case that the needs of trans people are ignored as part of the healthcare process and the language used is not inclusive. Trans people are more likely to experience poverty than the general population and may be adversely affected by increasing travel times/costs due to the implementation of these proposals.

The issues affecting trans communities in their access to healthcare are poorly understood and poorly addressed within healthcare services and among medical professionals if they are addressed at all. It is often the case that the needs of trans people are ignored and the language used to describe services is not inclusive. It is imperative that, in the advertisement and promotion of breast cancer services, the HSC Trusts meaningfully engage with trans community groups to ensure that they are not excluding trans people in their language and work to actively include and promote marginalised communities within their services.

In relation to this consultation trans people are more likely to experience poverty than the general population[15] and may be disproportionately affected by increasing travel times/costs due to the implementation of these proposals. As a community with generally poor public health experiences it is imperative that these services are not made even more difficult to access. It is often the case that trans people are not being alerted for long-term screenings and tests due to HSC systems handling of legal gender changes, so there are already significant barriers in place for trans individuals accessing screening and assessment. These proposed reforms would place more barriers to access for trans communities rather than removing them.

Dependants - Women are also likely to be more affected by these proposals as they are more likely to have caring responsibilities whether for children or other family members/friends/neighbours. Over the past 10 years there has consistently been more economically inactive women than men. At July-September 2018 a third of working age women were economically inactive, compared to 23% of men. The most common reason for inactivity among women was family and home commitments.[16] Women are more likely than men to provide unpaid care to family members, friends or neighbours. Of the total population who provide 50 hours or more unpaid care per week, 40% are male while 60% are female.[17]

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

[15] www.transgenderni.org.uk
[16] Women in Northern Ireland 2018, NISRA, December 2018 https://www.nisra.gov.uk/system/files/statistics/Women%20in%20NI%20-%20December%202018.pdf
[17] Census 2011 – Key Statistics for Gender, Research and Information Service Research Paper, Ronan Savage and Dr Raymond Russell, Northern Ireland Assembly, 5 September 2014 http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2015/general/3415.pdf

females over the age of 50 years and incidence rates greatest among women aged 80-89.[18]

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.[19] Research suggests that lesbians may have an increased risk of developing breast cancer because of a 'cluster of risk factors'[20] 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.[21] Lesbians are less likely to have been pregnant which is a factor in reducing the risk of breast cancer.[22] 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.[23]

Racial Group – Women from migrant communities have the potential to be adversely impacted by these proposals due to the additional barriers they face in accessing public services and because they are more likely to live in low-income households. Increasing travel times will impact on their ability to afford the cost of travel to these appointments particularly if they are more likely to

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[18] Breast Cancer Factsheet, Northern Ireland Cancer Registry https://www.qub.ac.uk/research-centres/nicr/FileStore/OfficialStats2017/Factsheets2017/Filetoupload,896072,en.pdf
[19] 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
[20] 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
[21] 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
[22] 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
[23] 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

rely on public transport. 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.

> "Elderly women for example – could they manage these changes?"
>
> - Participant at Consultation Event

> "Everyone is living longer and the risk of breast cancer increases with age. There is a difference travelling a great distance at age 50/60 than age 70/80. What about those elderly people that live in very rural areas who maybe don't have someone to ask to help them get to their assessment?"
>
> - Participant at Consultation Event

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?

3.39 See answer to Question 5 above.

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

3.40 Retaining breast assessment services at the existing 5-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?

3.41 The human right to health is recognised in a number of international instruments. This includes the Universal Declaration of Human Rights which affirms: *"everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care*

and necessary social services" (Article 25) and the International Covenant on Economic, Social and Cultural Rights ('ICESCR') (Article 12). Additionally, the right to health is recognised in the Convention on the Elimination of All Forms of Racial Discrimination (Article 5), the Convention on the Elimination of All Forms of Discrimination against Women (Articles 11 and 12), the Convention on the Rights of the Child (Article 24) as well as the revised European Social Charter (Article 11).

3.42 ICESCR provides the most comprehensive article on the right to health in international human rights law. ICESCR is legally binding on all States parties which are required to recognise *"the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"* (Article 12.1). To comply, States parties must take particular steps to *"achieve the full realisation of the right"* (Article 12.2).

3.43 The Committee on Economic, Social and Cultural Rights, which is the body responsible for monitoring ICESCR, has specified that to comply with the Convention, health services, goods and facilities must be **available, accessible, acceptable and of good quality**.[24]

3.44 The Committee provides further detail as to the meaning of **accessible**, which contains four overlapping dimensions (para 12):

a) **Non-discrimination**: services must be accessible to all, especially the most vulnerable or marginalised sections of the population in law and in fact.
b) **Physical accessibility**: services must be within safe physical reach for all sections of the population. The Committee specifically highlights the need to ensure accessibility for those living in rural areas.

[24] UN Committee on Economic, Social and Cultural Rights General Comment No 14: The Right to Health, 2000
http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1AVC1NkPsgUedPlF1vfPMJ2c7ey6PAz2qaojTzDJmC0y%2B9t%2BsAtGDNzdEqA6SuP2r0w%2F6sVBGTpvTSCbiOr4XVFTqhQY65auTFbQRPWNDxL

c) **Economic accessibility**: services must be affordable for all. The Committee highlights that poorer households should not be disproportionately burdened with health expenses.
d) **Information accessibility**: rights holders have the right to seek, receive and impart information and ideas concerning health issues.

3.45 It is this accessibility issue where there is the greatest potential for human rights violations to occur as a result of the proposal to close breast assessment services at Craigavon Area Hospital. This is particularly the case for rural women especially those reliant on public transport. As previously stated in our response travel times are likely to increase significantly for those women relying on public transport (the Department has provided no figures for public transport travel times) and this is likely to have an adverse impact on women's ability to get to and from breast assessment services. Increasing travel times also increases the costs involved not only in terms of transportation costs (by both public and private transport) but also other costs such as increased childcare costs. Those who are the most vulnerable and marginalised are likely to be disproportionately burdened by these extra expenses.

3.46 The Consortium does not agree with the Department's proposals to reduce breast assessment services to a 3-site model. However post-consultation if this proposal is implemented it is essential that the Department should commit to continue to work with stakeholders to monitor the impact of this decision.

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

3.47 There is no doubt that the actions/proposals set out in this consultation document are likely to have an adverse impact on rural areas.

3.48 Northern Ireland has a large rural population. Around 670,000 people live in rural areas amounting to 37% of the population.[25] The Department of Agriculture, Environment and Rural Affairs have stated that the cost of living is higher in rural than in urban areas, particularly in terms of fuel, transport and heating.[26] Research by the Joseph Rowntree Foundation shows that people in rural areas of the UK typically need to spend 10-20% more on their everyday needs than those in towns and cities and these costs increase according to the remoteness of the area.[27]

3.49 The closure of breast assessment services at Craigavon Area Hospital and the implementation of the 3-site model will mean that rural people will be disproportionately affected by these changes. Those who live in the South and South West of Northern Ireland will face the most disadvantage from the 3-site proposal. Locating the 3-sites in Altnagelvin, Antrim and Dundonald creates a line of service provision straight across Northern Ireland leaving many communities below that line facing longer travel times to attend breast assessment clinics.

3.50 In terms of rural transport women are much less likely to have access to their own private transport than men. This means that women depend much more on public transport. Feedback from NIRWN members clearly indicates that transport provision varies greatly across the region.[28]

3.51 Rural women are particularly vulnerable to access poverty. A lack of access to public transport, the cost of public transport and access to other services such as affordable childcare can impede women's ability to access services including healthcare.

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[25] http://www.rdc.org.uk/statistics
[26] Tackling Rural Poverty and Social Isolation – A New Framework, DARD, March 2016 https://www.daera-ni.gov.uk/sites/default/files/publications/dard/tackling-rural-poverty-and-social-isolation-2016-new-framework.pdf
[27] A minimum income standard for rural households, Joseph Rowntree Foundation, November 2010 https://www.jrf.org.uk/report/minimum-income-standard-rural-households
[28] Rural Women's Manifesto, NIRWN, September 2015 https://www.nirwn.org/wp-content/uploads/2016/12/NIRWN-Rural-Womens-Manifesto.pdf

3.52 The Department's own Rural Needs Impact Assessment shows that multiple deprivation is particularly prevalent in rural areas. It is women living in these rural areas, often vulnerable to access poverty as outlined above, that will be the most affected by the closure of an existing service.

3.53 If the Department intends to proceed with the 3-site model and consolidate services it needs to consider carefully how rural people access these services and take action to mitigate any adverse impacts as a result. This could include the provision of transportation or childcare for appointments or some kind of monetary contribution towards the cost of these.

3.54 Women in focus group discussions talked about how the voluntary sector was having to help some patients with travel to their cancer appointments. They were angry that this had fallen to the community and voluntary sector and felt that services such as these should be provided by government.

> "These proposals affect vulnerable rural people – it's totally unfair. This could put people off doing something about cancer – it could delay or put them off getting checked out."
>
> - Participant at Consultation Event

> "They have done a rural needs analysis but where are the mitigations for rural needs?"
>
> - Participant at Consultation Event

> "The community/voluntary sector are having to provide what should be government services in terms of transport for appointments. There should be no excuse that charities have to provide driving services to get people to cancer appointments. This should be provided by government."
>
> - Participant at Consultation Event

"I think of people out in the country who struggle to get to the next biggest town never mind travelling to an assessment centre even further away especially when there is no public transport."

- Participant at Consultation Event

"My friend travelled from Belleek to Belfast for assessment and treatment. It involved her and her husband being up in Belfast for the whole day. It is not just the person going through it but it affects their friends and family too."

- Participant at Consultation Event

"For rural people transport infrastructure is a big issue – what the road infrastructure is like and what the traffic is like – and how this impacts on journey times."

- Participant at Consultation Event

"The proposals are for hospitals that create a line across Northern Ireland and anyone below that line is not being served. It is total discrimination against rural communities."

- Participant at Consultation Event

"I live in the Glens and I have to travel for everything as there are no local services anymore. I can travel and would be prepared to in order to get seen quicker but what about those who can't?"

- Participant at Consultation Event

"A lot of rural people do not like travelling through Belfast because they do not know it."

- Participant at Consultation Event

4. Conclusion

4.1 We welcome the comments made by the Chief Medical Officer that this is a genuine consultation process. We hope to see that the views and experiences of the women in this consultation response are fully taken on board in relation to these proposals.

4.2 We believe that feedback from the Consortium and at the public consultation events shows the strength of feeling on this important issue and must shape the resulting proposals. We sincerely hope that this will result in a breast cancer service that works effectively and efficiently while keeping the needs of service users, their family and friends at its very heart.