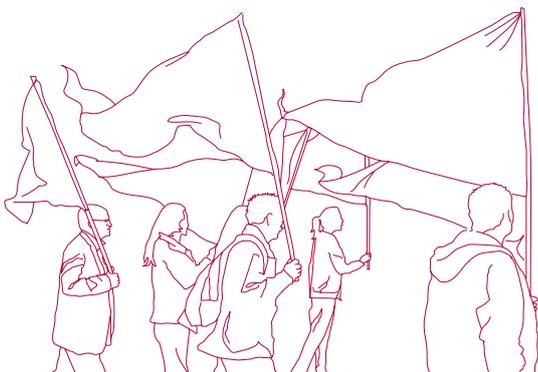




# Response to the Reshaping Breast Assessment Services Consultation Document



September 2019

NIPSA is the largest Trade Union in Northern Ireland with a membership of over 40,000. We organise on behalf of our member across the civil and public services in Organisations such as the Health and Social Care Trusts and others HSC arms length bodies, NI Civil Service and its Agencies, Education Authority, Further Education Colleges, local Government, Libraries NI, the NI Housing Executive as well as a number of Non-Departmental Public Bodies (NDPB's) and the Voluntary and Community Sector.

Please find the NIPSA response to the public consultation on "Reshaping Breast Assessment Services".

NIPSA welcomes the opportunity to give its views on this consultation, given not only the importance of the consultation and the widespread public interest on an issue with the potential to affect 50% of the population, but also the fact that this is one of the first service consultative processes to emerge from the TIG/TAB structures being run by the Department in the absence of any democratic oversight.

As a key HSC stakeholder NIPSA recognises that proposals such as those contained in the consultation document can be highly sensitive when considering change to better meet the needs of the population of Northern Ireland (NI). In submitting this response, we wish to emphasise, NIPSA attended all public consultation meetings and our response is based on the views expressed at these meetings by professionals, service users, NIPSA members who work across the Health Service and Public Sector generally, and critically the service user experience of the many, many NIPSA members and their families who have accessed the services being consulted upon.

NIPSA wishes to begin by placing on record our appreciation at the testimony of the many courageous women and members of the public who attended the consultation meetings and spoke so passionately about their experiences and services they received before, during and after their treatment. The strength, compassion and pain contained within the stories of their journeys was truly extraordinary to listen to, and NIPSA has attempted to capture some of these views in our response.

The strength of comment did not just reflect the testimony of service users. They reflected the excellence of the service experience HSC staff at all levels had shown to them as women, as families, as service users and as tax payers. Each of these testimonies is a stark reminder of the power of the social compact between the public and the NHS, and requires the most careful consideration by the Department of Health.

NIPSA's view is that this populations appreciation of excellence in service user experience, rather than the frankly self-serving platitudes on the reality of rationing that has underpinned previous consultation exercises should be clearly reflected in the consultative approach taken by the Department. Any change implemented must in NIPSA's view build and invest on a platform to further improve service user experience and outcomes in how Breast Assessment Services are structured across NI.

As Northern Ireland's biggest public sector trade union, NIPSA is cautious about the promises made in public consultations due largely to our member's experience of historic failed approaches of a bright new dawn for public services that never materialised and instead were counter-productive. NIPSA Branches and Officials, along with our other trade union colleagues, have participated on numerous occasions across all five Health Trust's on modernisation projects and reconfiguration of services at local level, so formal consultations on how services are delivered are not new to us. It is reasonable to say some of these projects have been challenging and have not had support from our members, whilst others have had a clear focus on improved service delivery.

### **Current Position**

It is NIPSA's view that there is general acceptance across the NHS from Consultants, to Nurses to Administration Staff to Porters that some areas of our Health Service needs investment and restructuring if it is to meet the current and future pressures we know it will face. But this is not a carte blanche to signal NIPSA's acquiescence in accepting the wildly outdated slash and burn approach our members have had to endure in so many parts of the HSC.

NIPSA the organisation, and our membership, have had a focus on planning and a commitment to quality and outcome improvement all across the long years of austerity. This is despite the legacy of the abdication of responsibility by the strategic leadership of the health service and their pursuit of short term and counterintuitive 'savings' strategies. This has hollowed out the capacity of the HSC to meet existing need never mind improve and respond to growing pressures

It is a matter of both the deepest regret and disappointment to NIPSA that this exercise, the first service reform consultation undertaken as part of Delivering Together is undertaken without democratic oversight. It is therefore NIPSA's view that current consultation processes are sorely missing co-production ethos that should be so central to every consultative exercise. We expect this is rectified in the near future.

However self-inflicted the wounds may be, NIPSA does acknowledge this consultation also comes at a time when the integrated health and social care system, which is the NHS here in Northern Ireland, is undoubtedly in crisis. Years of underfunding (Bengoa talks about an annual increase in the NHS budget of 6% just to stand still) and the complete absence of an effective workforce planning strategy (one of the many casualties of book balancing short termism) has created chronic recruitment and retention issues across all nursing and medical grades and indeed other grades such as Social Work and AHP's.

The massive increase in casual employment in Agency Staff as well as systemic issues such as massive waiting lists and chronic reliance on additional hours working have all impacted negatively on how the public perceive services being delivered. Further strain due to what will be inevitable pressures from an ageing generation and a shift in societal attitudes that will invariably increase the expectation that the NHS will be and should be able to meet these challenges, whilst offering the highest standards of care.

It is against this complex backdrop that NIPSA is responding to this and other consultations and it must be borne in mind the significant challenges across the health and social care system many of our members highlight to us on a daily basis that causes sickness, stress, early retirements and disillusionment within the service.

### **Consultation Documents**

NIPSA sought feedback from our members on two documents: Reshaping Breast Assessment Services (25th March 2019) and the Supplementary Information Document (2nd August). NIPSA notes that on page three of the supplementary information document the view of the Department of Health (DOH) is that the current model is unsustainable, as current services do not consistently provide appointments within national standard waiting times. Appendix 1 (p7) provides an overview of this rational in basic form using NI as a region as opposed to how individual centres performed.

As stated, NIPSA has always been of the view that reviewing how services are performing is a central tenet in the delivery of services in that the objective is always to make services better. However, it is NIPSA's view this was a poor example of how to outline arguments as to the rational for change. This is for a number of reasons:

- There is no clear analysis on why some Trust's may perform better than others
- We noted that in Appendix 1 there is significant fluctuations on waiting times longer than 14 days but these are not explained
- The document clearly fails to provide a balanced view of how individual services and Trusts are performing well at any particular time
- There is no relevant information in relation to staffing budgets set against costs across all Trust's that would provide the reader with an understanding of individual Trust financial pressures
- We are not provided with such issues as sickness absence, reasons for this and an analysis of how this may have impacted on services delivery
- There is little information on how patients experienced the service they received at each site

### **Workforce Analysis**

NIPSA was very surprised to find there was no clear analysis of the workforce across each of the Trust's in Breast Assessment Services and workforce requirements for any proposed new model. This is a startling omission given the DOH are fully aware of the current recruitment/retention problems that has resulted in significant vacancies in nursing and consultant medical posts across NI. When this issue was raised at the public consultation meetings NIPSA found the response from the panel nothing more than what appeared to be cursory acknowledgement that this crisis exists and what appeared to be no understanding of how this may impact on any new restructuring of service. While the DOH and individual Health Trusts have attempted to address this issue with recruitment sessions across NI and in various parts of the world, this issue remains hugely problematic with recruitment strategies

having limited affect so far. Given Breast Assessment Services require specialist staff to perform often-complex processes we must also be clear it also requires highly experienced staff in this particular field to offer emotional support to women and their families also, something which was commented on by women who used services in all of the public meetings.

The issue of increased reliability of Agency and Locum Staff and the associated significant increase in the cost of maintaining this has also impacted on workers and how services are delivered. This has led to:

- Instability in the workforce
- An unhelpful turnover of staff across sites
- Inexperienced staff working in complex areas
- A shortage of staff when there is a spike in referrals meaning potential delays in the assessment of women

The apparent notion from the DOH that staff will be willing to travel, or even move closer to a new site 30 or 40 miles away is both disrespectful and disingenuous. Many NHS staff go beyond their normal working hours to provide support and services to members of the public. The impact this also has in relation to work/life balance is also a crucial factor in retaining current staff and being able to recruit additional staff.

NIPSA sees no evidence that the DOH as part of this consultation has fully considered the significant implications of workforce as outlined.

### **Co-Production/Co-Design**

Increasingly, NIPSA is coming to the view that the DOH appear to view the co-production and co-design ethos as nothing more than a public soundbite as NIPSA members working in this area clearly stated there had been no engagement with them. The DOH therefore appear to be under the misguided view that staff working in this area will automatically move to wherever it is proposed the three centres will be. While staff are committed to providing the highest quality of care across all five sites of breast assessment, many contacted NIPSA stating this was an unrealistic expectation and they were not prepared to uproot or disrupt their family due to this and they would instead seek employment within the area they live. The DOH appear to be in denial about the extent of the nursing crisis across NI by even suggesting this as Nurses have options wherever they work due to the current vacancy rate of over 2600 that currently exist across NI.

We wish to also advise there have been suggestions that staff had been told that they could not voice their views at the public consultation meetings or other forums in relation to this consultation, which if true is concerning and unacceptable to NIPSA.

Recently NIPSA has had the opportunity to read information provided by [www.nesta.org.uk](http://www.nesta.org.uk) on how frontline staff working within complex health systems are often ignored, yet are vital in terms of a change agenda and how sustainable a particular service might be in developing and reaching its goals. It would be NIPSA's view that such an approach as proposed by organisations such as Nesta, could

provide benefits in terms of how services are provided locally within Health Trust's by people who work and understand the systems they work in. We are also of the view this would enhance services, retain staff and act as a good recruiting tool for newly and experienced qualified nurses. It would also show staff across the health and social care system that the DOH is serious about co-production/co-design and that this is something meaningful for them because their years of experience and professional view is being listened to.

We are also given little information about what is currently working well in relation to all five centres. The public view was that staff who work in the Breast Assessment Centres were among the best in their field and this was clearly something they did not want to lose.

It is also our view the DOH made generalisations throughout the consultation document and public meetings, that all centres are not working in the way they should. This is misleading. Many of the users of these services were vociferous in their praise for the services they received and it was noted that the two-week target for a red flag is currently being met in Craigavon. By using a genuine co-production and co-design approach, there is a real opportunity to build upon existing best practice/best outcomes to standardise five centres of excellence to meet the needs of public of NI.

## **Transport**

We would draw attention to the Supplementary Information Document Appendix 2, which deals with travel time. The fundamental flaw in this section is that it completely relates to car drivers or people who have access to a car. Nowhere does it consider or mention or is there an analysis of public transport, especially for those in rural locations where over the years access to public transport (i.e. buses) have been scaled back significantly. This is a glaring omission and fails also to take into account current environmental policies the Government are proposing and which trade unions in particular are campaigning for.

We are also given no oversight or analysis of work undertaken jointly between the DOH and Department of Infrastructure who have responsibility for roads in NI and any present and potential plans that may make travel to any proposed three-model service site easier for people undergoing the trauma of treatment for cancer. It is also extremely disappointing there is nothing of note in relation to the vital role Translink play in this scenario as the majority of people rely on public transport for their daily commute.

The lack of strategic approach outlined above on these issues is another glaring omission and as such renders this section as fatally flawed as it fundamentally fails to consider the time and impact this will have for women with young children, carers, those who are financially disadvantaged and the impact a significantly longer journey may have physically on individuals. It may mean appointments are delayed or some women may be deterred from attending an appointment having a delaying impact on diagnosis and even treatment.

Finally, if treatment services were to be relocated to the three-site model, given that driving is not recommended directly after treatment, patients could be adversely affected and an already difficult journey would be convoluted further with many women being dependent on partners, family and friends etc.

### **Financial Considerations**

Given the issues we have outlined above it is again with regret the DOH have not considered such issues as welfare reform, increasing use of foodbanks and the increase in poverty in NI. The DOH mantra of the right care, in the right place, at the right time also appears to be nothing more than another public soundbite.

NIPSA would refer to the findings of the Joseph Roundtree Foundation in February 2018, which examined the rise of poverty in Northern Ireland. In their report they found that:

- 370,000 people in Northern Ireland live in poverty.
- This figure consists of 110,000 children, 220,000 working-age adults and 40,000 pensioners
- Working-age adults without children are now at higher risk of poverty than ten years ago
- Northern Ireland has higher worklessness and lower employment than elsewhere, and the proportion of people in poverty in workless households has increased slightly over time, in contrast with the UK as a whole.
- Nearly two thirds of people in the poorest fifth are not paying into a pension, increasing their risk of future poverty.

We would also refer to the Trussell Trust's assessment that in 2018 alone more than 36,000 three-day emergency food packages were handed out to people in crisis in Northern Ireland with more than 15,000 of these going to children. This represented an increase of more than 13% of people reliant on foodbanks and we fear this has significantly grown since. We would further add that NI is yet to see the full impact of welfare reform which, in NIPSA's view, will drive more people into poverty.

It is NIPSA's contention that by moving to a three-site model there is serious risk that those impacted by the issues outlined above will be significantly and detrimentally impacted by this proposal. The decision as whether to feed your child or spend additional money on public transport because the nearest Symptomatic Assessment Centre has closed will be very real for many people and should be of major concern to those proposing the three-site model as it is potentially a significant public health issue.

### **Patient Care**

Anybody who attended the public meetings heard powerful testimonies from women who have undergone treatment and their support of particular sites where they received the highest level of care. For those staff and clinicians this was something to be proud of.

In this regard, the separation of assessment services from treatment services in the proposed three-site model will negatively affect the direct support women can expect during the course of their treatment.

A significant number of patients will require ongoing assessment throughout their treatment if they receive particular diagnoses. This may be in the form of genetic testing or trial research. This allows patients, especially those assessed and treated at the City Hospital, access to a fully integrated service that they can avail of when they are faced with a myriad of appointments. For instance, the ease with which patients can have an integrated service would be disrupted and potentially delayed, if the location of both services were to be decoupled across Belfast. Currently the vital service of research and genetics is housed at the City Hospital, which is of key importance to both patients and staff alike. To separate such a valuable area of work from assessment and potentially treatment would be a retrograde step away from the high functioning integrated level of service that operates currently.

The majority of breast patients will also need to receive treatment in the form of radiotherapy, chemotherapy or both. To remove treatment for the most common form of female cancer from a centre that is able to meet all of these needs (the City Hospital Cancer Centre) to a location that does not have the necessary developed facilities, is of utmost concern and potentially harmful to a sizeable population of those women who have received a cancer diagnosis. NIPSA noted that at one meeting a clinician challenged the suitability of the Ulster Hospital in being able to accommodate new services.

NIPSA was also concerned to hear the potential impact on the Breast Care Nurse Service, which forms an integral and invaluable part of the treatment and support that patients receive. Patients have advised that any disruption or change to this service would distress them greatly, as the level of professionalism and commitment from the Breast Care Nursing Team is one they rely on extensively. It is clear this service is of the highest quality and the physical, mental and emotional support that is provided by the entire team of doctors, surgeons, consultants, nursing staff, radiotherapy, oncology and support staff cannot be understated. A question of rationale hangs over these particular proposals, when the current excellent level of service provision is considered. This is further compounded by the fact that the statistical data used in the consultation presentation in relation to targets, appeared to be out of date by two years and the use of such data appeared to be selective.

A number of the hospitals also provide additional support on-site such as the Macmillan Centre, Friends of the Cancer Centre as well as Social Work services. These services provide invaluable information and support to patients throughout assessment and treatment and patients can pre-arrange appointments when they know they will be at the hospital. This would no longer be the case if relocation were to proceed and may deter patients from using the service if they were forced to make additional journeys to avail of such support.

### **Additional Points**

Throughout the public meetings, the DOH representatives were at pains to state that these consultations were not financially driven or were about reducing services but

about making services better for women. Yet it is reasonable to say this statement was simply not believed by those attending the public consultations. It is NIPSA's view that when Bengoa spoke about the "burning platform" and the need for Health Service reform, the public did not expect such an up-front cut to service provision on such a key issue affecting women in NI. From NIPSA's perspective, nothing our members heard at any of the public consultation events has assuaged this view.

The issue of NHS funding for an integrated health and social care system in NI is also a major concern in how if implemented these proposals will be structured in the future. As previously stated, years of underfunding (Bengoa 6% just to stand still) has meant all services are facing a highly uncertain future where retraction of services is more than likely. With this and the worrying economic future forecast, NIPSA and our members do not see any kind of increase in the health budget that will allow a reduced three-site model Breast Assessment Service to meet the needs of the population of NI.

Elsewhere, the proposal of a central booking system for all five Trusts would potentially ease growing pressures and challenges by allowing the option for a patient to attend another Trust if their current Trust has no availability within the recommended timeframes.

NIPSA would see a number of benefits in the development of this system:

- Reduction in scheduling delays
- Reduction in patient waiting times
- Improved patient through-put
- Improved clinical history information
- Patient choice of where they want to attend
- Access to surgeons to best suit their surgical needs
- Access to innovative procedures not offered at their locality such as Magseed and Vacuum Assisted Excision

NIPSA also had no objections to the establishment of a Breast Assessment Network. We believe this could be the conduit to building on the current excellent practice and care as well as providing a consistent and innovative approach to services.

## **Conclusion**

In drawing our submission to a conclusion, NIPSA cannot agree with the proposal to move to a three-site location for Breast Assessment Services. We would have serious concerns regarding the impact this would have on women particularly in the Southern region. Other concerns such as transport, finance to attend appointments that we have outlined in this response and which our members strongly feel have not been considered in any substantive way by DOH in relation to this proposal. While it may be argued current Breast Assessment Services are vulnerable to not meeting the needs of women in NI (and the original proposal we note was to reduce to four sites which was inexplicably rejected), NIPSA's contention is to keep all current sites and build on the current excellent work that clearly exists and which was spoken so passionately about publicly. This would mean that the DOH could, within a short

timeframe, have five centres of excellence where treatment and care pathways are of the highest quality and targets are met.

This concludes NIPSA's response.