

**Waiting Well across the North East and North
Cumbria**

Engagement Findings Report

DRAFT report v1.0

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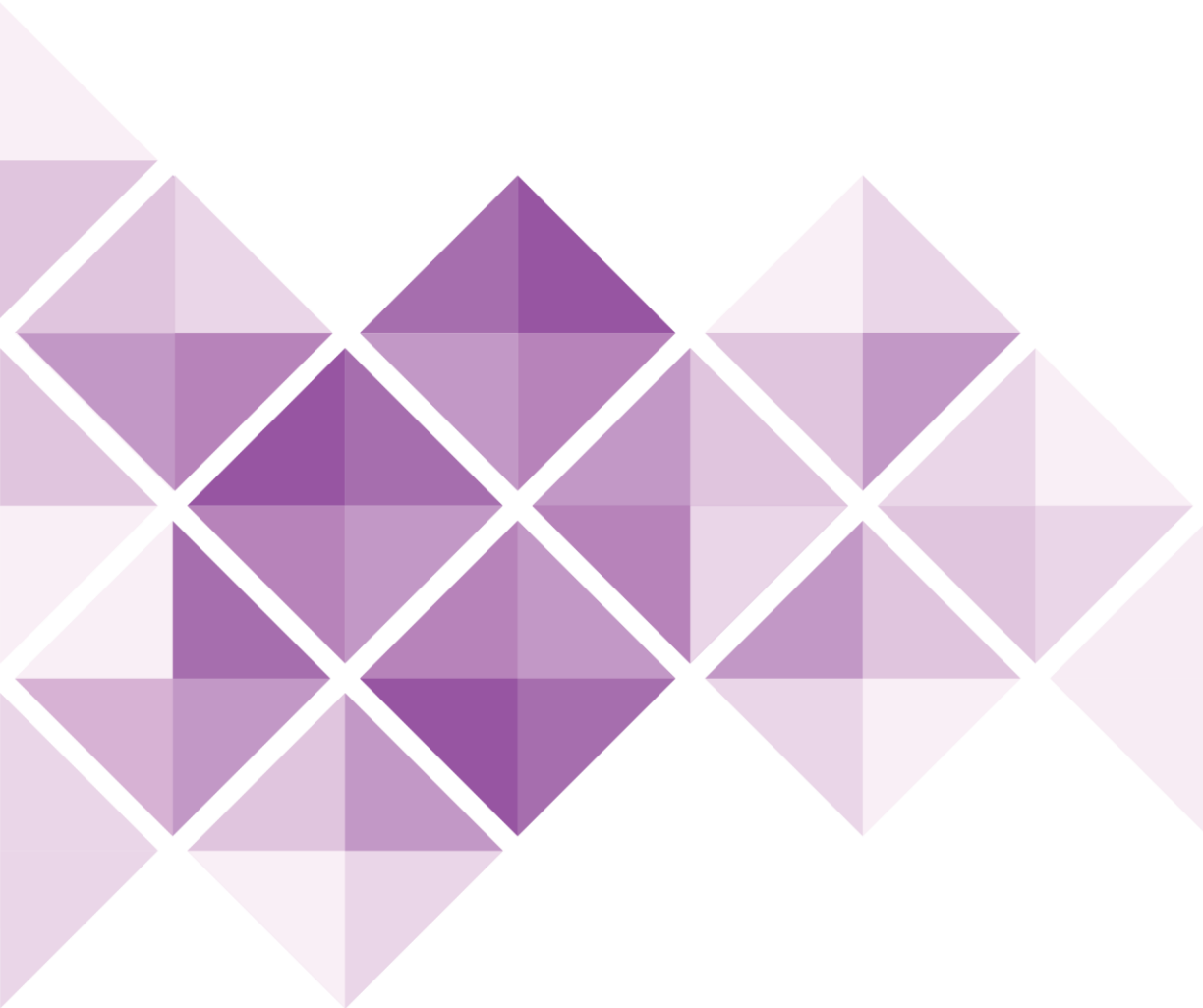


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1 Executive summary

1.1 Introduction

Eight areas across North East and North Cumbria (NENC) have received funding to deliver a programme of support for patients awaiting non-urgent surgery.

The Waiting Well programme aims to engage with patients to support them to adopt healthier lifestyles whilst waiting for surgery. It is hoped that not only will this help prepare them for surgery and the recovery but will inspire patients to continue their healthier lifestyle choices in the long-term.

Patients who fall within any of the following categories will be eligible for the programme: living within a deprived community, have a learning disability, have uncontrolled diabetes / are obese, and/or current smoker / user of preoperative opiates.

To explore perception of the Waiting Well programme, NENC Integrated Care Board (ICB) commissioned J. Harvey Research Ltd to carry out a piece of engagement with key stakeholders and members of the public. The engagement was carried out during a three-month period from December 22 to March 23 and gathered the opinion of 200 individuals.

1.2 Key findings

Perceived benefits of Waiting Well

The programme was generally perceived well by both members of the public and stakeholders. The favourable views amongst some stakeholders were reinforced by their experiences of involvement with similar prehabilitation projects.

Both members of the public and stakeholders discussed how patients can often feel 'left or abandoned' whilst awaiting surgery which can impact upon their physical and mental wellbeing. Participating in Waiting Well was therefore thought to bring the following benefits to patients, as well as the wider healthcare system:

- Helping patients to understand their own health and needs and make healthier lifestyle choices.
- Improved physical and mental health of patients whilst waiting for surgery.
- Opportunity to identify and address any other health issues / wider determinants.
- Increased readiness for surgery / helping patients to find out more information about possible timescales for their operation and recovery.
- Opportunity for patients to socialise / meet people in a similar situation to them.
- Opportunity to educate patients on latest clinical advice regarding their condition / surgery and self-care - supporting individuals to take ownership of their health.
- Possibility of surgery no longer being required.
- Less surgery cancellations / postponements, improved surgical outcomes, speedier recovery time and reduced hospital stays.
- Reduced bed-blocking, waiting lists and financial savings for the NHS.

- Long-term behavioural changes and ripple-effect on family members / friends / carers - reducing future pressure on the healthcare system.

Benefits for individuals with a learning disability were specifically identified in terms of:

- Providing reassurance that they have not been forgotten about and support during an anxious time.
- Giving them an opportunity to learn new skills and meet new people.
- Enabling them to ask questions and feel more independent and involved in decision making.
- Boosting their confidence through better understanding of their surgery.

Some members of the public were however more uncertain about the benefits of the programme due to the limited information they had about it and perceived that its impact would depend on several factors including how patients are invited to the programme, how the benefits of the programme are communicated to them, and the level / type of support offered.

Negative perceptions and perceived challenges of Waiting Well

The negative perceptions held by some members of the public, and the challenges identified in the programme's deployment by both members of the public and stakeholders are summarised here. Some of the challenges identified by stakeholders were based on experiences of involvement with smaller-scale pilot programmes.

- Perceptions that the programme adds pressure to an 'already stretched' healthcare system, including increased demand on support services.
- Perceptions that the programme is a 'waste of money'.
- Scepticism about the programme's motive i.e., whether it is an initiative to 'mask surgical waiting times'.
- Personal barriers to access including age, accessibility, time and commitments, physical health and pain, motivation, and desire to change, lack of support / isolation, cost, and health literacy.
- Concerns about the repercussions for patients who decide not to participate in the programme and whether this would impact on their position in the waiting list. In contrast, others questioned whether participation in the programme and the successful achievement of targets / goals, would enable patients to be moved up the list or given some guarantee that their surgery will take place.
- Concerns about the programme's eligibility criteria with suggestion that this should be broadened / available to all patients awaiting surgery.
- The support provided through the programme, with concerns relating to:
 - Resource implications of tailoring the programme to every individual.
 - The level of practical and emotional support on offer, recognising that some patients will require more intensive support.

- The timeline of support and the challenge of sustaining behaviour change post-intervention / operatively.
- The challenge of providing a consistent level of support to patients despite discrepancies in the offer of services within areas.
- The lengthy waiting lists for support services.
- Patient engagement and compliance; including challenges around engaging / building relationships with patients, particularly with those from the most deprived communities.
- Ensuring the support provided to those with a learning disability does not replicate the help / support already in place, is appropriately tailored and considers the massive variance in needs amongst this patient cohort.
- Communications / promotion of the programme; more specifically striking a balance between making those that are eligible aware, but then not upsetting those who aren't.
- Challenges of working across different trusts / areas and consistency of the programme, including challenges related to evaluation.
- Internal processes for identifying and contacting patients, as well as information governance / data sharing.
- Appropriateness of the name 'Waiting Well' with alternative suggestions including 'Preparing Well', 'Get Well Sooner', 'Wishing You Well' and 'Wishing Well'.

The ideal Waiting Well programme

If invited to participate in Waiting Well, most would feel happy perceiving that something positive was happening, that they had not been forgotten and/or that it was part of the preparation process for their surgery. However, this was not the case for all with some indicating they, or others, may feel patronised, angry, or apprehensive.

A patient's reaction to an invitation to take part in the programme was therefore felt to depend upon:

- Their demographics and circumstances i.e., the type of surgery required, their physical and mental health, comorbidities, level of pain, working status, caring responsibilities, whether they live alone etc.
- The time of year / weather.
- The wording of the invitation / how the programme is communicated with them.
- The support being offered.

When discussing what the support offered through the programme would look like in an ideal world, members of the public and stakeholders described how patients would receive personalised support tailored to their health and wider needs.

Addressing these wider determinants were felt by some stakeholders to be a prerequisite and something the programme must address to initiate patients on their pathway to

change. Establishing programme links with services that can support these wider determinants was therefore felt integral.

Stakeholders further discussed how the programme would be offered to every surgical patient, not just the identified groups, and how resources would be embedded in the hospital, at the point of initial outpatient consultation, to support patients on their journey.

Furthermore, the engagement with members of the public allowed a more comprehensive discussion of the type of support that would be available for patients. This covered:

- Development of individualised support packages with personalised plans / goals.
- The provision of regular support / contact from a named contact / support mentor to provide consistency and enable patients to build trusted relationships with options around communication format and frequency.
- Recognition that some will require more intensive support than others i.e., longer interventions, support to attend groups / activities.
- Support provided through links with existing programmes / services and social prescribing approaches with:
 - Options for group vs one-to-one activities.
 - Options for telephone / online vs face-to-face.
 - Flexibility around working / caring / other responsibilities.
 - Access to free / low-cost activities or reimbursement of costs associated with advice / recommendations.
 - Access to local services within easy reach of transport links and in trusted, safe spaces.
 - Availability of transport / connectivity to rural communities.
 - Option to be supported to attend appointments / groups / activities by a Waiting Well support mentor or to take along a friend or family member.
- Opportunities for patients to connect with others, particularly those who are in a similar situation to themselves. This social interaction and peer support was viewed as crucial to the success of the programme.
- The provision of follow-up appointments to support sustainability of behavioural changes and prevent relapse into old habits.
- Involvement of family members, friends, and carers. This again was viewed by some as crucial to the success of the programme.

1.3 Next steps

The findings from this insight report will be shared with the ICB project team to consider when planning the rollout of the Waiting Well programme across the NENC.

2 Introduction

Eight areas across North East and North Cumbria (NENC) have received funding to deliver a programme of support for patients awaiting non-urgent surgery. The programme is called the Waiting Well programme.

The eight areas include:

- County Durham
- Newcastle Gateshead
- North Cumbria
- North Tyneside
- South Tyneside
- Sunderland
- Tees Valley
- Northumberland

The Waiting Well programme aims to engage with patients to support them to adopt healthier lifestyles while waiting for surgery. It is hoped that not only will this help prepare them for surgery and the recovery but will inspire patients to continue their healthier lifestyle choices in the long-term.

Patients who fall into one or more of the following categories will be eligible for the programme:

- Living within a deprived community.
- Have a learning disability.
- Currently smoke.
- Have uncontrolled diabetes.
- Are obese.
- Use preoperative opiates.

It is estimated that there are approximately 8,000 patients that the programme would be available to.

To explore perception about the programme, NENC Integrated Care Board (ICB) commissioned J. Harvey Research Ltd to carry out a piece of engagement with key stakeholders and members of the public. The engagement was carried out during a three-month period from December 22 to March 23.

3 Methodology

3.1 Engagement with key stakeholders

Eight individuals were identified by the ICB project team to take part in a stakeholder interview; however, one did not respond to the engagement request.

The stakeholders included individuals working for NENC ICB, various NHS trusts across the region and other organisations such as First Contact Clinical and Healthworks.

The purpose of these interviews was to understand stakeholder's thoughts on the Waiting Well programme including anticipated benefits and challenges.

The interviews lasted approximately 20-30 minutes and a discussion guide was developed to ensure consistency between each.

All interviews were audio recorded and a transcript produced of each to support the analysis process.

3.2 Engagement with members of the public

To gather perspective of the programme from members of the public, Healthwatch organisations and other voluntary and community sector organisations (VCSOs) within NENC were approached to undertake a focus group with their service users on behalf of the ICB.

A discussion guide, recording template and an equality monitoring form were provided to each of the participating organisations. This ensured consistency in the questions covered and in the feedback.

Just one Healthwatch organisation in the region (North Tyneside) did not have the resource to support the engagement.

In total, 193 individuals participated in the focus groups during the period Jan – March 2023.

Table: Focus groups conducted

Healthwatch organisations			
Location	Date	No. of attendees	
Healthwatch Hartlepool	17 th Jan 2023	15	
Healthwatch Darlington	23 rd Jan 2023	8	
Healthwatch Middlesbrough	25 th Jan 2023	12	
Healthwatch North Tyneside	25 th Jan 2023	7	
Healthwatch Sunderland	25 th Jan 2023	10	
Healthwatch Northumberland	30 th Jan 2023	6	
Healthwatch Newcastle / Gateshead	1 st Feb 2023	5	
Healthwatch Cumbria	1 st Feb 2023	12	
Healthwatch Stockton	1 st Feb 2023	8	
Healthwatch Redcar	9 th Feb 2023	11	
Healthwatch County Durham	22 nd Feb / 8 th March 2023	6	
Voluntary and community sector organisations (VCSOs)			
VCSO	Area	Date	No. of attendees
North Cumbria Local Authority (LA)	North Cumbria	25 th Jan 2023	10
Northumberland Age UK	Northumberland	30 th Jan 2023	8
East Durham Trust	County Durham	31 st Jan 2023	9
*TIN Arts	County Durham	8 th Feb 2023	12
*Gateshead People - Your Voice Counts	Gateshead	8 th Feb 2023	10
Age Concern	South Tyneside	11 th Feb 2023	6
*Twisting Ducks	Newcastle	13 th Feb 2023	6
Patient and Public Involvement (PPI) Forum	North Tyneside	9 th / 10 th / 14 th Feb 2023	21
Healing Opportunities Provision Scheme (HOPS)	Sunderland	24 th Feb 2023	11
Total			193

*VCSOs supporting individuals with a learning disability.

3.3 Total sample

In total, the engagement reached a total of 200 individuals – 7 stakeholders and 193 members of the public.

3.4 Notes on analysis

Themes from the stakeholder interviews and public focus groups were identified using the principles of thematic analysis. Qualitative data does not allow for commentary on the number of times these themes are raised / discussed.

4 Engagement with key stakeholders

4.1 Overview

Seven interviews were undertaken with stakeholders identified by the ICB project team. This included individuals working for NENC ICB, various NHS trusts across the region and other organisations such as First Contact Clinical and Healthworks.

4.2 Thoughts on Waiting Well

The involvement of stakeholders with Waiting Well varied – whilst some were currently, or had been involved, in smaller-scale pilot programmes, others are currently involved in the development of the programme for the region / their locality.

Overall, there was strong agreement that the programme is needed.

“With the pressures that we have currently have in the system, anything that means we haven’t got to cancel somebody having their surgery would be really good.”

“Could be a game changer, fundamentally change someone’s care pathway.”

It was felt that using the time that patients are waiting for their operations as an opportunity was extremely valuable in terms of:

- a) targeting lifestyle related issues to support patients to become as ready as possible for their operations, thereby reducing the likelihood of cancellations / postponements.
- b) enabling and activating patients to take ownership of their health, not only for their operation and the outcomes from this, but more generally to allow them to live healthier lifestyles.

Some stakeholders had observed similar outcomes from this type of prehabilitation work, which further reinforced their favourable views of Waiting Well.

“Prehabilitation and having people in a better state for surgery is a proven benefit to the system, so I’m very much in favour of what is being done.”

In those areas that have been operating pilot programmes, stakeholders discussed the favourable reactions that patients have had.

“A lot of people have received it well.”

“A lot of people who engage do find it worthwhile – it’s something pro-active.”

With one of the focus areas of Waiting Well being deprived areas, it was felt by all stakeholders that this was particularly needed as these cohorts are often the hardest to reach and have the worst health inequalities. However, one stakeholder argued that solely focussing on this might mean that some patients who fall outside of these areas might be missed.

“Just focusing on a postcode, I don’t think is 100% the right thing to do – just because you live in a slightly nicer area doesn’t mean you aren’t socially deprived. They could have bought it 50 years ago and are still socially deprived.”

4.3 Benefits of Waiting Well

Stakeholders primarily cited increasing readiness for surgery as well as improved surgical outcomes as key benefits of the programme to patients. It was felt that supporting people to be in a better physical state prior to their operation would help ensure better surgical outcomes, including speed of recovery.

Further benefits related to patients’ physical health included:

- Reducing lifestyle risk factors related to their operation.
- Helping patients to lead a healthier life through increasing physical activity, healthy eating, and weight management.
- Investigating patients past medical history and long-standing health conditions and ensuring that they are attending their regular check-ups.

In terms of mental health, stakeholders noted how patients can often feel *‘that they have just been left’* whilst waiting for surgery. The programme was therefore viewed as an opportunity to keep in contact with patients and alleviate any feelings of *‘abandonment’*.

“I think the long waiters probably feel a bit lost in the system and forgotten about – so there will be an element that ‘you are still important – we’re working towards the waiting list to try to get to you, but why don’t we try to do something positive with the waiting time’”.

Stakeholders further acknowledged that often there can be a fear among patients around not knowing what is going to happen in hospital / during their surgery with many unlikely to have started to think about a recovery plan. Mental preparation was therefore also seen as a key benefit of the programme.

“What’s come out of it is the real lack of understanding of the pre-operative process and then their operation, what happens, what they will experience. So, it’s given us a real opportunity to pull people in and start to prepare them.”

With patients potentially being on surgical waiting lists for a length of time, it was recognised that the programme presents a great opportunity to tackle wider determinants that often cause / prevent patients, particularly those from more deprived communities, from making lifestyle related changes.

Furthermore, speaking to patients and understanding what matters to them most, was felt to be key in delivering personalised care and giving patients a renewed sense of motivation and empowering them to make behavioural changes.

“It’s giving people the information and the knowledge for them to make informed choices.”

Many perceived wider determinants as a prerequisite and something the programme must address to start patients on their pathway to change. This was particularly the case for financial support, with links to Citizens Advice Bureau viewed as essential.

“I think that a lot of patients now are financially really struggling, getting on a bus and attending an exercise programme isn’t likely, when they are worrying about how they are going to put the heating on. So, there will be things we have to work through first before we can get to the lifestyle issues.”

Some stakeholders shared examples of how they had addressed some of these wider determinants with patients in pilot programmes, and the type of support which had been looked at:

- Finances;
 - Financial assessments if support is needed post operatively.
 - Help with benefits whilst off work.
 - Foodbank vouchers, advice around eco shops/food pantries.

- Housing-related issues:
 - Home safety.
 - Home adaptations.
 - Occupational therapist referral.
 - Home energy advice.

- Emotional wellbeing:
 - Referral to counselling / mental health service.

- Social isolation:
 - Community support.
 - Social activities.

With patients being in a better physical and mental state prior to their operation, numerous benefits were additionally identified for the NHS, these included:

- Less surgeries being postponed or cancelled.
- Reducing waiting lists.
- Shorter hospital stays.
- Reducing bed blocking.
- Financial / more cost-effective.

Additional benefits of the programme related to partnership working in terms of Waiting Well staff being able to engage with partner organisations to deliver various interventions for patients i.e., health and wellbeing courses and weight management schemes. It was felt that this partnership working approach would enable interventions to be delivered in a more joined-up manner, playing to the strengths of services already in place, as well as ensuring that those most in need are targeted through the use of partner networks.

“We worked with a VSE partner and we trained them to be the trainers, so we used their marketing routes, their relationships to engage the people who needed it the most and the relationships that existed with some of the staff and trained them to co-deliver the courses.”

Stakeholders who have been involved in pilot programmes also noted how these experiences have allowed them the opportunity to really think about how the Waiting Well programme will be deployed, using the feedback they have gained from those that have been involved.

“There has been really positive support from those who have engaged, they are enjoying it – as this is the first one, they are really helping to co-create with us and understand what’s missing and what they would include going forward.”

4.4 Challenges of Waiting Well

Stakeholders were asked if they envisage any key challenges in the programme’s deployment. Many of the challenges identified were based on experiences of involvement with pilot programmes.

4.4.1 Engaging patients and communications

Stakeholders had concerns around whether the regional hub would be used to cold call patients. It was felt that by using this approach there was a danger that the programme might engage the wrong cohort i.e., the more activated and able.

“One of my concerns about the pathway is that they are going to be working from a hub and cold calling, making a generic offer and what we know about the people we are trying to reach, we need to use the relationships on the ground.”

Acknowledging the difficulties that are faced in engaging those from the most deprived communities, a tailored, personalised approach was deemed imperative with Waiting Well staff prepared to invest their time and patience to build the trust of these individuals. Working with partner organisations and using local relationships on the ground was also felt to play an integral role in this.

“Poorer communities will not necessarily receive it as well as others, so more work to be done to get them to access.”

“You find that those who take a little bit more time that need the help. It obviously just reading the patient and gaining the trust more than anything, personalising the care so that it is what matters to them.”

Stakeholders who have worked in similar pilot programmes, noted how there are some patients who are solely focussed on their operation who would be unwilling to engage with programmes such as this. For these patients, the challenges of ‘*selling the programme*’ and explaining what the benefits are to them as an individual, were highlighted.

Additionally, it was noted how some patients can be sceptical about the motive of programmes such as these asking questions such as ‘*if I don’t engage with the programme, will this affect the date for my operation?*’. Further scepticism was reported among patients who receive a letter or phone call ‘*out of the blue*’.

Stakeholders therefore highlighted the importance of ensuring that all health professionals involved in the treatment pathway are onboard with the programme, to ensure its credibility and authenticity; something that one felt should have already happened:

“Months ago, we should have been getting all the SLOs and teams of the trust together, so they know about it, and share out to the secretaries and the surgeons so they know about it.”

With not all patients waiting for non-urgent surgery eligible for the programme, a further challenge was identified in terms of promotion of the programme and striking a balance between making those that are eligible aware, but then not upsetting those who aren't.

“Think it's important we do communicate to patients but there will be a lot on the list, who initially don't fit the criteria – so it's letting them know without frustrating other people who might want to access it but can't at the moment.”

“We are working with our comms team to try and get the message out there without everyone thinking that they should be getting it and dealing with more people, and we can't help them.”

The name of the programme was additionally called into question by a few stakeholders. The alternative suggestion of 'Preparing well' was felt to be more appropriate.

“I would call it anything else but Waiting Well, because waiting is a passive action and we want people to be active - not doing it to them, doing it for themselves - or at the very least with us.”

“Preparing Well - this is something that is part of your treatment plan and something we would like you to engage actively with us to help you get a better outcome.”

4.4.2 Behaviour change and support

The discrepancies in the offer of services within different areas was recognised as a challenge by some stakeholders in terms of providing a consistent level of support to patients.

“I could have a patient in Stockton who wants to stop smoking and due they will get that paid for, yet if I come a bit further down the road in Hartlepool, I can't give the patient that same offer, they have to pay.”

“I find it frustrating as a health professional that I can't give every patient the same level of care.”

Additionally, with the waiting lists for some of these services being long, stakeholders highlighted the additional challenge of putting support in place for patients whilst they wait.

“Main challenge is waiting lists, because of COVID these are huge, especially for mental health services. So, then it's trying to put intervention in place in the meantime.”

Another challenge related to the difficulties of sustaining behaviour change post intervention / operatively. For this reason, ensuring that support is available to patients after the intervention / programme has ended through links with partner organisations, such as health trainers and teams located in primary care, was deemed imperative.

“The hope would be that if we can support patients appropriately in the run up to surgery that they will see the benefits and continue in their lifestyle behaviours afterwards. It doesn't always happen, but it can equip patients and signpost people so

that they are aware what support is available after the operation so they still have that support mechanism in place so that they can continue.”

“Every Primary Care Network has a programme with a social prescriber, a care co-ordinator and a health and wellbeing coach and between the 3 job roles they very much do what we do. So, if I feel a patient needs further support, I would then refer into their own GP surgery or one of those services so they still have that support longer-term.”

4.4.3 Working across different trusts / areas

Working across different NHS trusts and areas was felt to add complexities, particularly with the lack of communication and each area planning / having the ability to operate the programme in a different way.

“The regional team might want one thing, the local another. The challenge is having that agreement from all other teams of where we should work.”

An example of this related to the discussions that have been had about the point at which patients are invited to take part in the programme. The two schools of thought are as follows:

1. Targeting those who are going to be waiting the longest which would give the opportunity to effectively tackle wider determinants as well as physical health. It was however noted that this runs the risk of patients reverting to old habits prior to their operation.
2. Targeting those who have a shorter wait for their operation and supporting them to be as fit as they can be.

The ability to measure and demonstrate outcomes is seen as key to influencing this decision:

“If you are wanting outcomes and to prove that something works you won't be able to do this with people who have been added to a waiting list and might be on this for 2 years”.

4.4.4 Evaluation

Stakeholders further discussed the challenges of evaluating the programme with some indicating that 'harder' clinical outcomes are needed to show the success of the programme i.e., less cancellations and postponing of operations and reduced waiting lists.

It was felt that these more immediate short-term, quantifiable measurements were needed to evidence the programme and ensure its continuation. This was contrasted with 'softer' measurements such as the number of people supported on a waiting list or making behavioural changes, which for the latter can be difficult to quantify.

“I don't just think it is about supporting people on a waiting list...it's more about can we pick the process up to get more people through?”

“Demonstrating the success - bottom line, how do we get that data – show the patient has better outcomes, show shorter hospital stays etc.”

Additional challenges related to this, were identified in terms of:

- Benchmarking impact in the absence of control groups (i.e., those who don't receive any type of intervention).
- Comparing success across the region with areas operating the programme differently.

4.4.5 Internal processes

A further challenge to the programme's deployment was around internal processes for identifying and contacting patients, as well as information governance / data sharing.

It was noted how these processes were not been thought through sufficiently in the early stages of the development of the programme, which has resulted in this taking much longer than needed and additional support / resources being required.

“At the moment it's a bit disjointed, going round the houses to send from one team to another. The process bit is the hardest bit, delivering the programme and working with the patient is easier, it's what we have done for a long time.”

“It will be nice to have someone contact the patients for us. But there should have been a way to take the pressure off the localities by pulling the contact details of the patients instead of having to go back into the electronic record and do it ourselves.”

4.4.6 Supporting those with a learning disability

There were differing opinions about this cohort of patients. For some, focusing on people with a learning disability as part of the programme was felt to be positive:

“We don't really understand how much of a disadvantage those with a learning disability really have in accessing and receiving healthcare.”

However, others had concerns about this in terms of the huge variance in the needs of these individuals and also whether the support put into place through the programme will duplicate what is already there.

“Yes, we could offer more support to patients with learning disabilities, but it's what that support is, and should it be the waiting well programme?”

Stakeholders were honest in saying that they weren't experts in this area and were happy to work with people with this knowledge and partners such as MENCAP to ensure patients' needs were met by the programme. It was also felt that central support for people with a learning disability could be valuable because the numbers will be too small in each area.

4.5 The ideal Waiting Well programme

In an ideal world, stakeholders were asked what the Waiting Well programme would look like to them. Responses centred upon the following key themes:

- Something would be able to be offered to every surgical patient, not just the identified groups.
- Resources would be embedded in the hospital, at the point of initial outpatient consultation, to support patients on their journey.
- A robust evaluation would be in place with the involvement of economists.
- Patients would receive a very personalised, holistic plan.

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5 Engagement with members of the public

5.1 Overview

The following summarises the findings from the 20 focus groups conducted with 193 members of the public by Healthwatch and other VCOSs.

5.2 Participant demographics

All participants were asked to complete an equality and monitoring form; however, this was not a condition of their involvement.

The full demographic breakdown of participants can be found in the [Appendix](#); however, a summary is presented here. Percentages are calculated as a proportion of all respondents (N=193).

- A greater proportion were female (45%), with 27% male.
- Most were aged 65+ (25%), followed by those aged 55 – 64 (12%) and 35 – 44 (12%).
- 1% indicated their gender identity did not match their sex registered at birth.
- 48% have a physical or mental health condition(s) or illness(es) lasting or expecting to last 12 months or more.
- 1% were currently pregnant or had been in the last year.
- 22% have caring responsibilities.
- 63% stated their ethnic group was White (2% Mixed / Multiple ethnic groups & 1% Asian / Asian British).
- 23% were from a NE postcode, 21% a TS postcode, 5% a DL postcode, 3% a SR postcode and 2% a DH postcode.

A few additional questions were asked to participants to understand their eligibility for the Waiting Well programme should they be required to undergo non-urgent surgery in the future.

- 11% have a developmental condition such as Autistic Spectrum Disorder (ASD) or a learning impairment.
- 4% considered themselves to have uncontrolled diabetes.
- 22% considered themselves to be overweight and 4% obese.
- 9% smoke on a daily basis.
- 15% have been prescribed opiates in the last 12 months.

5.3 Thoughts on the Waiting Well Programme

Whilst waiting for an operation, participants discussed how patients are *'just left'* and *'expected to put their life on hold'* and how this has a significant impact on both their physical and mental health. For this reason, most perceived Waiting Well positively with participants noting how it seemed a *'good idea'*, *'made sense'* and would be *'helpful'*.

"I am waiting for corrective / second replacement knee surgery - I have no date / support or advice as to how to manage my knee, which is now affecting other joints. I also have had no pain relief." (Northumberland Age UK)

5.3.1 Perceived benefits of Waiting Well

The benefits that Waiting Well would bring to patients, as well as to the NHS, were discussed at length throughout the groups. The following provides an overview of these:

- Tailored support and information to help patients understand their own health and needs, and encourage positive behaviour change.

"I would like help to exercise. I don't know what exercises I should be doing to keep my muscles and joints healthy." (Age UK Northumberland)

- Improved physical and mental health / quality of life of patients whilst waiting for surgery for example, through weight loss / increased physical fitness, and the provision of reassurance and hope.

"This would be a great initiative to help with depression caused by living with intense pain and discomfort" (Age UK Northumberland)

- Long-term behavioural changes through patient education - reducing future pressure on the healthcare system. It was however noted that behaviour change in the post-operative period will be more difficult for patients to sustain and dependent on several factors including the individual and their circumstances, the type of surgery required, their recovery, and the longer-term support available.

"Could really support people to lead better live long-term" (Healthwatch Cumbria)

- Practical and psychological support to provide reassurance and help patients prepare for their forthcoming surgery and recovery. This was felt to be particularly important for those who have worries / anxieties about their operation, and/or those who don't have someone to talk to.

“It would help with the worries, having someone to ask and tell everything to” (Age Concern South Tyneside)

- Participants anticipated that participation in Waiting Well might help patients find out information about possible timescales for their operation and how long the recovery might be.

“People don’t know what’s going to happen to them, they think what’s going to happen to me, how long will I be waiting, how will I feel afterward and how will I manage” (Age Concern South Tyneside)

- Opportunity for patients to socialise / meet people in a similar situation to them, thus helping to counteract the sense of isolation and boosting their mental health. For many, social support was seen as integral to the success of the programme.
- Less surgery cancellations, improved surgical outcomes, speedier recovery times and reduced hospital stays, due to patients being in a better physical state prior to their surgery.

“One of the issues around waiting for surgery is that the condition can worsen during this time. Furthermore, the drugs that are often prescribed for pain can have some awful side effects. Also, the reduced mobility often leads to weight gain which exacerbates the risks associated with surgery.” (HOPS)

- Surgery no longer being required due to patients being in an improved physical state (i.e., weight loss), therefore reducing waiting lists for the NHS.

“It may mean my general health improves so much I don’t need the procedure.” (PPI North Tyneside)

- Opportunity to identify and address any other health issues and wider determinants that might impact on the physical and mental wellbeing of a patient.
- Opportunity to educate patients on the latest clinical advice regarding their condition / surgery and self-care (including awareness of support services) - supporting individuals to take ownership of their health. An example was noted where historically patients may have been advised to rest when suffering from some forms of back pain, now the advice is predominantly ‘*use it or lose it*’.
- Ripple effect / encouraging behaviour change amongst wider family members, friends, and carers.

“The trickledown effect will mean that neighbours, friends and hopefully the community as a whole will benefit from renewed motivation and health information.” (Healthwatch North Tyneside)

- An upstream, preventative approach to reduce surgical waiting lists and strain on the NHS and providing a duty of care to support people whilst waiting / keep them informed.

In contrast to the above, some were uncertain about the benefits of the programme due to the limited information they had about it, perceiving that its impact was dependent on several factors including how patients are invited to the programme, how the benefits of the programme are communicated to them, and the level / type of support offered.

For individuals with a learning disability, the specific benefits that participation in Waiting Well would bring to them included:

- Helping them to feel stronger and fitter.
- Providing reassurance that they have not been forgotten about and support during an anxious time.
- Giving them an opportunity to learn new skills and meet new people.
- Enabling them to ask questions, feel more independent and involved in decision making.
- Boosting their confidence through better understanding of their surgery.

Specific comments made by these individuals included:

“I think it’s good to know what’s happening...I get anxious if I don’t know what’s going to happen. It would make me more relaxed.” (Twisted Ducks)

“Being listened to and having a voice in relation to health, working together with health professionals to understand our own health better.” (Gateshead People)

“I would feel independent and that I was involved in the decisions being made” (TIN Arts)

5.3.2 Negative perceptions of Waiting Well

Negative perceptions about Waiting Well were held by some. This included most of those who participated in the Healthwatch Sunderland focus group and small numbers from other groups.

Participants had concerns about the programme adding pressure to an ‘*already stretched system*’ with questions asked about the cost of the programme, how it will be staffed, the

additional demand that will be placed on services / the current workforce, as well as the long-term commitment being made to the programme.

“I think there is a significant risk of the health service wasting money on this and at a time when every sector of the health service is screaming for more money.” (PPI North Tyneside)

For some, the programme was felt to be a *‘waste of money’* with suggestions made that the financial resources for this are better spent on reducing waiting lists. These individuals stressed the physical agony and poor mental state that some patients are in whilst waiting for surgery, and how they are *‘sick of being told what to do’*.

There was unanimous agreement in the Healthwatch Sunderland focus group that short and long-term behaviour changes would not result from this programme.

“While waiting for my hip replacements, I lost my job and was in constant agony. I was sent to repeated physio appointments and group exercise classes, which I felt just lengthened the waiting process. All I needed was to get the operations done. This brings back horrific memories for me”. (Healthwatch Sunderland)

Scepticism was also apparent amongst some who questioned the purpose of the programme and whether it is *‘just an initiative to mask / justify the lengthy waiting times for surgery’*.

“I would want to know about it first, I’d be worried it was just delaying things, like covering up the long wait. I’m not sure so sure about it.” (Age Concern South Tyneside)

The eligibility criteria for the programme was discussed by some with it felt that this should be broadened to include additional patient cohorts such as those with a mental health diagnosis and those over a certain age. Furthermore, others felt that the programme, or at least self-help resources, should be available to all patients waiting for non-urgent surgery regardless of the area where they are from.

Specific questions relating to the criteria included:

- How has the eligibility criteria been derived?
- Who will assess eligibility?
- Will there be a filtering of patients identified to ensure those struggling the most are given the help they require?
- What is available for those who fall outside the criteria?
- Will there be an option for patients to self-refer to the programme?
- What are the plans to expand the programme in the future?

“Others waiting could feel disadvantaged because they don’t fit the criteria, just because you have disposable income and have led a healthy lifestyle doesn’t mean you wouldn’t benefit from this initiative.” (PPI North Tyneside)

Finally, the name of the programme – Waiting Well – was questioned by some with it perceived that it implies that patients will be waiting a long time and/or that people are

'doing something that aren't meant to be doing'. Alternative suggestions included 'Get Well Sooner', 'Wishing You Well' and 'Wishing Well'.

"The title of 'Waiting Well' is patronising and indicates that people should just sit patiently and wait for their operation. It is somewhat tripe." (Healthwatch North Tyneside)

5.4 Taking part in Wating Well

If invited to take part in Waiting Well, most would be happy perceiving that something positive was happening, that they had not been forgotten and/or that it was part of the preparation process for their surgery.

"I'm already waiting so would definitely do it. It would help you to feel prepared and like you're doing something while waiting." (Age Concern South Tyneside)

"I would want to take part because I know that I should lose some weight." (Healthwatch Darlington)

However, this was not the case for all, with some perceiving that they, or others, may feel:

- Embarrassed / offended about being labelled as someone who needs support.
- Patronised about being told what to do.
- Frustrated / angry about their wait.
- Apprehensive about what the programme entails, and the commitment required.

"I might feel somewhat patronised as I already take care of myself. I would feel aggrieved that I was expected to take responsibility for a health problem that was probably not of my making." (PPI North Tyneside)

A patient's reaction to an invitation to take part in the programme was therefore felt to depend upon:

- Their demographics and circumstances i.e., the type of surgery required, their physical and mental health, comorbidities, level of pain, working status, caring responsibilities, whether they live alone etc.
- The time of year / weather.
- The wording of the invitation / how the programme is communicated.
- The support being offered.

"Some 'cared for' individuals have been in pain / distress for so long that they are resistant to any suggestions and devoid of hope beyond the idea that the proposed treatment might cure things." (HOPS)

"A friend of mine has been doing exercise while she is waiting, but this is agony and just needs her op." (Healthwatch Sunderland)

A common theme discussed within most groups was what the repercussions would be for patients who were invited to take part but chose not to, as well as those who decide to participate but then don't reach their set targets / goals, with question asked as to how this would impact on their position in the waiting list.

“Would it affect my care if I didn't want to participate?” (Healthwatch Darlington)

“Will they get the operation quicker if they do the programme? What happens if they fail?” (Healthwatch Redcar & Cleveland)

Additionally, others questioned whether participation in the programme and the successful achievement of targets / goals, would enable patients to be moved up the list or given some guarantee that their surgery will take place.

“Need a realistic time scale for surgery / a goal to work towards, such as if the patient follows programme and successfully reaches the required health goals when will surgery be happening?” (Healthwatch Cumbria)

When discussing the process of inviting patients to participate in the programme, the following points were considered important:

- The programme should be first introduced by the consultant, or GP, along with guidance about how patients can help themselves whilst waiting.
- Referrals should be timely and efficient when patients are more motivated and ensure that they have the time to make the required health changes.
- The approach and manner of the Waiting Well healthcare professional should be encouraging and supportive, and any discussion conversational.
- The Waiting Well healthcare professional making contact should have:
 - Awareness of / information specific to the type of surgery required e.g., the type of exercise that would be most appropriate.
 - An idea of when the person's operation might take place to help support mental health.
- Waiting Well healthcare professionals engaging with people with a learning disability should have a good knowledge of learning disabilities, in addition to awareness of the individual's support plan / health passport.
- Communications should:
 - Consider terminology to avoid stigmatisation / offending (i.e., 'deprived communities')
 - Highlight the benefits for individuals / patients undergoing different types of surgery – *‘what's in it for me?’*

- Ensure patients are aware of what it means to participate / not participate in terms of their position on the waiting list.
 - Provide case studies to illustrate real life examples.
 - Make patients aware that they can bring a family member / friend to any appointments / groups.
- Communications by post should:
 - Be accessible (i.e., easy-to-understand, font size 14, no jargon)
 - Provide information on the phone number patients will be contacted upon.
 - Offer a translation service and information in different formats.

“How the programme is sold to patients is important – the benefits need to be identified, communicated and shared” (North Cumbria LA)

“Need to be careful how they are explaining why they have been chosen to do the programme.” (Healthwatch Darlington)

5.5 Challenges of Waiting Well

Participants identified numerous challenges of Waiting Well, these related to difficulties of tailoring the programme to every individual, the level of practical and emotional support on offer, the timeline of support, sustaining behaviour change, and patient engagement and compliance.

Consideration was felt to be essential of the personal barriers that individuals will face to participation i.e., age, accessibility, cost, attitude and perceptions, time, and caring responsibilities.

Table: Challenges of Waiting Well

Tailoring the programme to every individual	<ul style="list-style-type: none"> - Patients will become disengaged / perceive the programme to be irrelevant if it is not tailored to them. - One-to-one assessments are imperative to identify patients' needs / barriers to access. - Resource implications.
Level of practical and emotional support on offer	<ul style="list-style-type: none"> - Challenge of changing deeply entrenched behaviours and keeping people motivated. - Some will require extensive support – signposting to a service or providing a phone number is not enough. - Difficulty of empowering patients / building up trust when point of contact seems mainly by letter and telephone. - Time spent chasing non-attendees / ensuring patients put advice into practice. - Resource implications. - Capacity and resource of support services (i.e., no extra income to deal with patients referred to them, existing staffing issues).

Timeline of support and sustaining long-term behaviour change	<ul style="list-style-type: none"> - Time-limited support. - Difficulty of sustaining behaviour change once support stops / patient has had their operation. - Long-term support / follow-ups essential for permanent behaviour change. - Resource implications.
Patient engagement and compliance	<ul style="list-style-type: none"> - Difficulty of engaging patients. - Drop-off when patients feel changes aren't happening quickly enough / initial enthusiasm wears off / experience long waiting times for support services. - Maintaining patient progress and satisfaction imperative.
Personal barriers	<ul style="list-style-type: none"> - Age - Accessibility <ul style="list-style-type: none"> o Patients with difficulties leaving the house due to poor mobility / mental health / COVID isolation. o Transport and cost, especially for those living in rural areas. o Sensory difficulties or comorbidities. o Online and digital access / skills. - Attitude and perceptions <ul style="list-style-type: none"> o Not wanting to be told what to do / feeling patronised. o Lack of recognition that they have a problem. o Frustration at wait. o Distrust / scepticism of purpose. - Time and commitments - Caring responsibilities - Physical health and pain <ul style="list-style-type: none"> o Not being well enough / in too much pain to commit. - Mental health, motivation and desire to change <ul style="list-style-type: none"> o Mental health affects ability to drive and connect. o Frustrations / patients fed up with waiting. o Perception of change being too hard. - Lack of support / isolation <ul style="list-style-type: none"> o Anxiety of taking part / going someone alone. o Lack of family / peer support. - Cost implications <ul style="list-style-type: none"> o Expense associated with following advice. o Cost-of-living crisis and poverty / low income. - Health literacy <ul style="list-style-type: none"> o Patient's capacity to make decisions regarding advice and recommendations. - People with a learning disability <ul style="list-style-type: none"> o Understanding of the programme and what is expected of them. o Resistance to change / new things. o Relationships / not having one point of contact.

Other	<ul style="list-style-type: none"> - Communication, collaboration and sharing of information between professionals. - Communication to different demographics / giving the right message at the right time. - Timeliness of referrals. - Managing patient expectations.
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Example quotes to illustrate some of these challenges are included below:

*“The programme needs to fit the person, not the person to fit the programme.”
(Healthwatch Redcar & Cleveland)*

“Very often people enrol on programmes very motivated. This can disappear when individuals get bored and see a lack of progress.” (Age UK Northumberland)

“Weight loss takes a long time and lots of support, so I have serious doubts about the programme. This won’t lead to long term change.” (Healthwatch County Durham)

*“Resistance to new ideas by patients who have waited for months or years and have become convinced that nothing will help except the proposed medical intervention.”
(HOPS)*

5.6 Support offered through Waiting Well

When thinking about the support that will be offered through Waiting Well, participants stressed the diverse and wide-ranging needs that patients will have. Considering this, discussions focused upon the need for the programme to provide tailored support to individuals. The key points from these discussions are summarised here:

- Behavioural change is a process, and some will require more intensive support than others (i.e., longer interventions, support to attend groups / activities).
- Regular support / contact is required from a named contact / support mentor (e.g., weekly catchups, contact telephone number etc.) to provide consistency and enable patients to build trusted relationships. It was felt important that patients are provided with an option as to whether these are carried out face-to-face, online / telephone, or via a home visit (for those with difficulties leaving the house), as well as their frequency.

“Someone to call on if I’m struggling” (PPI North Tyneside)

- Motivation and encouragement should be provided in a non-patronising, non-judgemental manner. Suggestions were made about regular reminders to patients via their preferred communication method.

“Someone talking to me, and I mean talking to me not telling me what to do. There’s a big difference” (Age Concern South Tyneside)

- Patients should be treated holistically with acknowledgement of any other health conditions or non-health related needs.
- Individualised support packages should be developed with personal plans / goals.
- Support options should be provided through links with existing programmes / services (i.e., physiotherapy, occupational therapy, pharmacy, holistic therapy, mental health / smoking cessation / weight management / medication management services) and social prescribing approaches (i.e., social activities and support groups). As part of this participants discussed:
 - Group vs one-to-one activities.
 - Telephone / online vs face-to-face options.
 - Flexibility around working / caring / other responsibilities.
 - Access to free / low-cost activities or reimbursement of costs associated with advice / recommendations.
 - Access to local services within easy reach of transport links and in trusted, safe spaces.
 - Availability of transport / connectivity to rural communities.
 - Option to be supported to attend appointments / groups / activities by a Waiting Well support mentor or to take along a friend or family member.

“Not everyone likes to be part of a group, I would benefit from one-to-one support” (Age UK Northumberland)

“I would need someone to pay for activities and my taxi as we do not have a car and don’t have enough money for a taxi” (TIN Arts)

- Providing opportunities for patients to connect with others, particularly those who are in a similar situation to themselves. This social interaction and peer support was viewed as crucial to the success of the programme.

“Could a support network be established to run alongside the programme, to tell their experiences or journey. Could this be a webchat / FAQ, etc? Stories are powerful.” (North Cumbria LA)

“Meet someone who is about to have surgery so you have a new friend” (TIN Arts)

- To support sustainability of behavioural changes and prevent relapse into old habits, it was felt strongly that support should not just cease or stop when the patient has had their operation. The importance of follow-up appointments was thus highlighted.

“Would need consistent support long term with someone specifically allocated to their case” (Healthwatch Cumbria)

“There cannot be an abrupt end to this, some level of continued support is required” (North Cumbria LA)

- Involving family members and carers was viewed as crucial to the success of the programme.

“Each person in partnership with carers should be allowed to choose the pathway that is best for them.” (PPI North Tyneside)

- Assessment of post-operative needs to establish how severe care needs are ahead of surgery and ensure these can be accommodated for on release.

The above points were also important for those with a learning disability, with individuals stressing the importance of:

- Face-to-face contact as opposed to telephone / online communication.
- Tailored communication from doctors / nurses with no medical jargon.
- Written easy-to-read information that they can refer to and being able to take someone with them to appointments to help them to understand the information.
- Having a consistent point of contact who has experience of learning disabilities and who they can build a relationship with and does not make judgements about their health.
- Not just being told what to do but supported to make changes. With regards to this, individuals expressed the anxiety they face when trying / doing something new.

5.7 Queries about Waiting Well

A plethora of questions about the programme were posed by participants to the ICB. A summary of these is included here:

- How will the programme be rolled out?
 - Will there be a pilot?
 - Will each place within the ICS be treated equally?
 - How will it be staffed?
- What is the role of the central hub?
 - Where it will be located? ICS / place level?
 - Will patients be required to travel there?

- What is the pathway / referral route?
 - Who is eligible? Who gets priority?
 - How are patients invited? GPs?
 - What operations are under the scheme?

- What support will be on offer?
 - What are the timescales of involvement?
 - Will post-surgery support be offered / at the same level?
 - Will there be any work with established community groups?

- How will the programme be promoted?

- What are the success indicators?
 - Will social impact be monitored as social return on investment?

- Will the ICB share best practice?

DRAFT

6 Conclusion

The report presents the key findings from the engagement with key stakeholders and members of the public undertaken over the months Dec 22 – March 23 to explore perception about the new Waiting Well programme.

Overall, stakeholders and members of the public spoke positively about the programme being introduced across the NENC to support patients awaiting non-urgent surgery.

Perceived benefits that participation in the programme would bring to patients included improved physical and mental health, increased readiness for surgery, opportunity for patients to socialise / meet people in a similar situation to themselves, and improved surgical outcomes with reduced hospital stays. Furthermore, external benefits to the wider healthcare system related to reducing pressure with less surgical cancellations, reduced waiting lists, decreased bed-blocking and behaviour change / health prevention.

Some members of the public did however have negative views of the programme. These primarily related to concerns about the pressure the programme adds to an 'already stretched' healthcare system, as well as its value and motive / purpose.

The insight provides an overview of the challenges that stakeholders and members of the public perceive the programme will face in its deployment which are important for the ICB to consider. These relate to issues around patient engagement and compliance, the eligibility criteria, the support provided through the programme, communications / promotion, internal processes, and challenges of working across different trusts / areas (i.e., consistency and evaluation).

Consideration was also felt to be essential of the personal barriers that individuals will face to participation i.e., age, accessibility, cost, attitude and perceptions, time, and caring responsibilities.

In an ideal world, stakeholders and members of the public would want the programme to provide personalised support tailored to the health and wider needs of patients. Furthermore, they would want regular support / contact from a named contact / support mentor, support / links with existing programmes and VCSOs, and options for post-intervention / operation follow-up appointments / support.

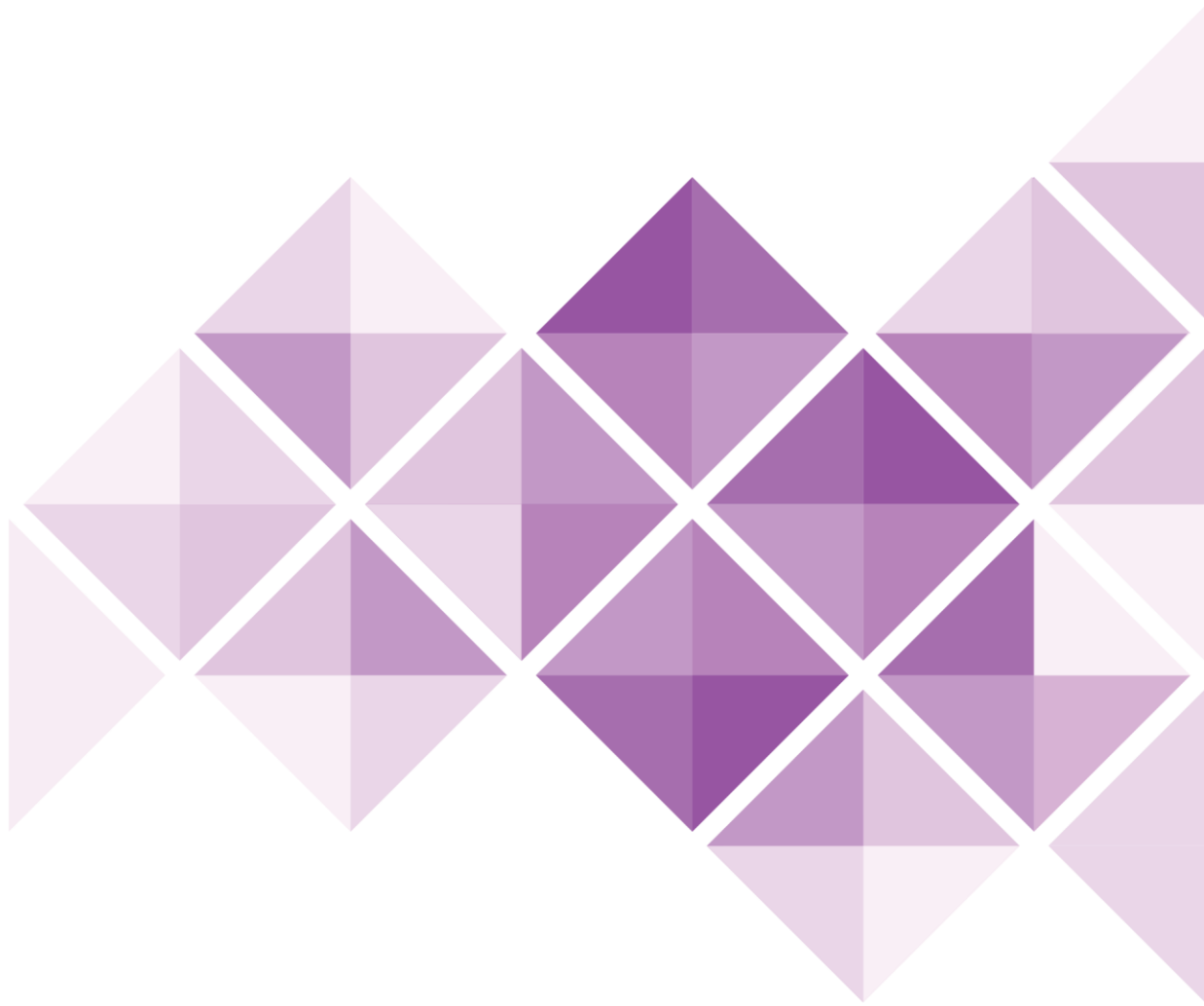
The findings from this insight report will be shared and considered by the ICB project team when planning the rollout of the Waiting Well programme across the NENC.

7 Appendix

7.1 Demographics of focus group participants

	Focus group participants (N=193)	
	No.	%
Age		
16 to 17	2	1%
18 to 24	9	5%
25 to 34	13	7%
35 to 44	24	12%
45 to 54	20	10%
55 to 64	23	12%
65 +	49	25%
Prefer not to say	53	27%
Sex	No.	%
Male	52	27%
Female	87	45%
Prefer not to say	54	28%
Gender identity match sex registered at birth	No.	%
Yes	123	64%
No	2	1%
Prefer not to say	68	35%
Marital status	No.	%
Single	35	18%
Cohabiting	11	6%
Married	45	23%
In a civil partnership	1	1%
Separated	2	1%
Divorced or civil partnership dissolved	7	4%
Widowed or surviving partner from a civil partnership	12	6%
Prefer not to say	80	41%
Physical / mental health conditions or illnesses lasting or expected to last 12 months or more	No.	%
Yes	92	48%
No	28	15%
Prefer not to say	73	38%
Physical / mental health conditions or illnesses	No.	%
Long standing illness or health condition	51	26%
Physical impairment or mobility issue	18	9%

Sensory loss	20	10%
Mental health conditions or illnesses	24	12%
Developmental conditions	21	11%
Genetic conditions	3	2%
Other	4	2%
Currently pregnant or have been in the last year	No.	%
Yes	1	1%
No / Not applicable	103	53%
Prefer not to say	89	46%
Caring responsibilities		
Yes	42	22%
No	57	30%
Prefer not to say	94	49%
Ethnic group or background	No.	%
White	121	63%
Mixed or Multiple ethnic groups	3	2%
Asian or Asian British	1	1%
Prefer not to say	68	35%
Sexual orientation	No.	%
Heterosexual or straight	89	46%
Bisexual	2	1%
Gay or lesbian	3	2%
Other	1	1%
Prefer not to say	98	51%
Religion	No.	%
Buddhist	1	1%
Christian	54	28%
No religion	39	20%
Prefer not to say	99	51%
Postcode	No.	%
TS1 / TS3 / TS4 / TS6 / TS7 / TS8 / TS25 / TS26	41	21%
DL3 / DL13	4	2%
NE3 / NE8 / NE9 / NE15 / NE16 / NE19 / NE20 / NE21 / NE23 / NE24 / NE26 / NE28 / NE30 / NE31 / NE32 / NE33 / NE34 / NE35 / NE45 / NE46 / NE63 / NE71	45	23%
DH4 / DH5 / DH7	3	2%
SR3 / SR4 / SR6 / SR7 / SR8	5	3%
CA1 / CA2 / CA3 / CA4 / CA8	10	5%
Prefer not to say	85	44%



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