



**Integrated  
Care System**  
Nottingham & Nottinghamshire

# **Integrated Care Partnership: Insight Report**

**October 2024**

**Nottingham and Nottinghamshire  
Integrated Care System**

## Table of Contents

1	Executive Summary .....	2
1.1	Introduction .....	2
1.2	Key Findings .....	2
2	Introduction .....	5
3	What's important to citizens? .....	7
3.1	Introduction .....	7
3.2	Top ten issues.....	7
3.3	Perceptions of the NHS.....	8
3.4	Perceptions of social care .....	9
3.5	Civil unrest and community cohesion in Nottingham and Nottinghamshire.....	9
3.6	Maternity services at Nottingham University Hospitals Trust .....	10
3.7	Mental health services in Nottingham and Nottinghamshire .....	10
3.8	Insights from Healthwatch Nottingham and Nottinghamshire .....	12
4	Working with people and communities across our Places .....	14
4.1	Introduction .....	14
4.2	Bassetlaw PBP .....	14
4.3	Mid-Nottinghamshire PBP.....	17
4.4	Nottingham City PBP .....	18
4.5	South Nottinghamshire PBP.....	19
5	Timely access and early diagnosis of cancer .....	20
5.1	Introduction .....	20
5.2	Cancer incidence and mortality .....	20
5.3	Risk factors .....	20
5.4	Diagnosis .....	21
5.5	Treatment and care – what's important to citizens?.....	23
5.6	Impact on patients and survivors.....	24
5.7	Impact on carers .....	27
6	Understanding the needs of children, young people and families .....	29
6.1	Introduction .....	29
6.2	Small Steps Big Changes – Community and Coproduction .....	29
6.3	Children and Young People with Special Educational Needs and Disabilities (SEND) in Nottinghamshire .....	33
6.4	Nottingham County Council Shadow Event 2024 .....	34
7	Next steps .....	36

# 1 Executive Summary

## 1.1 Introduction

In line with guidance from the Department of Health and Social Care<sup>1</sup> (DHSC), in March 2024, the Integrated Care Partnership approved the refreshed Nottingham and Nottinghamshire Integrated Care Strategy<sup>2</sup>.

To support the implementation of the Strategy and maximise its impact, work has continued across the system to continuously listen to our population to obtain key insights and intelligence from people and communities across Nottingham and Nottinghamshire. This report provides the Partnership with a summary of the activities and findings of work from across the Integrated Care System (ICS).

## 1.2 Key Findings

### 1.2.1 What's important to citizens?

#### National insights

- Hospitals and healthcare have risen from fourth to first place in public concern, increasing from 25% in August 2023 to 35% in May 2024, surpassing inflation, the economy, and environmental issues.
- The Cost of Living continues to be a significant concern for citizens.
- 50% of the British public rate the quality of healthcare that they and their family have access to as either “good” or “very good”, and only 19% rated as “poor” or “very poor”.
- 53% of people think that mental health is one of the biggest health problems facing the country. This figure has increased by 10% since the prior recording in 2022.
- There are concerns about social care: around half of people (48%) aren't confident that a friend or family member would receive a good standard of care in a care home, however, overall around the same amount (46%) believed that they would.

#### Local insights

- The civil unrest which took place in August 2024 across the England has resulted in joint stakeholder meetings being arranged in Nottingham and Nottinghamshire to learn more around what needs to be done alleviate the fear of our underserved communities:
  1. Community leaders felt strongly that more specialist intervention needs to be funded to involve young people influenced by the unrest and to work with perpetrators and victims.
  2. There is concern that schools are under supported and need advice from the government on what to do for students facing hate crime and challenging those who hold harmful and Islamophobic views.
  3. There was a consensus that the unrest was driven by islamophobia and Muslim people are not feeling safe in their community, but there was fear also felt by people with learning disabilities and members of the LGBTQ+ communities.
  4. Citizens wanted to know what is in place for people at risk of radicalisation.
  5. The police were keen to understand more about why people are hesitant to report hate crime.
- Donna Ockendon's review of maternity care at Queens Medical Centre and Nottingham City Hospital continues. Within the maternity improvement programme, NUH have a number of specific projects, including culture and engagement, to address feedback from women and families.

---

<sup>1</sup> [Guidance on the preparation of integrated care strategies - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/guidance/guidance-on-the-preparation-of-integrated-care-strategies)

<sup>2</sup> [Integrated Care Strategy 2023-27 \(healthandcarenotts.co.uk\)](https://www.healthandcarenotts.co.uk/integrated-care-strategy-2023-27)

- Healthwatch Nottingham and Nottinghamshire (HWNN) gathered the following insights from people and communities and have worked with local services to make improvements:
  - a) Diabetics using insulin to manage their diabetes found that it was distressing being an in-patient in hospital. Patients did not feel they were in control of managing their own insulin usage and instead, were dependant on nursing staff to provide injections.
  - b) A research project that aimed to understand people's experiences of accessing and using Specialist and Community Mental Health Services in Nottingham & Nottinghamshire highlighted gaps in various areas of care between how service providers think they are doing and how the service users perceive or experience it.
  - c) A member of the public reported stress associated with the carers assessment.
  - d) HWNN received communication concerning a group of older people with vision loss who reside in a rural part of Nottinghamshire. HWNN visited and heard directly from a group of older people with vision loss who reside in a rural part of Nottinghamshire on some of the challenges they were facing in accessing appointments in their local GPs and the added stress of vision loss and digital exclusion which made booking appointments online or on the phone difficult.

## **1.2.2 Timely access and early diagnosis of cancer**

### **Local insights**

- There was a range of experiences regarding the clarity of explanations when individuals were referred for diagnostic tests: 63% felt completely informed, while 25% understood to some extent, and 12% did not receive an explanation they could understand.
- Many felt adequately informed about their upcoming tests: 91% felt received all necessary information.
- The waiting period for test results varied. 79% considered the waiting time appropriate, while 15% found it slightly too long, and 5% felt it was significantly too long.
- The majority of respondents expressed that they had experienced a high level of privacy when receiving their test results (96%).
- 80% stated that the diagnosis information was explained in a way they could understand, while 19% felt it was only to some extent, and 1% did not find the explanation understandable.
- 84% completely agreed that their cancer treatment options were explained to them in an understandable manner.

### **National insights**

- Evidence suggests that fear of change in one's body image begins before surgery or other treatments, and express concern about these changes will have a negative impact on patients' quality of life and may result in depression, anxiety and overall psychological distress
- There is a disruptive impact of cancer on the social networks of some patients for reasons related to their ability to engage with social activities, and for not re-engaging with people with whom they lost connections while accessing the treatment.
- Cancer may cause substantial psychological distress as well as mental health disorders conditions. The most common mental health disorders include major depressive disorder, generalised anxiety disorder, adjustment disorder, panic disorder and post-traumatic stress disorder
- One of the implications facing cancer patients is the financial hardship that results from being diagnosed and living with cancer.

- Carers of people with cancer experience negative financial impact and negative impacts on both physical and mental wellbeing.

### **1.2.3 Understanding the needs of children, young people and families**

#### **Local insights**

- Small Steps Big Changes' (SSBC) focus on diversity, for example by consulting with fathers or including Parent Champions from different ethnic backgrounds, helps create services that are inclusive, culturally sensitive and accessible.
- A key learning of the SSBC programme is that service user experiences should help frame care delivery models. This insight helped professionals adapt their language, approaches and service offer to better align with community needs.
- SSBC coproduction approach created collaboration between families and service providers. Service offer becomes more aligned with the needs of the community by empowering and involving parents in service design. The lived experiences of parents provide insights that enhance the relevance and accessibility of services, making them more effective and tailored to local needs
- Young people with Special Educational Needs and Disabilities informed us that the outcome that would be most important to them in their life would be education that can meet their needs, independence, feeling supported, opportunities, having nice things/ good life and job/employment.
- Through the Nottinghamshire County Council Shadow event, 370 children and young felt that mental and physical health, school, waiting times, cost of living, vaping, crime and healthy lifestyles were worrying them the most.

## 2 Introduction

In line with guidance from the Department of Health and Social Care<sup>3</sup> (DHSC), in March 2024, the Integrated Care Partnership approved the refreshed Nottingham and Nottinghamshire Integrated Care Strategy<sup>4</sup>.

As part of the workplan of the Integrated Care Partnership (ICP), it was agreed that an annual Insight Report would be produced to provide evidence and insight to the Partnership. This report is intended to support the ambition of the Integrated Care Partnership to act as the “guiding mind” of the system and enable it to consider how we continue to meet the needs of local people and communities.

The ICB Engagement Team produced the first Citizen Insight Report<sup>5</sup>, which was presented to the ICP on 6 October 2023. The report included:

1. Census data, to describe what our population looks like, including a summary of population changes.
2. A summary of all recent activity involving working with people and communities across our system.
3. Deep dive on key topics:
  - ICS Partners Assembly (15<sup>th</sup> May 2023)
  - Frailty (VCSE Alliance led write up)
  - Race health inequalities (maternity and mental health access)
  - The impact of the cost of living crisis on people and communities

The Chair and ICP members welcomed the rich collection of information contained within the report, noting the need to connect back to the feedback in the actions the system needed to take.

Regarding future iterations of the report, several suggestions were put forward including:

- Focusing the report on findings of strategic importance for future policy development
- Future reports to be broadened to make it more of a local system report, as opposed to a mainly NHS-focused report.
- For the ‘children’s voice’ to be heard.
- To include Place-Based Partnership-specific information.

The feedback from the ICP at that time has been considered in the development of this report.

To support the ongoing delivery and implementation of the Strategy, and as part of their business-as-usual activities, all system partners have continued to listen to our population and this work is shared and coordinated through the ICS’s Engagement Practitioners Forum. This report summarises the insights and intelligence which has been gathered across the system and offers a synthesis of its combined findings, set against 7 (in bold) of the 14 priorities of the Integrated Care Strategy:

- 1. We will support babies, children and young people to have the best start in life with their health, development, education and preparation for adulthood (sections 4.3.3 and 6).**
- 2. We will support babies, children, young people and adults with the greatest needs (the 20% most deprived, those in vulnerable or inclusion groups and those experiencing severe multiple disadvantage (sections 4.4 and 6).**

---

<sup>3</sup> [Guidance on the preparation of integrated care strategies - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/guidance/guidance-on-the-preparation-of-integrated-care-strategies)

<sup>4</sup> [Integrated Care Strategy 2023-27 \(healthandcarenotts.co.uk\)](https://www.healthandcarenotts.co.uk/integrated-care-strategy-2023-27)

<sup>5</sup> [Integrated Care Partnership insight report - English \(healthandcarenotts.co.uk\)](https://www.healthandcarenotts.co.uk/integrated-care-partnership-insight-report-english)

3. **We will focus on health, wellbeing and education for children and young people to help improve employability and life chances for future generations (sections 4.3.1 and 6).**
4. **We will support frail older people with underlying conditions to maintain their independence and health (sections 3.7, 3.8.4 and 5).**
5. **We will focus and invest in prevent priorities, like tobacco, alcohol, healthy weight, oral health and mental health, to support independence, prevent illness, poor birth outcomes and premature death from heart attack/stroke/cancer/chronic obstructive pulmonary disease, asthma and suicide (sections 4 and 5).**
6. **We will “Make Every Contact Count” (MECC) for traditional areas of health, for example mental health and healthy lifestyle and incorporate signposting to other services which support people to improve their health and wellbeing (sections 3.3, 3.7, 4.2 and 4.4).**
7. **We will adopt a consistent system-wide approach to quality and continuous service improvement sections 3 and 4).**
8. We will establish a single health and care recruitment hub.
9. We will bring our collective data, intelligence and insight together.
10. We will align our Better Care Fund programme to our strategic priorities.
11. We will make it easier for our staff to work across the system.
12. Use our collective funding and influence to support our local communities and encourage people from the local area to consider jobs in our organisations.
13. We will add social value as major institutions in our area.
14. Work together to reduce our impact on the environment and deliver sustainable health and care services.

This report provides the Partnership with a summary of the activities and findings of work from across the Integrated Care System. It includes in particular information about what is important to citizens and deep dives on timely access and early diagnosis of cancer and experiences of children, young people and families.

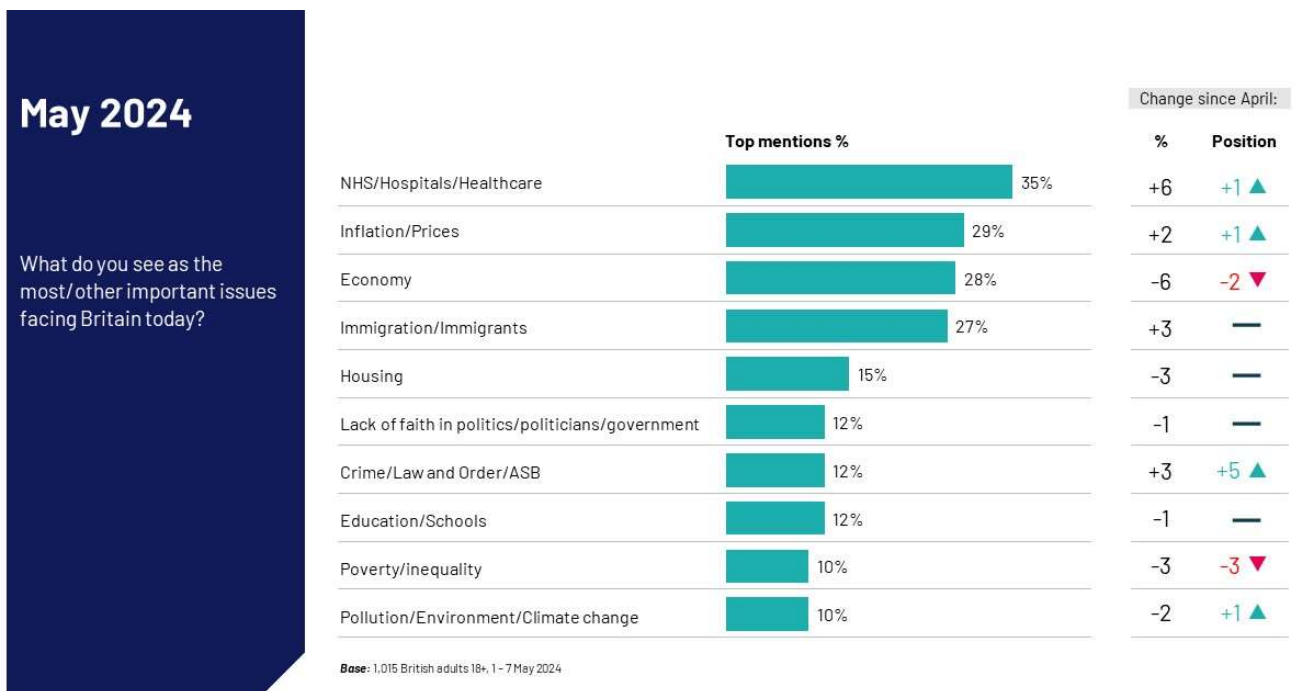
### 3 What's important to citizens?

#### 3.1 Introduction

The following section provides an insight into public opinions on the most important issues currently, according to national research. Using these findings, we can infer the issues important to the citizens of Nottingham and Nottinghamshire. However, it is important to remember this inference and not assume all findings are like for like for our population.

#### 3.2 Top ten issues

The top ten most important issues according to those polled in a recent Ipsos Mori survey<sup>6</sup> can be found in Figure 1. Hospitals/Healthcare has risen from being the fourth in this ranking to the top position, rising from 25% in August 2023, to 35% in May of this year. This means it has now taken priority over the following topics in the public's perspective: Inflation/Prices, Economy, and Pollution/Environmental/Climate Change.



© Ipsos | Issues Index | May 2024 | Version 1 | Public

2



Figure 1. Top ten most important issues to citizens (Ipsos, 2024)

A recent ONS study<sup>7</sup> did not find much change in their answers over a similar time period. Based on a survey conducted between 22 May and 2 June 2024, Cost of Living (87%) continued to surpass issues around the NHS (85%). This highlights a very slight decrease compared to figures releases in the second half of last year. However, the gap separating the NHS from being the most pressing issue has shrunk over this period.

Overall, this research highlights the growing focus on the NHS and healthcare as a key issue and cause for concern from the public, compared to other factors.

<sup>6</sup> <https://www.ipsos.com/en-uk/nhs-economy-inflation-and-immigration-set-to-be-biggest-election-issues>

<sup>7</sup> [Public opinions and social trends, Great Britain - Office for National Statistics](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandcare/publicopinionsandsocialtrends/greatbritain)



### 3.3 Perceptions of the NHS

The NHS faces ongoing challenges, including financial pressures, extended waiting lists for planned care, staffing shortages, and increased demand.

Media and political attention continue to draw attention and add to the public's perception of the NHS. The findings from the most recent British Social Attitudes (BSA) survey<sup>8</sup> found the lowest levels of satisfaction with the NHS since their records began in 1983. Satisfaction with NHS and social care was 24% and 13% respectively. The survey included 3,374 people, of which just under one fifth (18%) were asked for the reasons behind their dissatisfaction, they gave the following answers:

- Among the most significant issues, taking too long to get a GP or hospital appointment (71%), a lack of NHS staff (54%), and not enough government expenditure in the NHS (47%) were clear leaders.
- There was almost a third of respondents who mentioned that they thought money is wasted in the NHS (32%).
- Other notable responses included government reforms of the NHS (19%), the quality of NHS care (16%), and not being able to access some services unavailable under NHS (14%) as reasons for their dissatisfaction.
- Attitudes and behaviour of staff, stories in the media, and other responses were mentioned by 9%, 6%, and 2% of the respondents respectively.

Despite the overall concern for the NHS, the study found that there is still widespread support for its principles. Almost half (48%) of the 1,206 respondents to another question added that they would support paying more tax if it would contribute to increasing government spending on the NHS. Those in top earning brackets were even more likely to support this idea, with 62% of those in the highest income quartile agreeing.

In the 2024 Ipsos Health Service Report, it was reported that 50% of the British public surveyed rate the quality of healthcare that they and their family have access to as either “good” or “very good”, and only 19% rated as “poor” or “very poor”. However, marginally more people expect their healthcare to decline over the coming years (27%) compared to those who believe it will improve (26%).

In the UK, 53% of people said that mental health was one of the biggest health problems facing the country, this figure is up by 10% since the prior recording in 2022. However, the impact of the ongoing COVID-19 pandemic at the time is likely to have influenced this. The most recent pre-pandemic figure from Ipsos is from 2018, where 50% of people reported mental health to be the biggest problem, so there has still been an increase during this period.

When asked if the healthcare system in their country is overstretched, 82% of UK participants agreed with the statement. 75% also agreed that waiting times to get a GP appointment were too long.

However, the UK ranked well on both the availability of information on looking after health and patients being able to find information about healthcare services when they are needed, with 67% and 64% respectively agreeing to the statements.

---

<sup>8</sup> [Public Satisfaction With The NHS And Social Care In 2023 | BSA | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/publications/public-satisfaction-with-the-nhs-and-social-care-in-2023)

### **3.4 Perceptions of social care**

A recent study from Ipsos<sup>9</sup> shows that the British public are concerned about the state of social care. More than three quarters (76%) of those polled said there are too few care workers in Britain relative to the need for social care, with less than one in 10 (6%) believing there is the correct amount.

The majority of those polled (63%) feel care workers are paid too little. This group of workers ranked highest for being underpaid, ahead of nurses (57%), ambulance workers (53%), NHS Healthcare Assistants (52%), and social workers (35%).

Around half of people (48%) aren't confident that a friend or family member would receive a good standard of care in a care home, however, overall around the same amount (46%) believed that they would. As respondents aged, they became less confident in the quality of care that would be received. Those in the 18-34 age group were split approximately six to four in confidence (58% Very/fairly confident to 37% Not that/at all confident), while the perceptions of those in the 55-75 years age category were equally weighted in the opposite way (38% Very/fairly confident to 56% Not that/at all confident)

However, according to research from The Health Foundation<sup>10</sup>, views towards the general standard of social care services improved between May 2023 and May 2024, despite the overall perception remaining negative. Half of the public (50%) think the standard of social care services declined over the year, down by 9% compared to the year prior. Instead, they are more likely to think the standards have remained consistent (up from 22% in May 2023 to 27% in May 2024). Three quarters of people (73%) believe that the government should focus on improving pay and conditions for social care workers to incentivise more people from the country to join the profession.

### **3.5 Civil unrest and community cohesion in Nottingham and Nottinghamshire**

On 29 July 2024 three young girls were fatally stabbed at a dance class in Southport, UK. The incident also left two adults and eight other children injured. Hate-fuelled disorder and riots followed in towns and cities across the UK. Two protests took place in Nottingham, the largest of which was attended by 400 protesters and 600 counter protesters. A reduction in community cohesion in our area is of concern due to the knock-on impact on trust in public services and willingness to engage with public authorities. All partners within the ICP will want to support a return to positive community relations both as part of their "anchor institution" roles but also to support the reduction in inequity of access to services offered.

A Stakeholder Meeting jointly hosted by Nottingham City Council, Nottinghamshire Police and Police and Crime Commissioner was held on 22<sup>nd</sup> August at Nottingham Central Library. The purpose of the meeting was to hear directly from communities following the recent unrest in Nottingham. Both community leaders and citizens were in attendance. The Chief Constable for Nottinghamshire, Police and Crime Commissioner and leader of Nottingham City Council gave opening statements. A number of themes emerged from that conversation:

#### **3.5.1 A call for more specialist intervention in schools**

Community leaders felt strongly that more specialist intervention needs to be funded to involve young people influenced by the unrest and to work with perpetrators and victims. There is concern that schools are under supported and need advice from the government on what to do for students facing hate crime and challenging those who hold harmful and Islamophobic views.

---

<sup>9</sup> [3 in 4 Britons say there's too few care workers in Britain relative to the need | Ipsos](#)

<sup>10</sup> [Public perceptions of health and social care: what the new government should know - The Health Foundation](#)

### **3.5.2 Fear in communities**

There was a consensus that the unrest was driven by islamophobia and Muslim people are not feeling safe in their community. The fear was also felt by people with learning disabilities who take note of social media where misinformation was frequently being circulated. The PRIDE flag had been defaced recently which caused concern in the LGBTQ+ community, Temples and domestic abuse organisations closed for a week to protect staff and beneficiaries. During the unrest people from people from Black and Asian communities also received abuse regardless of religion.

### **3.5.3 Working with the police**

The police were thanked and praised on several occasions for the sensitive handling and management of police resource throughout the period of unrest. There was a preference for the police and councillors to more frequently attend meetings held by groups and organisations, to share concerns and task police with issues rather than having to attend new meetings. People wanted to know what is in place for people at risk of radicalisation. The police were keen to understand more about why people are hesitant to report hate crime. It was also made clear from the Police and Crime Commissioner that Nottingham experienced disorder but not riots. The police and Nottingham City Council would like to continue conversations with citizens and community leaders taking a coproduction approach.

### **3.6 Maternity services at Nottingham University Hospitals Trust**

Maternity services in Nottingham are currently under scrutiny as Donna Ockendon continues the review of maternity care at Queens Medical Centre and Nottingham City Hospital. As of 13<sup>th</sup> September 2024, contact has been made with 2,979 families, and 789 members of staff and engagement continues. There is a commitment from Nottingham University Hospitals (NUH) to improve maternity services. This is indicated in the last independent Care Quality Commission report September 2023, where Nottingham City Hospital and Queens Medical Centre both improved the score from inadequate to requires improvement.

Within the maternity improvement programme, NUH have a number of specific projects, including culture and engagement, to address feedback from women and families received via the Independent Medical Review.

The NUH Inclusion Project focussed on underrepresented communities to increase engagement and reduce health inequalities. June 2024 saw the first community engagement session take place with the Muslim Women's Network taking part in discussions around experiences of giving birth and where services can be improved. The Mojatu Foundation and Heya will take part in the next discussion in September, with a future session planned with the Nottingham Refugee Forum.

Positive responses have been received about the Ante Natal classes offered to African Caribbean and Urdu speaking women. Reverend Clive Foster Senior Minister is supporting engagement directly with Black African and Caribbean women across local communities and churches. Work to improve engagement with the Roma community is being undertaken to feed into a staff workshop to discuss the Roma Community experiences and how to better engage.

### **3.7 Mental health services in Nottingham and Nottinghamshire**

In June 2023, Barnaby Webber, 19, Grace O'Malley-Kumar, 19, and Ian Coates, 65 were fatally stabbed with three others severely injured by an individual under the care of mental health services in Nottingham and Nottinghamshire. This incident led to a review of mental health services in

Nottingham and Nottinghamshire. In January 2024 a report of the special review into mental healthcare was published by the Care Quality Commission (CQC).

From January to March 2024 a number of reports about mental health services provided by Nottinghamshire Healthcare Foundation Trust (NHFT) were published by the CQC. The first reports addressed: Wards for Older People with Mental Health Problems, Rampton Hospital, Psychiatric Intensive Care Wards and Acute Wards for Adults of Working Age. The reports fed into a rapid review 'Section 48' report ordered by the Secretary of State for Health and Social Care into these concerns.

The 'Section 48' rapid review aimed to assess improvements at Rampton Hospital, review community safety and crisis services and review the care and treatment of Valdo Calocane. A number of key findings were highlighted within the report:

### **Risk assessment and record keeping**

- Inconsistencies in risk assessment processes included lack of key information and risks related to consent and up to date record keeping.

### **Care planning and engagement**

- The rapid review found that there were timely referrals into mental health services and patients were allocated to care coordinators promptly.
- Care plans were in line with national guidance however improvements could have been made to make the plans more holistic and person-centred.
- There were issues with engagement of patient with the services.
- The CQC identified concerns over the out-of-area beds.
- There was a lack of GP involvement in discharge planning.

### **Medicines management and optimisation**

- The decisions and wishes of Valdo Calocane in regards to his medicine and treatment preferences were not always balanced with other information.
- Issues were found with medicine monitoring whilst patients were in the community.
- There was no real change to Valdo Calocane's treatment despite evidence that he was still symptomatic.

### **Discharge planning**

- The review of the 10 benchmarking cases found that most discharges from NHFT were handled well.
- There were problems around communication of discharge decisions and difficulties in transitions of care between inpatient and community services.
- NICE guidelines recommend the use of a depot antipsychotic medicine and/or a community treatment order for those who do not comply with taking oral medicines but there was no evidence of a discussion of this in Valdo Calocane's case.
- Discharge planning was not robust and there was a 'lack of clarity of thinking' regarding discharge decisions.

### **3.8 Insights from Healthwatch Nottingham and Nottinghamshire**

Healthwatch Nottingham and Nottinghamshire (HWNN) is the local independent patient and public champion. They hold local health and care leaders to account for providing excellent care by making sure they communicate and engage with local people, clearly and meaningfully, and that they are transparent in their decision making.

Between April 2023 and March 2024<sup>11</sup>, the following insights were gathered and reported locally.

#### **3.8.1 Empowering patients to manage their own insulin in hospital**

HWNN participated in an information session around diabetes, organised for local people to better understand the disease. The event was aimed both at those living with diabetes and those interested in understanding the condition better. Diabetics using insulin to manage their diabetes found that it was distressing being an in-patient in hospital. Patients did not feel they were in control of managing their own insulin usage and instead, were dependant on nursing staff to provide injections. This made people feel nervous and less in control of something they normally manage every day.

This was raised with NUH, explaining how the situation feels to patients living with diabetes. This conversation prompted high level discussions amongst nursing staff at NUH, with an undertaking to put in place a system to respect patient choice. NUH has now settled on a policy whereby patients on a ward can request that they manage their own insulin usage, and this will be respected unless there are overwhelming clinical reasons not to take this option.

The difference this has made to our health and care system:

- Training is being rolled out to all nursing staff to help them understand the options and reassure them around any worries they may have in letting a patient take control of their own medication.
- Planning has involved the hospital pharmacy department to cope with the prescribing side of insulin availability.
- Active steps will be taken to let patients know that this is an option they have, and that they can choose not to take it up if their disease makes it difficult for them.
- This discussion has also raised the more general question of patient agency and capacity whilst being treated in hospital.

#### **3.8.2 Specialised Community Mental Health Services**

In 2022/23, NHT was undertaking a transformation programme of the delivery of mental health services across adult pathways. The ethos of the transformation programme was 'no wrong door', aiming to deliver integrated, personalised, place-based, and well-coordinated care. This came on the back of the NHS Long Term Plan (2019)<sup>12</sup>, alongside Nottingham and Nottinghamshire ICS's Integrated Mental Health and Social Care Strategy (2019)<sup>13</sup>. Concerns had also been raised previously by the Care Quality Commission (CQC) about some of the Trust's services<sup>14</sup>.

In 2023, the NHT commissioned HWNN to undertake a research project that aimed to understand people's experiences of accessing and using Specialist and Community Mental Health Services in

---

<sup>11</sup> [PowerPoint Presentation \(hwnn.co.uk\)](https://www.hwnn.co.uk)

<sup>12</sup> [The NHS Long Term Plan – a summary](#)

<sup>13</sup> [ICS Mental Health and Social Care Strategy FINAL.PDF \(strategyunitwm.nhs.uk\)](#)

<sup>14</sup> [Trust - RHA Nottinghamshire Healthcare NHS Foundation Trust \(25/11/2022\) INS2-12325588311 \(cqc.org.uk\)](#)

Nottingham & Nottinghamshire. They heard from 367 people via interviews, an online survey and through focus groups.

The report<sup>15</sup> highlighted gaps in various areas of care between how service providers think they are doing and how the service users perceive or experience it. HWNN have had and continue to have ongoing dialogue with the Trust and with other relevant partners on the implementation of our recommendations, most of which have since been repeated by the CQC.

The findings and the recommendations from the report have had a significant impact and generated much attention and discussion amongst stakeholders. The report has been cited and used as supplementary evidence by the CQC as part of its latest special review of mental health services at Notts Healthcare NHS Foundation Trust, which was triggered by (among other things) the killing of Barnaby, Grace and Ian in June 2023

### **3.8.3 Improving the experiences of carers and their families**

A member of the public reported stress associated with the carers assessment provided by Nottinghamshire County Council (NCC). HWNN contacted the service lead who provided information regarding Adult Carers Assessments. They informed HWNN that they had recently undertaken an engagement exercise with people accessing the service and the feedback confirmed a need for improvement. NCC said that the issue HWNN raised was not in line with 'our aim to provide excellent support to carers' and thus improving the experience of carers is now one of the department's top 6 priorities. The provider informed HWNN that they have co-designed new standards of practice with people and carers who draw on support, which have been shared with all teams and include communicating with compassion and empathy.

### **3.8.4 Getting services to involve the public to adjust services to meet the needs of different groups**

HWNN received communication concerning a group of older people with vision loss who reside in a rural part of Nottinghamshire. HWNN visited and heard directly from group members on some of the challenges they were facing in accessing appointments in their local GPs and the added stress of vision loss and digital exclusion which made booking appointments online or on the phone difficult. They convened an urgent meeting with key leads both from the ICB and from primary care to put mitigative mechanisms in place to improve care and access for this vulnerable group of patients. One of the key actions was to facilitate regular touch points between the group and service leads

#### **Points for discussion**

- What factors could help restore or maintain trust in local health and social care services?
- What role can the ICS have in healing divisions and developing long-term social cohesion?
- How can local communities, especially those most affected by the unrest, have a greater voice in the ICS?
- How can the ICS support NHT to deliver their Integrated Improvement Plan?
- How will the ICS ensure an ongoing dialogue with people and communities regarding their mental health and services that support them?

<sup>15</sup> [HWNN-SMI-Report-Specialist-Mental-Health-Services.pdf](#)

## 4 Working with people and communities across our Places

### 4.1 Introduction

This section provides an overview of some of the key programmes of engagement and involvement work undertaken across our four Place-Based Partnerships (PBPs). The PBPs are partnerships of the NHS, Local Authorities, the Voluntary Sector and others and offer the most vibrant examples of how working closely with our people and communities can support the rapid transformation and delivery of responsive health and care service.

### 4.2 Bassetlaw PBP

#### 4.2.1 Suicide prevention in rural communities

Bassetlaw Focus on Farmers is a collaborative initiative aimed at providing joined up suicide prevention, mental health, and cancer support in the Bassetlaw rural community (which includes rural residents, families of rural residents, farmers and equestrians). The project, led by the Bassetlaw Place-Based Partnership, Bassetlaw Action Centre, and Retford and Villages Primary Care Network, and co-produced with the agricultural and rural community, aims to tackle the issues that these residents face on a daily basis.

During the initial planning stages of the project in 2023, over 70 farmers, farming families, and rural residents were engaged with, to understand what barriers to accessing health and care they experienced, what mattered to them most, what information they felt they needed and the best formats for sharing this. The Project Team then worked with small groups of local people from the rural community to co-produce the design of the project including the name, logo, posters and an online information page. Since then, over 100 rural residents, farmers and young farmers have been engaged through an open evening and various events and talks.

In addition to the core co-production with the rural community, a variety of local Voluntary, Community and Social Enterprise (VCSE) organisations and health partners have been involved: Aurora Wellbeing for cancer services; mental health and suicide prevention charity, In Sam's Name; Nottinghamshire Police; and several others who bring a wealth of specialised support.

#### **Impact of Suicide on the Farming Community**

- Between 6,000 and 7,000 people die by suicide each year in the UK.
- In England, one person dies by suicide approximately every two hours.
- Suicide is the leading cause of death among people under 35 years old.
- In males under 50, suicide remains the leading cause of death, with rates particularly high among young males aged 15-19—the highest in over 20 years.
- Females in the same age group are also seeing their highest rates in over 40 years.
- In 2020, there were 84 deaths by suicide in the Agricultural and Related Trades in England (79 males and 5 females), with more than one person a week working in agriculture dying by suicide, according to the ONS.

This project has been co-produced with local people to ensure that the project is tailored to the unique needs of the farming community, recognising the importance of making healthcare services accessible and trusted.

As a result of the initial engagement within the agricultural community, the following top priorities emerged:

- Mental health support

- Community support
- Physical health
- Cancer screening and support
- Firearms – barrier to accessing mental health support

The engagement has aimed to dispel some of the myths and misconceptions about accessing mental health services, particularly concerns around confidentiality. This is still a key topic and an ongoing complex issue, which the team are working on alongside Nottinghamshire Police, with the concerns being around gun licences, mental health, how the two are interlinked and how they can be a barrier to accessing support.

The project team have taken multiple steps to build engagement and support within the community:

- Marketing and Communications:
  - Dedicated website coproduced and email address for the project to streamline communication. [www.bassetlawfocusonfarmers.org.uk](http://www.bassetlawfocusonfarmers.org.uk)
  - The branding of the website, logo, and contents required on the website have all been coproduced with local people to ensure it was meeting their needs and was a website that they found easy to use and could easily relate to.
  - Coverage in Retford and Worksop Life Magazines secured, which are distributed to every village in Bassetlaw, and have a Bassetlaw Focus on Farmers Facebook page and Instagram account.
  - Mug mats which feature a QR code directing residents to our dedicated website have been produced. These have been distributed to over 60 rural pubs that are frequently accessed by rural residents and farmers.
  - To engage with younger farmers, we worked with the Young Farmers Groups to co-produce tractor air fresheners and window stickers that also have the QR code and website on. These have been distributed across local Young Farmers Groups and we have worked with a local tractor supply who has included these with all tractors that are sold locally.
- Engaging with people and communities:
  - Attendance at multiple local events, such as the Nottinghamshire Show and Young Farmers meetings, to raise awareness and connect with the community.
  - In addition to the early engagement and fact-finding, we hosted an open evening (case study below) and have attended various events to engage with the community and learn from what they tell us.

**Bassetlaw Focus on Farmers – Case study of Co-production in Action for Farmer and Rural Wellbeing in Bassetlaw Focus on Farmers Open Evening**





The Bassetlaw Focus on Farmers Open Evening was held on World Suicide Prevention Day, 10 September 2024, facilitated with support from Nottinghamshire Wildlife Trust at their Idle Valley location. The event attracted over 60 attendees, with a balanced mix of farmers, rural residents, and local organisations offering support. Guest speakers from “We Are Farming Minds”<sup>16</sup> (a Hereford-based charity focused on mental health in farming) and “Riders Minds”<sup>17</sup> (an equestrian mental health charity) shared their insights. We also discussed tools like the NHS app and had a talk from Nottinghamshire Police.

We distributed a short survey to the attendees of our event to gather feedback on their thoughts and what else they might be interested in with regards to the project and its future.

Survey Results so far:

- **High Engagement: 95%** of respondents found the event interesting and engaging, highlighting the relevance of the topics covered.
- **Target Audience Reached: 50%** of the survey respondents were either farmers or rural residents, showcasing that the event successfully reached our intended demographic.
- **Increased Awareness and Knowledge: 78%** of survey respondents reported learning something new and felt more informed about where to seek support for their mental health and wellbeing needs.
- **Farmer Representation:** Of the farmers that completed the survey, **57%** expressed that they felt heard and valued, indicating the project’s success in addressing the unique challenges faced by this group, with room to grow to improve this figure ever more.
- **Excitement for the Future: 50%** of respondents shared enthusiasm about the future of the project, expressing interest in its potential growth and future activities.

Of the survey responses so far, it shows us that the event had a significant positive impact on both farmers and rural residents, with strong engagement and a clear increase in knowledge and awareness about mental health resources. The feedback demonstrates enthusiasm for future initiatives, such as farm walks and tractor rallies, and the potential to build a larger, more involved community. The voices of farmers were acknowledged, and the interest in expanding the project offers a promising outlook for its future development.

### **What’s Next?**

We are committed to continuing to listen to what rural residents and farmers want, ensuring they know where to find local support without needing to search endlessly online.

We are working with Young Farmer to co-produce a Tractor Rally in February 2025 to raise awareness of the project. We are also actively encouraging the farming community to host their own events, such as wellbeing walk and open farm days, to which we have offered our support if they need any assistance.

This project exists with the aim of ensuring that no one in Bassetlaw’s agricultural community faces challenges in isolation. Achieving this requires a collective effort, which is why we’re committed to working collaboratively, involving as many rural residents and farmers as possible in all co-production moving forward.

By pooling resources and expertise from across Bassetlaw, in a collaborative and co-produced way, we have formed a dedicated team of individuals and organisations who share the same goal of supporting and strengthening the powerful potential of this project.

---

<sup>16</sup> [Tackling mental health in the farming community of Herefordshire \(wearefarmingminds.co.uk\)](https://wearefarmingminds.co.uk)

<sup>17</sup> [Riders Minds – Improving the mental health & wellbeing of equestrians](#)

## **4.3 Mid-Nottinghamshire PBP**

### **4.3.1 My Support Network**

The Newark Local Design Team (LDT), who are a group of community representatives and professionals, created the My Support Network initiative after a community consultation demonstrated that people struggle to know what services they or the person they care for receive, what they do and how to contact them. Patients and carers felt they were repeating their stories and healthcare professionals were spending too much time trying to find out information and asking questions instead of delivering their service.

The LDT designed some simple documents where the care information regarding the patient can be kept, alongside the contact details for their relatives, carers, and healthcare professionals and providers. Storing key information in a yellow folder at the patient's home ensures it is easily accessible and standardised for those who need it.

### **4.3.2 Multi-agency Best Start Plus**

As part of the Nottinghamshire Best Start Strategy (2021 -2025), work has taken place with partner agencies to improve the life chances of all children in Mid-Nottinghamshire to engage and support families prior to conception, in pregnancy, and across the early years providing an opportunity for partners, families and communities to work collaboratively to ensure every child has a healthy and fulfilling start to life.

Groups are now established in all three districts, providing an opportunity for colleagues to identify, understand and collaborate on locally identified priorities. Rather than focus solely on the original Best Start age group of pre-birth to two, it has been agreed that the groups will work to support improved outcomes for children, young people and families in the 0-19 age range (25 if the young person has Special Educational Needs or Disabilities (SEND)).

To bring together agreement on where to focus activities across Mid-Nottinghamshire PBP, a workshop was held in November 2023, hosted by Newark and Sherwood District Council. Colleagues from CAMHS, Perinatal Psychology, Healthy Families Team, Children's Centre Service, Voluntary Sector services, Nottinghamshire County Council Public Health, Nottinghamshire County Council Early Childhood Services, Mid-Nottinghamshire Place Team (ICB) and District Councils came together to discuss proposals for the overarching Best Start Plus Plan, with agreement that efforts should be focused where the greatest impact could be made. Supporting the physical and emotional health and wellbeing of children and young people was identified as a key theme.

Priorities agreed included:

- Targeting support at families in priority neighbourhoods/circumstances.
- Developing a whole system approach to Family Hub Networks.
- Supporting the Best Start Strategy: Healthy Pregnancies, child development.
- Encouraging Childhood Vaccinations and Immunisations.
- Promoting healthier lifestyles for children and families (healthy eating, weight and moving more).
- Supporting Positive Activities for children and young people (feeling safe and raising aspirations).

## 4.4 Nottingham City PBP

### 4.4.1 Race Health Inequalities Programme

The Race Health Inequality (RHI) and mental health programmes are critical to the City PBP, reflecting priorities in Nottingham's Health and Wellbeing Strategy. These programmes are focused on addressing long-standing health inequalities, especially within diverse communities who experience significant mental health challenges.

The collaborative approach with Nottingham City PBP and Nottingham Community and Voluntary Service (NCVS) aims to ensure better health outcomes for historically underserved populations. The RHI work is feeding directly into the Donna Ockenden review of maternity services and small community organisation representing minority communities are well represented.

The RHI programme made progress to address racial health inequalities in Nottingham city in Q1 2024/25 by engaging in various events and collaborations. A key activity was the Race Health Inequalities Workshop on Mental Health on 13 May 2024 which reviewed recommendations from the 'Local Routes to Change' report<sup>18</sup>. The purpose of the session was to pick 2-3 priorities to focus on over the next 12 months. Each group discussed the priorities and provided a rationale for their selection. There was a clear consensus across the four groups to select the following two areas:

1. **Working in partnership with communities and community organisations.** Only by working in partnership with our communities can we properly understand their needs and why some people may not be accessing services. Working in partnership with people and communities creates a better chance of creating services that meet people's needs, improving their experience and outcomes. We need to build relationships based on trust, especially with communities impacted by inequalities and structural racism.

#### Key actions:

- Involve volunteers, community connectors, community organisations, HWNN and community leaders.
  - Establish a two way process of listening and sharing information.
  - Look for opportunities within integrated neighbourhood working models.
  - Provide information and education tailored to the needs of communities in a way that is accessible to them.
  - Provide training opportunities to community leader, volunteers and community organisations.
  - Learn from what works and build on the assets of all partners – networks, relationships and activity in local places.
2. **Embedding cultural competence at all levels within organisations.** In order to provide culturally competent care, knowledge of cultural beliefs, values and practices is necessary. Developing culturally sensitive practices can help reduce barriers to effective treatment. The cultural appropriateness of mental health and health services may be the most important factor in the accessibility of services by global majority communities.

#### Key points:

- Not limited to NHS organisations – smaller CVS organisations supported to access training for their staff.
- Embedded at all levels of leadership and positively promoted by the most senior leaders.
- Develop training that encourages organisational learning e.g. actions are taken as a result.

---

<sup>18</sup> [Race-Health-Inequality-Report-January-2024.pdf \(healthandcarenotts.co.uk\)](https://www.healthandcarenotts.co.uk/wp-content/uploads/2024/01/Race-Health-Inequality-Report-January-2024.pdf)

- Training utilises experiences and feedback from local communities.
- Agreed quality standards for cultural competency training.

NCVS plays a central role in engaging minority communities within the city, encouraging Black-led organisations to participate in health forums, and contributing to the PBP Mental Health group. NCVS facilitated an introduction for the Care Quality Commission (CQC) to work with the RHI group to better reach diverse communities. The introduction of the CQC team members to the RHI work will ensure a coordinated approach to ensuring a diverse representation in their work. The CQC have struggled to reach seldom heard from individuals but building relationships organically with the RHI group will ensure better outcomes for local people.

Next steps for the programme involve updating leadership groups, forming a joint RHI-MH group, exploring funding opportunities, and mapping local assets such as community champions. There is an ambition to embed the RHI Maturity Matrix into all City PBP workstreams.

## **4.5 South Nottinghamshire PBP**

### **4.5.1 Future of Healthcare in Rushcliffe**

Over 100 people attended "The Future of Healthcare in Rushcliffe" event on 27 June 2024, held in Cotgrave. Feedback was gathered from delegates on various topics to support the development of recommendations for follow-up activities believed to improve the future health and wellbeing of residents of Rushcliffe. Insights from attendees included:

- A consensus on the importance of integrating technology to address the needs of an aging population. Effective use of digital tools is seen as both a strength and a challenge, with calls for better training and accessibility.
- Social prescribing was highlighted as a powerful method for connecting patients to community resources. There is a need for broader recognition and integration of volunteer networks and organisations such as U3A to enhance community wellbeing.
- Stakeholders emphasised the necessity of clear, consistent messaging about available health services and changes within GP practices.
- Ongoing research into digital literacy, missed appointments, and social prescribing outcomes is essential. Engaging more people in volunteering and ensuring every patient contact is optimally utilised were also key recommendations for future action.

## 5 Timely access and early diagnosis of cancer

### 5.1 Introduction

This section provides information about cancer, specifically experience of diagnosis, treatment and care and longer term impacts on patients, carers and families.

### 5.2 Cancer incidence and mortality

Incidence rates for all cancers combined are lower in the Asian and Black ethnic groups, and in people of mixed or multiple ethnicities, compared with the White ethnic group, in England<sup>19</sup>. However, there are there are some exceptions:

- Prostate cancer (2.1 times higher in males of Black ethnicity).
- Myeloma (2.7–3.0 times higher in people of Black ethnicity).
- Several gastrointestinal cancers (1.1–1.9 times higher in people of Black ethnicity and 1.4–2.2 times higher in people of Asian ethnicity).
- Hodgkin lymphoma (1.1 times higher in males of Asian ethnicity and 1.3 times higher in males of Black ethnicity).
- Thyroid cancers (1.4 times higher in people of Asian ethnicity and 1.2 times higher in people of Black ethnicity).

### 5.3 Risk factors

An individual's risk of developing cancer depends on many factors. Whilst some of these factors are fixed and cannot be changed, e.g., sex and age, the majority are modifiable meaning that there is an opportunity for individuals to decrease their cancer risk.

#### 5.3.1 Age

Age is the most important risk factor for cancer with risk increasing with age. Incidence rates are strongly related to age for all cancers combined, with the highest incidence rates being in older people. In the UK in 2016-2018, on average each year more than a third (36%) of new cases were in people aged 75 and over. Age-specific incidence rates rise steeply from around age 55-59. The highest rates are in the 85 to 89 age group for females and males. Adults aged 50-74 account for more than half (54%) of all new cancer cases, and elderly people aged 75+ account for more than a third (36%)<sup>20</sup>.

#### 5.3.2 Lifestyle factors

It is estimated that 38% of cancers could be prevented through changes to lifestyle changes<sup>21</sup>. An overall summary of these risk factors can be found in Figure 3.

---

<sup>19</sup> [Differences in cancer incidence by broad ethnic group in England, 2013–2017 | British Journal of Cancer \(nature.com\)](#)

<sup>20</sup> [Cancer incidence by age | Cancer Research UK](#)

<sup>21</sup> [Cancer risk statistics | Cancer Research UK](#)

4 in 10 cancer cases can be prevented...



Figure 2. Preventable Cancer Risk Factors

## 5.4 Diagnosis

### 5.4.1 National Cancer Patient Experience Survey (2022), Nottingham and Nottinghamshire Data

The National Cancer Patient Experience survey results shed light on various aspects of individuals' experiences in receiving a cancer diagnosis which can be drilled down to a Nottingham and Nottinghamshire dataset. Not all respondents answered all questions therefore respondent numbers are variable. The data presented taken from the following sections of the survey: Support from your GP practice, diagnostic tests and finding out you had cancer.

#### 5.4.1.1 Timelines and communication with GP

Out of a survey of 650 respondents, when asked how long it took from the time they first thought something might be wrong until they first contacted their GP practice to talk about it, 43% acted within three months, 9% contacted their GP between 3-6 months, and 3% of respondents contacted their GP either between 6-12 months or more than 12 months respectively. 27% never contacted their GP and for 12% of people said this wasn't applicable, as their GP initially identified the issue.

#### 5.4.1.2 Clarity of referrals and diagnostic tests

There was a range of experiences regarding the clarity of explanations when individuals were referred for diagnostic tests. Out of 442 respondents, 63% felt completely informed, while 25% understood to some extent, and 12% did not receive an explanation they could understand.

The majority of respondents, 90% of 657 people, had undergone diagnostic tests in the last 12 months that helped to diagnose their cancer. Many felt adequately informed about their upcoming tests with 91% of 566 felt they received all necessary information.

85% of 588 individuals stated that the healthcare staff appeared to have all the information they needed about them, 13% agreed to some extent, with 2% stating that healthcare staff did not have all the information needed about them.

79% of 588 individuals found the explanations for test results completely understandable, 19% understood the explanation to some extent, 1% did not understand the explanation, and 1% did not receive an explanation but desired one.

#### **5.4.1.3 Wait times for test results**

The waiting period for test results varied. 79% of 582 respondents considered the waiting time appropriate, while 15% found it slightly too long, and 5% felt it was significantly too long.

#### **5.4.1.4 Receiving the cancer diagnosis**

The majority of respondents expressed that they had experienced a high level of privacy when receiving their test results, 96% of 590 respondents felt they always received enough privacy and most respondents found the location appropriate for receiving the cancer diagnosis, with 86% out of 659 feeling it was appropriate.

73% of 659 felt they were told they had cancer in a sensitive way, 22% felt it was only sensitive to some extent, and 5% did not find the delivery sensitive.

The source of the cancer diagnosis of 653 respondents varied, including specialist doctor or consultant (80%), specialist cancer nurse (11%), team member at the hospital (4%), someone at their GP practice (4%), and other sources (1%).

#### **5.4.1.5 Understanding of diagnosis**

80% of 661 stated that the diagnosis information was explained in a way they could understand, while 19% felt it was only to some extent, and 1% did not find the explanation understandable.

When asked whether they were told that they could go back for more information after time to reflect on what it meant, 86% out of 564 respondents were told they could do so, and 14% were not informed of this possibility.

In summary, these percentages illustrate the diverse experiences of individuals in dealing with potential health issues, undergoing diagnostic tests, and receiving a cancer diagnosis. They highlight areas where improvements in communication, information provision, and support could enhance the overall patient experience.

### **Case Study: Nottingham University Hospital Prehab Service**

The Nottingham University Hospital Prehab Service is aimed at helping cancer patients prepare for surgery. This initiative, known as "Prehab," focuses on enhancing physical and emotional resilience to better equip patients for their impending cancer treatment. The service emphasises exercise, nutrition, and psychological interventions to assist patients in readying themselves for surgery. The Prehab Team at NUH was co-designed with patients from the outset and collaborates with A Better Life (ABL) and Self Help UK to provide patients with comprehensive, personalised Prehab Programmes within their local communities. The intended benefits of this programme include:

- Fewer post-treatment complications
- Improved recovery
- Shorter hospital stays
- Enhanced cardiorespiratory fitness
- Better neuro-cognitive functions
- Enriched quality of life for patients

The innovative Prehab service highlights the positive impact of exercise and support in bolstering patients' resilience and overall quality of life. It is an example of using insight to create a holistic service and achieve better overall outcomes for the patient.

Patients have reported that they are more in control and feel better physically and mentally, like they're more in control. The project has also made financial savings by reducing the average time spent in hospital.

## **5.5 Treatment and care – what's important to citizens?**

### **5.5.1 National Cancer Patient Experience Survey (2022), Nottingham and Nottinghamshire Data**

The survey findings reflect several key themes related to the experiences during treatment of cancer patients within Nottingham and Nottinghamshire.

#### **5.5.1.1 Understanding treatment options and involvement in decisions**

84% of 630 respondents completely agreed that their cancer treatment options were explained to them in an understandable manner. A further 15% agreed to some extent, while only 1% did not feel their treatment options were adequately explained. Similarly, 83% of 651 patients reported being definitely involved in decisions about their treatment options, 15% agreed to some extent, and 2% felt they were not involved as desired.

The ability of family and carers to be involved in these decisions closely mirrored the patients' experiences. 85% of 530 respondents stated their family was able to be involved, 13% agreed to some extent, and 2% believed their family's involvement fell short.

#### **5.5.1.2 Seeking second opinions**

Out of 206 patients, 59% were able to obtain more information or a second opinion before making treatment decisions. However, 33% were unaware of this option, and 8% were unable to access a second opinion.



### **5.5.1.3 Addressing needs and concerns**

In terms of discussing their needs or concerns before treatment, 73% of 586 respondents had these discussions with healthcare staff, 24% agreed to some extent, and 3% wished for a discussion but did not receive one.

92% of 352 patients reported that a member of the healthcare team helped them create a plan to address their needs or concerns, while 8% did not receive this desired support.

### **5.5.1.4 Plan review**

A significant 98% of 273 respondents had their care plans reviewed to ensure they continued to address their needs and concerns. Only 2% reported that their plan should have been reviewed but was not.

### **5.5.1.5 Waiting times**

Patient perceptions of waiting times at the clinic or day unit for cancer treatments varied. 78% of 638 believed the waiting time was just about right, 17% thought it was slightly too long, and 5% found it to be much too long.

### **5.5.1.6 Support from GP practices**

When asked whether it came to support from staff at their GP practice during cancer treatment, 44% of 253 respondents felt they definitely received the right amount of support, 35% considered it to be to some extent, and 21% believed they did not receive the appropriate level of support.

Patients were asked whether they got the right amount of support from staff at their GP practice during cancer treatment 78% of 620 respondents stated they had not had a review, while 22% had received a review.

## **5.6 Impact on patients and survivors**

Patients' and survivors' long interactions with cancer are roughly divided into the following stages: pre-diagnosis, post-diagnosis before treatment, short-term after treatment, and long-term after treatment<sup>22</sup>. Having cancer may lead to various issues at different stages. On a personal level, it can cause psychological distress, making people question their beliefs and purpose<sup>23</sup>. It may also affect social functioning and relationships, making it harder to connect with others<sup>24</sup>. It may also have an impact on a patient or survivors ability to do practical day-to-day tasks.

### **5.6.1 Impact on day to day activity – Case study: Support provided by Self Help UK**

SM (age 69) had recently received a palliative metastatic colorectal cancer diagnosis after repeatedly going to the doctors. SM and her husband were struggling in their current house, living far away from their daughter who was having to travel to support them most days. They wanted to move to a bungalow closer to their daughter but were in a low priority band because they had a stair lift.

When speaking with SM, she reiterated that housing was her main concern – how much she was struggling with her mobility and worrying about her daughter spending a lot of money from travelling back and forth.

---

<sup>22</sup> [Self-concept and cancer in adults: theoretical and methodological issues - PubMed \(nih.gov\)](#)

<sup>23</sup> [Psycho-oncology - PubMed \(nih.gov\)](#)

<sup>24</sup> [Psychological and physical impact in women treated for breast cancer: Need for multidisciplinary surveillance and care provision - PubMed \(nih.gov\)](#)

SM was very worried about her own health and how her husband would manage on his own. She was also dealing with a lot of anger with her GP as by the time the cancer was diagnosed, it was too late to do anything.

SM was managing most practical aspects, although she said that they had been struggling with collecting their medication from the pharmacy.

To support SM, Self Help UK:

- Liaised with adult social care about SM's care needs assessment, discussing her mobility and housing situation. We also gave her additional information of services that could help, such as Housing Choice services. Referral made to the community nursing team for support with mobility at home. SM was previously unknown to the community nursing team so this put her on their radar. This led to the OT from adult social care liaising with the Ashfield Housing team to up SM's priority and putting her case through as urgent.
- Liaised with the colorectal Clinical Nurse Specialist (CNS) team to find out who SM's CNS was as this was unclear.
- Provided SM with information on carer support to ease her mind about how her husband may cope when she was at appointments.
- Provided SM with information on support lines and emotional support services for her isolation and sadness.
- Gave SM information on services that could help with collecting medication and ways to arrange her medication being delivered.

Unfortunately, SM was admitted to a hospice and shortly after passed away before her housing situation was resolved. Self Help UK offered support to her husband but at that time, he was receiving the support he needed from his family.

### **5.6.2 Body image**

Body image is a direct personal perception and appraisal of one's appearance. As a consequence, body image dissatisfaction may be detrimental to psychosocial well-being. Cancer may profoundly change a patient's body appearance and function during the different treatment stages because of, for example, surgical interventions, chemotherapy, radiotherapy and drug use. This could result in scarring, hair loss, body shape alteration, and other temporary or permanent consequences.

Evidence suggested that fear of change in one's body image begins before surgery or other treatments, and express concern about these changes will have a negative impact on patients' quality of life and may result in depression, anxiety and overall psychological distress<sup>25</sup>. Body image concerns affect many cancer patients, but researchers have mainly focused on specific groups. For instance, people with head and neck cancer and women with breast cancer have been studied more. For example, one study found that female patients dealing with breast loss felt conflicted and uncertain, struggling with societal views of femininity and womanhood and how that contradicted their self<sup>26</sup>. Similarly, some survivors of penile cancers, who went through Penectomy, report a post treatment negative impact on their quality of life because of this significant change in their bodies<sup>27</sup>.

---

<sup>25</sup> [Depression is associated with higher body image concerns in cancer patients with either visible or non-visible tumors: Findings from a psychiatric oncology clinic - PubMed \(nih.gov\)](#)

<sup>26</sup> [Losing the breast: A meta-synthesis of the impact in women breast cancer survivors - PubMed \(nih.gov\)](#)

<sup>27</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5673805/>

### 5.6.3 Social connections

Cancer patients from five NHS Trusts in England participated in a study aimed to explore the influence of social networks on cancers survivors<sup>28</sup>. The study showed the disruptive impact of cancer on their social networks for reasons related to their ability to engage with social activities, and for not re-engaging with people with whom they lost connections while accessing the treatment. Some cancer treatments associate with significant changes in the patient's body that affect their social life. For example, bone cancer treatment that includes extensive surgery result in mobility issues/disability that make it challenging for survivors to re-engage with their usual social activities and cause disruptions in other aspects of patients' daily life like climbing stairs and showering <sup>29</sup>.

### 5.6.4 Emotional wellbeing

Being considered a major life stressor, cancer may cause substantial psychological distress as well as mental health disorders conditions. The most common mental health disorders include major depressive disorder, generalised anxiety disorder, adjustment disorder, panic disorder and post-traumatic stress disorder<sup>30</sup>. Research suggested that a poor psychological state is always related to a less satisfying quality of life and a worse prognosis<sup>31</sup>.

The same study evidences that, any cancers are associated with shame and guilt, with some patients experiencing disease-related stigma. For example, lung cancer has been proven to be significantly correlated with smoking behaviour; consequently, patients with lung cancer are prone to developing self-stigma and thoughts of self-blame. Due to the nature of the illness, cancer patients and survivors often feel a self-perceived burden.

Another national study described the severity of depression experienced by some cancer patients where made a reference for suicidal ideation<sup>32</sup>. The same study explored the association between anxiety and fear of recurrence.

### 5.6.5 Financial consequences and employment

One of the implications facing cancer patients is the financial hardship that results from being diagnosed and living with cancer. Known as Financial Toxicity, this financial burden usually results from difficulties such as losing jobs and other sources of income and spending from savings<sup>33</sup>. It is also known that financial hardships affect people's ability to maintain their social life due to not being able to afford social activities and struggling with affording life essentials such as food and medications. In the UK, 141 patients participated in a study showed that 55% of the participants have experienced financial implications associated with the diagnosis and treatment of cancers<sup>34</sup>. The same study also noted the lack of other studies in the UK that aim to understand the financial impact of cancer on patients in the UK.

---

<sup>28</sup> <https://onlinelibrary.wiley.com/doi/full/10.1111/ecc.13578>

<sup>29</sup> <https://bmjopen.bmj.com/content/9/9/e028693.abstract>

<sup>30</sup> [Associations between mental health and surgical outcomes among women undergoing mastectomy for cancer - PubMed \(nih.gov\)](#)

<sup>31</sup> [Depressive symptoms among patients with lung cancer: Elucidating the roles of shame, guilt, and self-compassion - PubMed \(nih.gov\)](#)

<sup>32</sup> <https://bmjopen.bmj.com/content/9/9/e028693.abstract>

<sup>33</sup> [Financial Burdens of Cancer Treatment: A Systematic Review of Risk Factors and Outcomes in: Journal of the National Comprehensive Cancer Network Volume 17 Issue 10 \(2019\) \(jnccn.org\)](#)

<sup>34</sup> [Financial burden and financial toxicity in patients with colorectal, gastro-oesophageal, and pancreaticobiliary cancers: A UK study - ScienceDirect](#)

## **5.7 Impact on carers**

The diagnosis of a life-threatening disease not only affects patients negatively but also impacts other individuals involved in the patient's recovery, especially those who have unpaid caregiving responsibilities.

The State of Caring research<sup>35</sup> completed by Carers UK in 2022 gathered feedback from over 13,400 individuals currently or recently providing care. Whilst the respondents lived across the UK and were caring for patients with conditions not limited to cancer, there are some useful insights that may inform work in Nottingham and Nottinghamshire. These are set out in the section below.

### **5.7.1 Financial impact of caring**

A quarter of carers (25%) said they were cutting back on essentials such as food or heating, and over three quarters (77%) said that the rising cost of living is one of the main challenges they will face over the coming year. Many carers have been finding ways of saving money, but this can be difficult for those who need to use life-saving care equipment or ensure the person they care is kept warm.

Over half of carers (63%) said they were extremely worried about managing their monthly costs. 62% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (93%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.

### **5.7.2 Support and services**

With the health and social care system under intense pressure, many carers have experienced delays in accessing healthcare appointments and services. A fifth (19%) of carers who had requested a GP appointment said they had had to wait over a month for this, and over a third (34%) of carers who were waiting for specialist treatment or assessment had been waiting for over a year. This has caused additional stress and anxiety and resulted in many carers feeling isolated and forgotten about. 67% of carers waiting for specialist treatment or assessment said that waiting was having a negative impact on their mental or physical health, with 38% of those strongly agreeing. Many carers told us that they were experiencing considerable physical pain as a result of an untreated condition, making their caring role more difficult.

### **5.7.3 Health and wellbeing**

Many carers are struggling with poor mental and physical health. A fifth said their physical health was bad or very bad (21%) and 30% said their mental health was bad or very bad. Over a quarter of carers (29%) said they felt lonely often or always. Although carers are providing many hours of support to the person they care for, few are taking a break from caring, resulting in tiredness and, in some cases, exhaustion and burn-out. 41% of carers haven't taken a break from their caring role in the last year. Many carers would like to do more physical activity, to improve their health, but simply don't have the time to do so. Nearly half of carers (45%) said they had been less active in the last six months, which may be due to increased anxiety and stress as a result of the cost-of-living crisis.

While public health measures around COVID-19 have significantly reduced, the pandemic continues to impact on carers' lives, with some carers still shielding or reducing their contact with others to protect themselves or the person they care for. A fifth of carers (20%) said that concerns over catching COVID-19 were a barrier to accessing services.

---

<sup>35</sup> [cukstateofcaring2022report.pdf \(carersuk.org\)](https://www.carersuk.org/state-of-caring-2022-report)

### **Discussion points**

- How well are mental health and emotional support services integrated into cancer care?
- What more can social care and VCSE organisations play in providing holistic support to patients and their families affected by cancer?
- To what extent does the Integrated Care Strategy meet the needs of those who provide unpaid care?
- How can system partners work together to promote cancer prevention, raise awareness of symptoms, and encourage healthy lifestyles in communities at higher risk of cancer?

## **6 Understanding the needs of children, young people and families**

### **6.1 Introduction**

This section describes insights gathered from children, young people and families through work undertaken by Small Steps Big Changes, engagement with children and young people with special educational needs and disabilities (SEND) and from the Nottinghamshire County Council Shadow Event.

### **6.2 Small Steps Big Changes – Community and Coproduction**

#### **6.2.1 Introduction**

As Small Steps Big Changes (SSBC) comes to an end, the programme team is reviewing the work to ensure its legacy endures—this sections highlights the efforts made to involve people and communities.

SSBC is one of five A Better Start Partnerships funded for a ten-year period (2015- 2025) by The National Lottery Community Fund (TNLCF), taking a test-and-learn approach to commissioning early intervention and prevention services for families, so babies and children can have the best start in life. SSBC is a partnership including health, early years, early help, community and voluntary sector providers and local parents, coming together to improve the lives of babies and children in Nottingham.

An important ambition for SSBC and the wider ‘A Better Start’ (ABS) programme nationally is to improve the way that organisations work with families, and reduce inequalities. Two main commitments guide this approach in SSBC:

- Putting the family at the centre of services: including a commitment to coproduction, ensuring the voices of parents, families and young children contribute to service design and delivery, and that services meet the needs of children and families.
- Parent and community-led services: a focus on empowering parents and communities so, they have the skills, confidence, and experience to deliver and lead.

Within SSBC, coproduction has been embedded through the voices of local parents and families. Parent Champions are local parents who are well connected to their local communities and understand the needs of local families. They have been involved with every aspect of the SSBC programme – from the initial funding application, the design and delivery of the programme’s services, and the evaluation of the programme.

#### **6.2.2 Embedding coproduction in governance, policy and decision-making**

Inclusive and integrated governance arrangements were outlined in the bid and enacted with the funding award. The SSBC Partnership Board, comprised of Parent Champions who hold 40% of the vote, alongside representation from other key leaders across the system. To complement the strategic oversight offered by the SSBC Partnership Board, Parent Champions were also integral members of other key groups which supported the programme at different points of time.

### **Learning and Recommendations**

To enable meaningful coproduction with parents, the programme paid particular attention to:-

The principles of accessibility and equity.

1. For board meetings, pre-meetings are organised with the independent chair to ensure parents are supported in their role and could access the meeting fully.
2. Parents were provided with additional specialist training on areas such as conflicts of interest and finance so they felt well equipped to discuss and understand these.

3. Relationships were key so parents felt able to comment and challenge and 'professionals' able to counter challenge. Board development sessions took place to help understand the power dynamics in the room.
4. Across the different partnership groups, timings of meetings were scheduled to ensure childcare commitments were not an exclusion to attending, babies were always a welcome feature of meetings and creches were provided for preschool age children as needed.
5. SSBC provided expenses for parents so they were able to access meetings without any financial burden.

### **6.2.3 Embedding coproduction in service commissioning and design**

Alongside the governance of the programme, coproduction with parents was also a key feature of SSBC commissioning and design. SSBC has undertaken direct service user engagement across the course of the programme alongside insights from Parent Champions.

To support the SSBC programme's ambition to embed father inclusive practice across commissioning and service design, SSBC undertook a fathers' consultation in 2020. The views of 93 fathers and male caregivers were gathered via interviews and surveys, these informed the direction and delivery of the Father Inclusive activity. In the same year, the SSBC programme was at a midway point and a review of the portfolio of activities was undertaken. To enable local parent voice to feed into future development and service design, SSBC undertook a parent consultation. The aim was to hear from parents with children between the ages of 0 -3, about what was important for them in supporting their child's development, wellbeing, and health with a focus on prevention.

Two questionnaires were developed, and views were sought on topics including Breastfeeding, Healthy weight, Healthy teeth, Smoking in pregnancy, Support for parents, Attachment & Bonding and Mental health. The questionnaires were distributed via SSBC Parent Champions, acting as leaders in their local communities and gathering information from other parents, through social media, home visits and during groups and activities where parents were present. The findings from the consultation provided the programme with an increased understanding of projects and initiatives that parents were likely to take up, with this forming an equitable and key pillar of complementary evidence of what works for new project development and the development of existing services.

Parent Champions were also invited to coproduce with the SSBC programme team tenders for services that the programme intended to commission. Parents were an equal panel member in tender moderation meetings.

### **Learning and Recommendations**

To enable meaningful coproduction with parents, the programme paid particular attention to:

The principles of diversity and reciprocity.

1. Time was taken to explain tender process and legal matters, in some cases decisions were made with parents to ask them to focus on elements of a tender – and what was most important to them.
2. Training was provided and portals/IT access etc was considered.
3. SSBC services have been more accessible and acceptable due to parent involvement in their design – their lived experience alongside cutting edge science and evidence-based interventions has meant that SSBC services have been tailored to meet community needs.

4. Parents and community members became advocates for services/offers and approaches with many taking up voluntary or paid work in commissioned activity, providing additional social value benefits.
5. Some myths and 'suspicions' at a community/ward level were able to be addressed by involving parents in service design and explaining the benefits.
6. Professionals learnt how to adapt their language and better promote services to parents in a way that was acceptable and resonated – e.g., families found risk reduction messaging controlling and emphasized the need for intrinsic motivation to breastfeed.

#### **6.2.4 Parents leading the way – Case Studies**

Parent Champions have brought expertise from their lived experience, which has been diverse in terms of gender, family makeup, residential wards, and the connections they have to communities.

A key principle of coproduction is reciprocity, where all involved benefit from working in this way. Below are extracts from case studies of two of the current Parent Champions involved in the SSBC programme. Written in the parent's own words, these provide compelling benefits for parents, of working in this way.

##### **Parent Champion Amanda**

*"I first got involved with SSBC when I was recruited from a playgroup. They offered me toast and a hot cup of tea while my son went into Creche. Having an 8-month-old son, hot tea and a babysitter were the height of luxury, so I signed up immediately. My reason for staying and continuing to volunteer has morphed over the years. It started with doing it for my family to branching out and doing it for my community and their families that live in it now and generations to come.*

*The impact on my family has been huge. I am a better parent for being a part of SSBC. My children are more confident and have been able to witness the power of our voices making a difference. They have excelled more at school because they were taken to so many different events and regularly were in Creche for meetings. The community has been impacted because I have been able to use my skills learned at SSBC to continue to make a difference through my local community centre and schools. I have done this by planning events, sharing free or low-cost events and offers via social media platforms and being someone that families that can come to for advice or help.*

*My learning from volunteering at SSBC is that it's easy to complain about a service but infinitely harder to step up and help change one. I learnt the art of compromise the need to see the world through a variety of viewpoints means we can change it to be better for everyone.*

*I have also gained the passion for coproduction and the great things it can achieve. This passion has enabled me to take a completely different career path. I have gone from food retail to being the maternity lead for maternity and neonatal voices partnership Nottingham and Nottinghamshire. I am often told I'm crazy for volunteering giving so much of my time and energy up for 'free' however I have achieved and done so many things I am proud of since joining SSBC. I have gained skills, knowledge and friends and I don't regret a single second of it."*

##### **Parent Champion Jin**

*"Upon arriving in the UK in 2016 to pursue my studies, I suddenly found myself as part of a minority group in the country. Diversity surrounded me in every aspect of life here. From interactions on campus to forming friendships with teachers and peers, I experienced diversity first-hand. Although I was still somewhat isolated due to the large number of fellow Chinese students, I began to explore cultural diversity more actively. However, I often felt hesitant to step out of my comfort zone and engage more deeply with other cultures.*



*Shortly after discovering I was pregnant, SSBC reached out to me. The service manager, Stacey, introduced me to the family mentor service. My Family Mentor, Stephanie, began visiting me regularly. She provided invaluable guidance on parenting skills, emotional support, and child development knowledge. Through SSBC baby groups, my child and I made friends from diverse backgrounds, and we began to explore diversity more actively. With SSBC's support, my child Jamie experienced positive development from birth.*

*I have observed SSBC's passion for designing services that people in our communities want and need. The organisation endeavours to adapt its services to cater to the racial, cultural, and religious backgrounds of individuals. For example, its translation services have enhanced the accessibility of sessions and surveys, while its engagement with families through cultural celebrations fosters inclusivity. The diverse composition of SSBC's employees and volunteers underscores the importance of diversity in the workplace.*

*My volunteering for SSBC, represents a journey into diversity—a journey for both myself and my child to be born and raised within a diverse environment. I am grateful for the opportunity SSBC offered me initially, and I have grown immensely through my experiences with the organization. No longer do I feel the loss of my majority status; instead, I relish being part of the diverse fabric of society.*

*In China, there is a saying: "When three people walk together, there must be one from whom I can learn." I came to this country and community to learn the language. To my surprise, through my volunteer work at SSBC, I learned about diversity. Meanwhile, I am continuing to learn about other values of this community from everyone I meet and hear about. SSBC may complete its 10-year journey in 2025 but I will continue to carry forth what I have learned and benefited from into my future day-to-day life."*

### **6.2.5 Conclusion**

SSBC's core principle, 'Children at the heart, parents leading the way, supported and guided by experts,' captures the programme's commitment to working collaboratively with parents. In practice, this commitment is encapsulated by four key principles: equality, diversity, accessibility, and reciprocity.

#### **Equality**

By working in collaboration with local parents, with service providers and their teams, and by partnering with communities and organisations, SSBC has supported systems change in local coproduction practices. This has required commitment at senior leadership level to accommodate the involvement of service users. In addition to providing opportunities for involvement through surveys and focus groups to gather service user feedback and supporting Parent Champions with training, SSBC has integrated coproduction into its organisational decision-making processes. This is evidenced by allocating 40% of the SSBC board's voting power to Parent Champions.

#### **Diversity**

Diversity has been crucial in the coproduction of the work of the SSBC Programme to ensure that the needs of currently underserved groups are met. Engaging with community and voluntary sector organizations that have strong connections to diverse communities within Nottingham helps to increase the understanding of how they experience services and what they need from services. Enabling this engagement requires resources to practically enable people to interact with the programme, for example through translated surveys, and at times targeted engagement, for example aimed at fathers. Additionally, involving Parent Champions from varied ethnic backgrounds, family structures, and parenting experiences, who are well-connected to their local communities, ensures that a wide range of perspectives is considered, making services more inclusive and responsive to the communities' needs.

## **Accessibility**

Accessibility is a key element in the coproduction of services, as it helps ensure that people can engage with the work of the SSBC Programme at various levels and with varying degrees of commitment. For example, the SSBC programme has shown appreciation for parents' time and effort by providing incentives for evaluation, which helps to break down obstacles that could otherwise inhibit engagement. This approach not only facilitates broader involvement but also acknowledges the value of every participant's contribution.

## **Reciprocity**

Reciprocity is a fundamental aspect of coproduction in SSBC, ensuring that all local people who participate in coproduction activities can see the benefit from their contributions. For local parents and families involved in these initiatives, this means not only having their views heard but also sharing decision-making power, resulting in services that are more suited to the needs of their communities. The input from local parents has generated new ways forward for services, rather than merely debating and selecting existing interventions for local implementation. Additionally, by providing continuous development opportunities, the programme has empowered Parent Champions, helping them to secure other paid work based on the skills and competencies they have gained.

### **6.3 Children and Young People with Special Educational Needs and Disabilities (SEND) in Nottinghamshire**

The Nottinghamshire Local Area SEND Partnership has developed their strategy<sup>36</sup> with stakeholders including parents, carers and children and young people with SEND. Engagement activities have included a survey, seven engagement events open to all partners and feedback from groups of children and young people attending various education settings in Nottinghamshire.

The Department for Education funded Research and Improvement for SEND Excellence (RISE) Partnership supported the Local Area Partnership to develop the outcomes for this strategy. RISE initially supported three workshops with SEND leaders across Nottinghamshire including parents and carers in Autumn 2023. An underpinning aspect of this work was a wide reaching series of engagement activities. This included:

- The SEND outcomes survey that was shared through a range of networks in December 2023
- A series of five in person SEND strategy engagement events as well as two online events with adults in Spring 2024
- A series of engagement activities with young people including a survey questionnaire and in-person visits to schools in Spring 2024. The SEND outcomes survey received 557 responses with 85% of respondents agreeing to the outcomes. 77% of responses were from parents and carers, 16% from multi-agency professionals and 5% from children and young people. Responses were also spread evenly across the seven Nottinghamshire districts.

Close to 300 people from across the local area partnership attended the SEND strategy engagement events. This included more than 100 school leaders, approximately 75 health colleagues and over 60 parents and carers, and staff from county council services, including children's social care. During the events, attendees discussed and agreed the final wording of the outcomes in this strategy, which was then signed off by the Nottinghamshire SEND Partnership Assurance Improvement Group (PAIG) in March 2024.

---

<sup>36</sup> [nottinghamshiresendstrategy.pdf](#)

As part of the SEND outcomes survey, 99 young people with SEND responded to the specific question 'Can you please tell us the outcome you would like for your life?' The key responses are:

- Education that can meet my needs
- Independence
- Supported
- Opportunities
- Nice things/ good life
- Job/employment

In addition, the Nottinghamshire SEND Co-production Officer visited six education settings and spoke to over 60 children and young people with SEND to gather their views in person, using a range of accessible communication strategies.

The insights gathered supported the development of six co-produced outcomes for children and young people:

- I need to be listened to and heard.
- I need to be the healthiest I can be.
- I need to be safe and feel safe.
- I need to be accepted and valued by people I trust.
- I need to be prepared for my future.
- I need to enjoy life and have fun.

## **6.4 Nottingham County Council Shadow Event 2024**

### **6.4.1 Context**

On 5 October 2024 the ICB Engagement Team attended the annual Shadow Event held in Sherwood Forest. This event is organised and co-ordinated by Nottinghamshire County Council and this year celebrated its 50<sup>th</sup> anniversary.

This event was attended by over 370 children and young people from across Nottingham and Nottinghamshire, including young adults with learning disabilities and their support workers/carers and also leaders from the Youth Centres.

The aim of the event was to work in teams to navigate and orienteer around Sherwood Forest to different locations to carry out activities with organisations who were in attendance.

### **6.4.2 Engagement methods**

At the event the Engagement Team used two different engagement involvement methods:

1. Health and Wellbeing Bingo. The teams were handed out bingo score cards with answers relating to health and wellbeing included. The team then read out a series of questions with the teams guessing the answers first before being provided with the correct answer. The teams would then mark off the right answer if they had this on their sheet. The first team to complete a full line were announced as the winners and given a medal on a lanyard as a prize.
2. The groups then were asked to provide us with feedback on something they feel positive about, something that they feel negative about and what's causing them concerns. They wrote down their responses as individuals or as groups and stuck their suggestions on a board.

### 6.4.3 Insights gathered

The feedback received has been thematically analysed and listed from most to least comments received.

When asked about what is causing them concerns, the groups/individuals noted the following key themes:

1. School, colleagues and exams
2. Physical and mental health
3. Waiting times for appointments and diagnosis of conditions, lack of ADHD medication and also the pressures in the NHS with staff leaving and recruitment
4. Cost of living, being poor, not having enough food, money and not being able to obtain employment after school
5. Vaping and knife and other crimes – feeling unsafe at night time when walking home in the dark
6. Family, friends, and relationships
7. Having a healthy lifestyle i.e. exercise and eating the right foods

When asked about what matters most:

1. Family, friends, and relationships
2. Physical and mental health
3. Hobbies, sports, sports, cadets, computer games, completing tasks, family camera
4. Society, climate change, environment, learning other about cultures
5. College, the future

When asked about what made them feel positive:

1. Family, friends, and relationships
2. Hobbies
3. Community groups (RAF Cadets, Youth Groups and clubs, and dance clubs)
4. Access to good healthcare (staff are friendly and everyone can access high quality care)
5. Staying healthy

#### Discussion points

- How do we continue to understand the needs of children, young people and families?
- How can system partners effectively communicate with children, young people and families?
- How can the ICP address concerns we are hearing from our children, young people and families and embed these into our Integrated Care Strategy?

## **7 Next steps**

The Integrated Care Partnership are asked to consider the insight contained within this report and to support the findings in the further development of our Integrated Care Strategy. The report highlights several points for discussion:

1. What factors could help restore or maintain trust in local health and social care services?
2. What role can the ICS have in healing divisions and developing long-term social cohesion?
3. How can local communities, especially those most affected by the unrest, have a greater voice in the ICS?
4. How can the ICS support NHT to deliver their Integrated Improvement Plan?
5. How will the ICS ensure an ongoing dialogue with people and communities regarding their mental health and services that support them?
6. How well are mental health and emotional support services integrated into cancer care?
7. What more can social care and VCSE organisations play in providing holistic support to patients and their families affected by cancer?
8. To what extent does the Integrated Care Strategy meet the needs of those who provide unpaid care?
9. How can system partners work together to promote cancer prevention, raise awareness of symptoms, and encourage healthy lifestyles in communities at higher risk of cancer?
10. How do we continue to understand the needs of children, young people and families?
11. How can system partners effectively communicate with children, young people and families?
12. How can the ICP address concerns we are hearing from our children, young people and families and embed these into our Integrated Care Strategy?