

Norfolk Health & Wellbeing Board

Date: **Wednesday 04 December 2024**

Time: **09:30 - 12:30**

Venue: **Council Chamber, County Hall, Martineau Lane, Norwich**

Representing

Borough Council of King's Lynn & West Norfolk
Breckland District Council
Broadland District Council
Cambridgeshire Community Services NHS Trust
East Coast Community Healthcare CIC
East of England Ambulance Trust
East Suffolk Council
Great Yarmouth Borough Council
Healthwatch Norfolk
James Paget University Hospital NHS Trust
Norfolk Care Association
Norfolk Community Health & Care NHS Trust
Norfolk Constabulary
Norfolk County Council, Cabinet member for Adult Social Services
Norfolk County Council, Cabinet member for Children's Services
Norfolk County Council, Cabinet member for Public Health and Wellbeing, Leader (nominee)
Norfolk County Council, Executive Director Adult Social Services
Norfolk County Council, Executive Director Children's Services
Norfolk County Council, Director of Public Health
Norfolk & Norwich University Hospital NHS Trust
Norfolk & Suffolk NHS Foundation Trust
NHS Norfolk and Waveney Integrated Care Board (Chair)
NHS Norfolk and Waveney Integrated Care Board (Chief Executive)
North Norfolk District Council
Norwich City Council
Place Board Chair Great Yarmouth & Waveney
Place Board Chair Norwich
Place Board Chair North Norfolk
Place Board Chair South Norfolk
Place Board Chair West Norfolk
Police and Crime Commissioner
Queen Elizabeth Hospital NHS Trust
South Norfolk District Council
Voluntary Sector Representative
Voluntary Sector Representative
Voluntary Sector Representative

Membership

Cllr Jo Rust
Cllr Tristan Ashby
Cllr Natasha Harpley
Anna Gill
Ian Hutchison
David Allen
Cllr David Beavan
Cllr Emma Flaxman-Taylor
Patrick Peal
Mark Friend
Angela Steggles
Lynda Thomas
ACC Chris Balmer
Cllr Alison Thomas

Cllr Penny Carpenter

Cllr Bill Borrett

Ian Wake

Sara Tough

Stuart Lines
Tom Spink
Zoe Billingham
Rt Hon Patricia Hewitt

Tracey Bleakley

Cllr Liz Withington
Cllr Adam Giles
Jonathan Barber
Tracy Williams
Dr James Gair
Allan Petchey
Carly West-Burnham
Sarah Taylor
Chris Lawrence
Cllr Kim Carsok
Tim Gardiner
Dan Mobbs
Daniel Childerhouse

Substitute

Cllr Bal Anota
Cllr Sam Chapman-Allen
Cllr Eleanor Laming
Steve Bush
Andy Wood
Nicolas Smith
Cllr Jan Candy
Cllr Donna Hammond
Alex Stewart
Joanne Segasby
Jack White
Laura Clear
DCS David Freeman
Cllr Shelagh Gurney

Cllr Karen Vincent

Nicholas Clinch

Sarah Jones

Suzanne Meredith
Rachael Cocker
Tricia Fuller

Andrew Palmer

Cllr Wendy Fredericks
Cllr Claire Kidman
Sheila Oxtoby

Heather Farley
Karen Bradley
Oliver Judges
Dr Gavin Thompson
Alice Webster
Cllr Andy Evans

Additional members (non-voting)

Norfolk Health Overview and Scrutiny Committee (Chair) Cllr Brenda Jones
Suffolk County Council, Cabinet Member for Adult Care Cllr Beccy Hopensperger
Suffolk County Council Representative Nicholas Pryke
University of East Anglia Representative Prof Nicole Horwood

For further details and general enquiries about this Agenda please contact the Committee

Officer: Maisie Coldman on 01603 638001 or email: committees@norfolk.gov.uk

Norfolk and Waveney Integrated Care Partnership

Date: **Wednesday 04 December 2024**

Time: **on rise of the Health and Wellbeing Board**

Venue: **Council Chamber, County Hall, Martineau Lane, Norwich**

Representing

Borough Council of King's Lynn & West Norfolk
Breckland District Council
Broadland District Council
Cambridgeshire Community Services NHS Trust
Chair of Voluntary Sector Assembly
East Coast Community Healthcare CIC
East of England Ambulance Trust
East Suffolk Council
Great Yarmouth Borough Council
Healthwatch
James Paget University Hospital NHS Trust
Norfolk Care Association
Norfolk Community Health & Care NHS Trust
Norfolk Constabulary
Norfolk County Council, Cabinet member for Adult Social Services
Norfolk County Council, Cabinet member for Public Health and Wellbeing
Norfolk County Council, Cabinet member for Children's Services
Norfolk County Council, Director of Public Health
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Norfolk & Norwich University Hospital NHS Trust
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Norfolk & Waveney Integrated Care Board (Chair)
Norfolk & Waveney Integrated Care Board (Chief Executive)
North Norfolk District Council
Norwich City Council
Police and Crime Commissioner
Place Board Chair Great Yarmouth & Waveney
Place Board Chair Norwich
Place Board Chair North Norfolk
Place Board Chair South Norfolk
Place Board Chair West
Primary Care Representatives TBC
Queen Elizabeth Hospital NHS Trust
South Norfolk District Council
Suffolk County Council, Cabinet Member for Adult Care
Suffolk County Council, Representative
Voluntary Sector Representative (1)
Voluntary Sector Representative (2)

For further details and general enquiries about this Agenda please contact the Committee Officer:

Maisie Coldman on 01603 638001 or email: committees@norfolk.gov.uk

Norfolk Health & Wellbeing Board and Norfolk and Waveney Integrated Care Partnership

Wednesday 04 December 2024

Agenda

Time: 09:30 - 12:30

08:45 - 09:25: There will be a networking opportunity available prior to the start of the meeting in the Margaret English Room next to the Council Chamber at County Hall, Norfolk County Council.

Advice for members of the public:

This meeting will be held in public and in person.

It will be live streamed on YouTube and members of the public may watch remotely by clicking on the following link: [Norfolk County Council YouTube](#)

We also welcome attendance in person, but public seating is limited, so if you wish to attend please indicate in advance by emailing committees@norfolk.gov.uk

Current practice for respiratory infections requests that we still ask everyone attending to maintain good hand and respiratory hygiene and, at times of high prevalence and in busy areas, please consider wearing a face covering.

Please stay at home if you are unwell, have tested positive for COVID 19, have symptoms of a respiratory infection or if you are a close contact of a positive COVID 19 case. This will help make the meeting safe for attendees and limit the transmission of respiratory infections including COVID-19.

1. Apologies	Committee Officer	
2. Chair's opening remarks	Chair	
Norfolk Health and Wellbeing Board		
3. HWB Minutes	Chair	(Page 5)
4. Actions arising	Chair	
5. Declarations of interests	Chair	
6. Public Questions (How to submit a question: HWB) Deadline for questions: 5pm, Thursday 28 November 2024	Chair	
7. Urgent arising matters	Chair	
8. Norfolk Drugs and Alcohol Partnership (NDAP) Annual Report (HWB)	Stuart Lines / Diane Steiner	(Page 15)
9. Better Care Fund 2024-2025 Quarterly Reports (Q1, Q2) (HWB)	Ian Wake	(Page 28)
10. Becoming a 'Marmot Place': West Norfolk's work with the Institute of Health Equity (HWB)	Cllr Jo Rust / Mark Whitmore / Ciceley Scarborough	(Page 51)

Norfolk and Waveney Integrated Care Partnership

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|--|---|------------|
| 1. ICP Minutes | Chair | (Page 5) |
| 2. Actions arising | Chair | |
| 3. Declarations of Interest | Chair | |
| 4. Public Questions (How to submit a question: ICP)
Deadline for questions: 5pm, Thursday 28 November 2024 | Chair | |
| 5. Launching the Norfolk & Waveney Health Inequalities Commitment (ICP) | Tracey Bleakley / Stuart Lines / Tracy Williams | (Page 54) |
| 6. Driving Integration through system wide training opportunities update (ICP) | Ian Wake / Paul Wardle / Tracey Bleakley / Sharon Crowle / Sandy Oosthuysen | (Page 66) |
| 7. Driving Integration through Digital, Data and Technology including Digital Inclusion (ICP) | Ian Wake / Geoff Connell
Tracey Bleakley / Ian Riley | (Page 71) |
| 8. Preparing for Seasonal Pressures: ICS Framework for 2024/25 (ICP) | Ian Wake / Nicholas Clinch
Tracey Bleakley / Marcus Bailey | (Page 76) |
| 9. 2023/2024 Learning from Lives and Deaths: People with a Learning Disability and Autistic People (LeDeR) Annual Report (ICP) | Tracey Bleakley / Andrew O'Connell | (Page 83) |
| 10. All Age Carers Strategy for Norfolk and Waveney 2024 – 2029 (ICP) | Ian Wake / Sharon Brooks / Bethany Small / Edward Fraser | (Page 151) |

Further information about the Health and Wellbeing Board can be found on Norfolk County Councils website at: [About the Health and Wellbeing Board](#)

Information regarding the Integrated Care Partnership can be found on the Integrated Care System website at: [About the Integrated Care Partnership](#)

**Health and Wellbeing Board and Integrated Care Partnership
Minutes of the meeting held on 04 September 2024 at
in the Council Chamber, County Hall.**

Present:

Cllr Jo Rust
Cllr Eleanor Laming
Anna Gill
Andy Wood
Cllr David Beavan
Cllr Emma Flaxman-Taylor
Patrick Peal
Mark Friend
Lynda Thomas (arrived at 10:10)
Chris Balmer
Cllr Alison Thomas
Cllr Penny Carpenter
Cllr Bill Borrett

Debbie Bartlett
Sara Tough
Stuart Lines
Tom Spink
Rt Hon Patricia Hewitt
Tracey Bleakley
Cllr Liz Withington
Cllr Adam Giles
Jonathan Barber
Tracy Williams

Heather Farley
Carly West-Burnham
Cllr Kim Carsok
Emma Ratzer
Dan Mobbs

Representing:

Borough Council of King's Lynn & West Norfolk
Broadland District Council
Cambridgeshire Community Services NHS Trust
East Coast Community Healthcare CIC
East Suffolk Council
Great Yarmouth Borough Council
Healthwatch Norfolk
James Paget University Hospital NHS Trust
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North Norfolk District Council
Norwich City Council
Place Board Chair Great Yarmouth & Waveney
Place Board Chair Norwich

Place Board Chair South Norfolk
Place Board Chair West Norfolk
South Norfolk District Council
Voluntary Sector Representative
Voluntary Sector Representative

Additional members present (non-voting):

Cllr Brenda Jones Norfolk Health Overview and Scrutiny Committee (Chair)
Cllr Beccy Hopensperger Suffolk County Council, Cabinet Member for Adult Care 09:40
Prof Nicole Horwood University of East Anglia Representative

Officers Present:

Stephanie Butcher Policy Manager Health and Wellbeing Board
Stephanie Guy Advanced Public Health Officer
Maisie Coldman Committee Officer

Speakers:

Abigail McGarry Executive Director of Adult Social Services, NCC
Walter Lloyd-Smith Safeguarding Adults Board Manager (Business Lead), NCC
Nicholas Clinch Director of Communities, Prevention and Partnerships, Adult Social Services, NCC
Stuart Lines Director of Public Health, NCC
Sarah Barnes Public Health Commissioning Manager, NCC
Gail Harvey Technical Project Manager, NCC
Paul Wardle Strategic Human Resource Business Partner - Adults
Sharon Crowle Head of Professional Education, Training and Development, ICB
Tracy Williams Clinical Lead for Health Inequalities & Inclusion Health, ICB
Geoff Connell Director of Digital Services, NCC
Ian Riley Executive Director of Digital & Data, ICB

Norfolk Health and Wellbeing Board (HWB)

1. Apologies

- 1.1 Apologies were received from Nick Davison (substituted by Chris Balmer, Ian Hutchison (substituted by Andy Wood), Dr James Gair (substituted by Heather Farley), Cllr Natasha Harpley (substituted by Cllr Eleanor Laming), Zoë Billingham and her substitute, and Sarah Taylor and her substitute. Cllr Tristan Ashby, David Allen, Angela Steggles and Nicola Roper were also absent. Please see Appendix A for a record of attendance.

2. Chair's Opening Remarks

The Chair welcomed members to the meeting. It was reported to members by Tracy Williams, Clinical Lead for Health Inequalities & Inclusion Health for the ICB, that the Core20plus5 Ambassador programme for the third cohort, was now open for expressions of interest. The programme was open to Local Government and Voluntary Sector partners and recruitment was due to close on the 20 September 2024. Interested members were encouraged to speak with Steph Butcher.

Members were encouraged to sign up to the Integrated Care System Conference due to take place on the 16 October 2024.

The Chair used this opportunity to thank Debbie Bartlett, Executive Director Adult Social Services, ahead of her retirement, for all her valuable work for Norfolk.

3. Minutes

- 3.1 The HWB minutes of the meeting held on 12 June 2024 were **AGREED** as an accurate record and signed by the Chair.

4. Actions arising

- 4.1 None.

5. Declarations of Interests

- 5.1 None.

6. Public Questions

- 6.1 None.

7. Urgent Matters Arising

- 7.1 The Chair shared with the HWB that the Domestic Homicide Review for "Sarah" had been published on the Norfolk Constabulary's website. Section 12 states that it would be shared with the Norfolk Health and Wellbeing Board. Members would be emailed a link to the report.

8. Norfolk Safeguarding Children Partnership (NSCP) Annual Report for 23/24

- 8.1 Sara Tough, Executive Director of Children Services, NCC introduced the appended (8) report.
- 8.2 Abigail McGarry, Head of NSCP Business Delivery, NCC, provided the board with a brief overview of each section of the annual report which summarised the local arrangements for safeguarding children. The NSCP had also produced a Children and Young People's (CYP) version of the annual report. The Board heard that this was co-produced with CYP and that they showed insightfulness and a data-

driven mindset. The NSCP was awarded an All Together Quality Mark in which they were commended for including the views of CYP. Areas of improvement that were suggested included a wider variety of CYP and for it to be more widely distributed.

8.3 The following points and comments were discussed:

- The involvement of the voluntary sector was appreciated.
- The involvement of CYP voices was commended and it was commented that their inclusion was the result of developed relationships.
- A member shared anecdotal evidence of the difficulties of getting safeguarding support for a child attending school. Sara Tough, Executive Director for Children Services noted that although she was not aware of the specific circumstances, work had been carried out to reorganise school systems and arrangements to make them accessible and manageable. Local areas will know what partners are available to them. Additionally, Abigail McGarry added that each local area has a safeguarding group that explores local issues and how best to respond. The Chair reminded members that if they have any concerns, these can be raised outside of the meeting.
- Following a member's question, it was noted that reducing the rate of CYP mental health admissions to hospitals was a top priority. The focus of the Health and Care Collaborative was CYP mental health more broadly. The board heard that there had been a reduction in acute hospital settings related to mental health. Additionally, following the introduction of a single front door for children's mental health services, there had been a 66% reduction in the Norfolk and Suffolk Foundation Trust thus illustrating the value of early intervention.
- The Chair thanked the team for a thorough and impressive report.

8.4 Following members comments, the HWB **RESOLVED** to **endorse** the annual report.

9. Norfolk Safeguarding Adults Board (NSAB) Annual Report for 2023/24

9.1 Debbie Bartlett, Executive Director, Adult Social Services, NCC, introduced the appended report (9) and highlighted to members that there was joint working with the NSCP with respects to transition and coverage of safeguarding activity.

9.2 Walter Lloyd-Smith, Safeguarding Adults Board Manager (Business Lead), NCC, noted that the NSAB annual report highlights the NSAB and the wider partnership's adult safeguarding activity during 2023/24 and provided an overview. The report assured the work that was being carried out to protect people at risk of abuse and harm and showed the positive impact that this work was having. The Board heard that the conversation around safeguarding was moving from being 'everyone's business' to being 'everyday businesses. NSAB had taken up opportunities to raise the profile of Norfolk through a collaboration with the Durham Safeguarding Board. Walter expressed thanks to all those involved.

9.3 The following points and comments were discussed:

- Members endorsed the NSAB report and thanked the team for their work.
- There was an ambition for the NSAB to expand the data used to ensure nothing was being missed. The practical challenges of this were shared and discussed.
- A member questioned how the voluntary sector could be more involved. In response, it was noted that a second seat was established on the board and that the NSAB was looking at VCSE representation and wider engagement.
- Following a member's question about what trends could be drawn from those who had multiple safeguarding instances, it was shared that each safeguarding case was different. People may return if new risks emerge or continue to be at risk. One theme that could be drawn was that

people often did not accept the support which could result in additional safeguarding cases for an individual.

- District Council safeguarding groups were able to explore local concerns.
- It was confirmed that information and signposting material had been produced for carers and families; the board heard of the encouraging number of downloads of the materials. There was a consideration to ensure that the wording was appropriate and meaningful for the audience it aimed to inform.
- Following a member's query, assurance was offered that cases of domestic abuse are being picked up and noted as such but that safeguarding concern often notes physical abuse as the primary case of abuse. The Hidden Harms animation was mentioned, and it was shared with members that this aimed to start the conversation about domestic abuse in the older population.
- Members of Norfolk County Council had the opportunity to attend a briefing on safeguarding, the Chair felt that it would be useful for district council members and officers to be offered the chance to participate.

9.4 The HWB **RESOLVED** to:

- a) **Endorse** the annual report.
- b) **Encourage** all NCC elected members to attend a specially arranged briefing for them on 25 September 2024.
- c) **Promote** the work of NSAB to partner organisations and stakeholders.
- d) Use media and communications channels to **promote** the safeguarding messages.

10. **Better Care Fund (BCF) 2023-2024 Annual report, the BCF 2023-2025 Submission and the Market Sustainability Improvement Fund (MSIF) return**

10.1 Debbie Bartlett introduced the appended Better Care Fund (BCF) 2023-2024 Annual report, the BCF 2023-2025 Submission and the Market Sustainability Improvement Fund (MSIF) return report (10).

10.2 Nicholas Clinch, Director of Communities, Prevention and Partnerships, Adult Social Services, NCC provided a brief overview of the two reports and highlighted to members that the purpose of presenting the Market Sustainability and Improvement Fund was to highlight the join up between these two important funding streams. It has been acknowledged that overall delivery of the BCF has improved joint working between Health and Social Care in the system. The updated 2024-25 plan included the recommendations from the review presented to the Board in June 2024, in particular consolidating schemes into the new themes. The increased pressure on funding across NCC and the ICB was noted.

10.3 The following points and comments were discussed:

- Following a member's comment on the absence of detail in some of the output columns, it was noted that NHS England required specific details and outcomes for some, but not all, schemes. Additionally, it was shared that the BCF review identified that clearer outputs and outcomes were needed.
- A member asked if there was any evaluation of the programmes focused on avoidable admissions. The board heard that the BCF funds schemes aimed at discharge and admission avoidance and that the BCF had a role in reviewing the schemes. The Urgent and Emergency Transformation Board, within the ICS, also performed this function and that the links are made between the BCF and UEC Transformation Board.
- The Urgent and Emergency Care Board was working on intermediate care provision. NCC was working closely with Norfolk Community Health and Care NHS Trust and East Coast Community Healthcare to ensure that people who require intermediate care had a community hospital stay available to them. It was felt that the work being carried out would put Norfolk in a good position over the winter period.

- It was noted that a breakdown in funding between District Councils was included in the report.
- Following a member's question about whether some funding could be used to fund a handyperson's service in Norwich, it was confirmed that this was included in some schemes in the BCF but was not a uniform approach.
- A member asked if feedback was received back from NHS England to indicate how Norfolk was performing. Feedback was received annually and when returning in-year submissions. NHS England approved those submissions and indicated that the BCF was meeting the criteria. Regional benchmarking was available and there could be scope to include this within future reports to the board.
- It was agreed that a huge amount of work had gone into this, and the hard work of the Team was acknowledged.

10.4 The HWB **RESOLVED** to:

- a) **Agree and sign off** the BCF 2023-24 End of Year Report.
- b) **Agree and sign off** the BCF submission for 2024-25.
- c) **Endorse** the work of the Market Sustainability Improvement Fund (MSIF) and how the funding has been allocated against the target areas, identified as part of the grant requirements and priorities for Adult Social Care.

11. Norfolk Health Protection Assurance Board (HPAB) Report 2024

11.1 Stuart Lines, Director of Public Health, NCC, introduced the appended (11) report that provided an update on local health protection assurance arrangements. The Covid-19 Pandemic highlighted the importance of preventive measures and systems that can respond to emergencies. Members heard that the Board includes representation from local councils, the UK Health Security Agency, NHS England, Norfolk and Waveney Integrated Care Board and the Laboratory Medicine and Eastern Pathology Alliance.

11.2 Sarah Barnes, Public Health Commissioning Manager, NCC, noted that health protection was more visible following the Covid-19 Pandemic and shared with the committee the breadth of the HPAB, this included horizon scanning and coordination of mutual support. The HPAB provided assurance that the system was working to protect the populations health.

11.3 The following points and comments were discussed:

- The importance of vaccinations, screening, and handwashing was highlighted to members.
- Concerning Whooping cough vaccinations, a member asked what factors contributed to low uptake. It was confirmed that women may not be aware of the vaccine and that it was required to be had during every pregnancy. The system organisation was noted as a factor and that work was being done to make it easier to get vaccinations.
- Members discussed barriers to vaccinations generally and heard of the initiatives being done to encourage uptake. This included a recall contact system where people would be directly contacted to arrange a convenient time to have the vaccination.
- It was noted in response to a member's question regarding drainage and mosquito risks, that the public health team at NCC would work with the District Council to advise on any planning applications that posed a risk of infectious diseases or environmental hazards and any Health Impact Assessments that may be required.
- It was confirmed that the HWB would receive annual reports from the HPAB which would indicate the work completed.

- A dashboard of key metrics was being developed to draw data together and make it easier to use.
- Sara Tough, Executive Director of Children’s Services, noted that there could be an opportunity for joint working and the Extended Family Hubs and Start for Life hubs to be involved in the encouragement of vaccination uptake.

11.4 The HWB **RESOLVED** to:

- Endorse** the work of the HPAB.
- Support** appropriate representation on the HPAB from key agencies.
- Agree** to receive annual reports from the HPAB.

The Health and Wellbeing board closed at 11:09

Cllr Flaxman-Taylor left the meeting at 11:09.

Integrated Care Partnership

1. Integrated Care Partnership (ICP) Minutes

1.1 The minutes of the Integrated Care Partnership (ICP) meeting held on 12 June 2024 were **AGREED** as an accurate record and signed by the Chair.

2. Actions arising

2.1 None.

3. Declarations of Interest

3.1 None.

4. Public Questions

4.1

5. Driving Integration through Digital, Data and Technology including Digital Inclusion

5.1 Debbie Bartlett introduced the appended report (5), noting the importance of digital integration and inclusion. Tracey Bleakly, Chief Executive of the ICB commended the teams’ achievements to date.

5.2 Ian Riley, Executive Director of Digital & Data, ICB – digital inclusion, shared with the partnership an update on the Shared Care Record, Electronic Patient Record, and Patient Portal. Geoff Connell, Director of Digital Services, NCC, introduced the work that had been carried out on digital inclusion. Additional detail was added by Gail Harvey, Technical Project Manager, NCC, who provided members with a deep dive into the Digital Inclusion programme and the Tech Skills for Life scheme. A video showcasing the successes of the Tech Skills for Life scheme was shown to members. The video can be accessed via this link: [Making a Difference - Tech Skills for Life \(youtube.com\)](https://www.youtube.com/watch?v=...) If you have any difficulties accessing the link, please contact the committee’s team at committees@norfolk.gov.uk.

5.3 The following points and comments were discussed:

- Members thanked the team for their work, particularly the work on the Tech Skills for Life scheme.

- A member noted the difficulties that can occur when accessing websites on a mobile and suggested that we encourage website layouts that are optimal for mobile usage.
- There was an ambition to roll the Tech Skill for Life scheme across other areas of the county. The areas with the highest need for connectivity and skills would be prioritised. The rollout would be dependent on funding.
- It was confirmed that a lot of work was being carried out to understand the impact of the landline telephone digital switchover and that communications had gone out to raise awareness about the changes. There were data sharing agreements with telephony providers to share the details of vulnerable people.
- Scam awareness was part of the digital skills programme.
- A member highlighted the need to consider those individuals who do not have younger family or friends to support them with accessing digital services and devices.
- The Chair noted that digital inclusion was a significant area for prevention.

5.4 The ICP **RESOLVED** to:

- a) **Note** the updates on the progress taken around the collaboration as a system and raise any potential gaps or priorities to further inform the plan.
- b) **Review, comment, and advise** on the potential impact and actions which are being taken to support digital inclusion in the county.
- c) **Consider** how as a partnership we can continue to raise awareness of the digital switch for our vulnerable residents.
- d) **Consider** how we can obtain permanent funding in order to make the Digital Inclusion offer into a business-as-usual service.

6. Integrated Care System (ICS) Health Inequalities Strategic Framework for Action Update

6.1 Stuart Lines, Director of Public Health, introduced the appended report (6) which provided an overview of the proposed governance and oversight arrangements to implement the Health Inequalities Strategic Framework for Action. An Operational Coordination group was established to support the implementation of the Strategic Steering Groups.

6.2 Tracy Williams, Clinical Lead for Health Inequalities & Inclusion Health, ICB, shared with members an overview of the action so far on the priority action areas. The Living & Working Conditions priorities required further development and there had been a workshop with the District Councils and Voluntary sector to facilitate this development. The priorities would be launched at the ICS conference in October 2024. The system was not starting from scratch and the governance arrangements sought to coordinate the efforts of the system.

6.3 The following points and comments were discussed:

- Members welcomed the paper.
- It was noted by Stuart Lines that one of the difficulties was identifying the priorities and key focus areas because Health Inequalities covered such a wide area.
- In response to a member's question, it was noted that the focus areas are evidence lead, and although it was not explicitly referenced, Public Health was driven by evidence and thus, their involvement in the steering group provided assurance that the research was being considered. Members heard examples of how research was used. It was felt that the role of evidence could be highlighted further.
- A member asked how the work of the steering group would be translated to partners to deliver the work. In response, it was noted that as the delivery agents, it was important to have strong

relationships with partners. There was close working already and this was still being improved on.

- It was felt that the Health and Wellbeing Partnerships and Place Boards with their knowledge of the local areas should be utilised.
- Digital inclusion was likely to feature in all the steering groups and would need to be considered as the groups progress.

Cllr Brenda Jones left the meeting at 12:03

6.4 The ICP **RESOLVED** to:

- a) **Agree** delegation to the Strategic Steering Group to approve proposed governance structures and Terms of Reference as they develop.
- b) **Agree** to receive regular progress updates from the new ICP Health Inequalities Strategic Steering Group.
- c) **Agree** that representation from partner organisations within the governance structures will be determined with a view to having local council, Voluntary Community and Social Enterprise (VCSE) and NHS provider representation distributed across the structure

7. Update on driving integration through system wide training opportunities

7.1 Debbie Bartlett introduced the appended report (7) on the update on driving integration through system-wide training opportunities.

7.2 Paul Wardle, Strategic Human Resource Business Partner – Adult Social Care, provided the ICP with an update on the current activities taking place within the Integrated Care System (ICS) and highlighted the progress that had been made. Sharon Crowle, Head of Professional Education, Training and Development, ICB discussed the Health and Care Academy and careers programme and the Restorative Just Culture programme. It was also highlighted that there were practical challenges to system-wide training opportunities but that the ICS and the education community would continue to explore these.

7.3 The following points and comments were discussed:

- It was noted by a member that this was an opportunity to look at training in a new way and to explore the different opportunities to provide training.
- Following a member's question, it was shared that there were avenues that could be explored to gain funding for system-wide training. Although not all of it would require funding; the expertise already within the system, and the desire to share this, was highlighted.
- Concerning the future workforce and their expectations of them, it was noted that this was still being explored but that there was collaboration happening to explore different training styles. It was important for the system to understand how care would be delivered in the future. Additionally, it was added that a lot of work had gone into the strategic long-term workforce planning that looked at future workforce modelling. Members could receive an update on the strategic planning at a future meeting.
- It was suggested that there was an opportunity to look at the successful Practice weeks that take part in Childrens Services and to join this up. It was noted that it is important to ensure that the whole system was aware of all the training opportunities available across the system.

7.4 The ICP **RESOLVED** to:

- a) **Consider** the ongoing activities taking place across the ICS in respect of educational and training opportunities.
- b) **Consider** the update on shared apprenticeship opportunities across the ICS.
- c) **Consider** the joint approach to system leadership and training for the ICS being developed as part of the “Improving Lives Together” transformation programme.
- d) **Endorse** the Initial conversation to scope out the development of a system “skills passport.”
- e) **Consider** the need for further work on an approach to pooling training resources including all ICS partners.
- f) **Acknowledge** that the ongoing work between health and social care is not yet inclusive of other partners.

Meeting concluded at 12:25

Bill Borrett

Chair, Health and Wellbeing Board and Integrated Care Partnership



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Health and Wellbeing Board and Integrated Care Partnership Attendance Record (From the last 3 meetings)

Member Organisation Represented	Named Member	06 Mar 2024	12 Jun 2024	04 Sept 2024
Borough Council of King's Lynn & West Norfolk	Cllr Jo Rust	X	X	X
Breckland District Council	Cllr Tristan Ashby	X	X	
Broadland District Council	Cllr Natasha Harpley	X	X	X*
Cambridgeshire Community Services NHS Trust	Anna Gill	X	X	X
East Coast Community Healthcare CIC	Ian Hutchison		X	X*
East of England Ambulance Trust	David Allen	X	X	
East Suffolk Council	Cllr David Beavan	X	X	X
Great Yarmouth Borough Council	Cllr Emma Flaxman-Taylor	X		X
Healthwatch Norfolk	Patrick Peal	X	X	X
James Paget University Hospital NHS Trust	Mark Friend	X	X*	X
Norfolk Care Association	Christine Futter Angela Steggles	X*		
Norfolk Community Health & Care NHS Trust	Lynda Thomas			X
Norfolk Constabulary	ACC Nick Davison	X	X	X*
NCC, Cabinet member for Adult Social Services	Cllr Alison Thomas		X	X
NCC, Cabinet member for Childrens Services	Cllr Penny Carpenter	X	X	X
NCC, Cabinet member for Public Health and Wellbeing	Cllr Bill Borrett		X	X
NCC, Interim Executive Director Adult Social Services	Debbie Bartlett	X*	X	X
NCC, Executive Director Children's Services	Sara Tough	X	X	X
NCC, Director of Public Health	Stuart Lines	X	X*	X
Norfolk & Norwich University Hospital NHS Trust	Tom Spink	X*	X	X
Norfolk & Suffolk NHS Foundation Trust	Caroline Donovan Zoe Billingham	X*		
NHS Norfolk and Waveney Integrated Care Board (Chair)	Rt Hon Patricia Hewitt	X	X	X
NHS Norfolk and Waveney Integrated Care Board (Chief Executive)	Tracey Bleakley	X*	X*	X
North Norfolk District Council	Cllr Liz Withington	X		X
Norwich City Council	Cllr Claire Kidman Cllr Adam Giles	X	X	X
Place Board Chair (Great Yarmouth & Waveney)	Jonathan Barber			X
Place Board Chair (Norwich)	Tracy Williams	X	X	X
Place Board Chair (North Norfolk)	Dr James Gair		X*	X*
Place Board Chair (West)	Carly West-Burnham	X*	X*	X
Place Board Chair (South Norfolk)	Dr Ge Yu Allan Petchey		X	
Police and Crime Commissioner	Giles Orpen Smellie Sarah Taylor			
Queen Elizabeth Hospital NHS Trust	Chris Lawrence	X		
South Norfolk District Council	Cllr Kim Carsok	X	X	X
Voluntary Sector Representative	Emma Ratzer		X*	X
Voluntary Sector Representative	Dan Mobbs		X	X
Voluntary Sector Representative	Alan Hopley Daniel Childerhouse	X		
Norfolk Health Overview and Scrutiny Committee (Chair)	Cllr Fran Whymark Cllr Brenda Jones	X	X	X
Suffolk County Council, Cabinet member for Adult Care (Guest)	Cllr Beccy Hopfensperger		X	X
Suffolk County Council Representative (ICP)	<i>Bernadette Lawrence</i> Nicola roper	X	X*	
University of East Anglia Representative (Guest)	Prof Nicole Horwood	X	X	X

X member attended, * Indicates Substitute attended

Report title: Norfolk Drugs and Alcohol Partnership (NDAP) Annual Report

Date of meeting: 04 December 2024

Sponsor

(HWB member): Stuart Lines, Director of Public Health, Norfolk County Council

Reason for the Report

In November 2022, the Board agreed to provide oversight of the Norfolk Drug and Alcohol Partnership (NDAP), and in November 2023 the Board provided their endorsement of the priorities and progress of NDAP's work.

This annual report seeks to update the Board on priorities, progress and work underway by NDAP and gives a brief overview of the equivalent Suffolk Combating Drugs Partnership (SCDP) (for information only – see Appendix D). It also highlights uncertainty over supplemental government funding to the services within the partnership and the potential impact of this on some of the partnership's work. It is requested that the Board provides its endorsement of the current work and agrees continued commitment to and engagement with the partnership.

Report summary

Over the past year, the NDAP has continued to develop, with its work featured in a Local Government Association report. [Go to www.local.gov.uk to read this report: Two years on: a progress review of 'From harm to hope': A 10-year drugs plan to cut crime and save lives'](http://www.local.gov.uk). The partnership has been extended to cover further areas of work including setting up a new group to focus on children and young people. A joint needs assessment has been undertaken and new priorities considered. There has been progress on a number of workstreams. Government decisions on whether significant supplemental funding for substance misuse in Norfolk will continue are awaited.

Recommendations

The HWB is asked to:

- a) Provide executive support to the work that HWB Board members' teams are engaged in, for example senior leaders of commissioners and providers of mental health and drug and alcohol services helping to accelerate the work on dual diagnosis that continues within the context of structural re-organisation.
- b) Continue to support their organisations to identify drug and alcohol users in their care and support them to engage with drug and alcohol treatment to reduce the risk of drug and alcohol related deaths.
- c) Continue to support relevant staff to take up drug and alcohol and mental health training coordinated by the partnership.
- d) Acknowledge the progress of the current workstreams and endorse the work of the partnership.
- e) Ensure HWB Board member organisations are appropriately engaged with NDAP.
- f) Acknowledge that other partnerships – e.g. some Health and Wellbeing Partnerships – may also contribute to this agenda, e.g. through Community Alcohol Partnerships.

1. Background

1.1 The NDAP was established to increase our ability to respond to drug and alcohol issues, including the aims of the national drugs strategy, *From Harm to Hope*, and in line with government guidance for local areas. [Go to Gov.uk to read the policy paper From harm to hope](#). The terms of reference for the group, including a list of key stakeholders, can be found in Appendix A. The partnership covers the county of Norfolk. The last NDAP Annual Report to the Board outlined progress on workstreams and highlighted the issue of dangerous new synthetic opioids.

2. NDAP Updates (partnership working, workstreams and funding)

2.1 **NDAP partnership working:** The partnership continues to evolve to meet local needs:

2.1.1 The positive, collaborative work of the partnership was highlighted in a report from the Local Government Association on progress against the national drug strategy. [To view our case study \(NDAP\) go to local.gov.uk](#).

2.1.2 The structure has expanded to include groups on Data and Emerging Trends, Children and Young People, and Synthetics Response (see Appendix B).

2.1.3 The joint NDAP and Serious Violence Duty Programme Group was split back into two groups, though the link between the two work areas remains, and drugs and alcohol was identified as a priority area for the serious violence work.

2.1.4 A dedicated NDAP Manager started in post in December 2023, jointly funded for two years by Norfolk Constabulary, Office of the Police and Crime Commissioner Norfolk, and Norfolk County Council Public Health.

2.1.5 Work with the Office of Health Improvement and Disparities (OHID) highlighted in last year's report has yielded improved numbers in drug and alcohol treatment and higher rates of successful transitions from prison to community treatment services, while consistently maintaining a treatment progress level higher than the national average.

2.1.6 A new delivery plan was developed and signed off by the NDAP Strategic Group. Outcomes from the Joint Needs Assessment were considered by the NDAP Strategic Group in October 2024 and new priorities until March 2026 agreed, while maintaining three existing priorities, with all of the priorities covering children and young people as well as adults:

- Embedding the voice of lived experience across the partnership.
- Developing a multiagency response to improving outcomes for those with complex needs.
- Responding to the emerging risks of changing drug trends in the county (e.g. from ketamine and synthetic opioids).
- Joint priority with SVD: tackling exploitation, e.g. from County Lines and cuckooing.
- Continuing work on dual diagnosis pathways.
- Continuing to improve rates of continuity of care from prison to community.
- Continued workforce development.

2.2 **Updates on NDAP workstreams:** Updates on the following NDAP workstreams can be found in Appendix C:

- Dual diagnosis (mental health and substance misuse)

- Prison to community continuity of care (CoC)
- Workforce development
- Project Adder expansion
- Work with the Office of Health Improvement and Disparities (OHID)
- Reducing drug and alcohol related deaths (DARD)
- Synthetic substances
- Exploitation
- Ketamine.

2.3 Funding uncertainty

- 2.3.1 As part of the previous government's commitments to the 10-year drug strategy, Norfolk was awarded circa £4.3 million of additional drug and alcohol treatment funding in 2024/25, creating over 70 new roles in the drug treatment system. This is made up of a number of OHID grants which cover areas such as improved treatment outcomes, housing related support including rough sleeping, and employment support. At present, all of the supplemental grants are due to end in March 2025. OHID have been in dialogue with the new government around continuation of funding, and an initial short-term decision is expected following on from the Chancellor's autumn budget statement by the end of November 2024.
- 2.3.2 **Enforcement:** Addiction, Diversion, Disruption, Enforcement and Recovery (ADDER) Home Office funding has been in place since 2020 and funds both divisionary and enforcement work through various Constabulary posts, alongside Norfolk-funded roles. An efficient and effective model has been developed over a 5-year period to enable a robust response to County Lines drugs' supply into the county. From the inception of Project ADDER and the formation of a central County Lines team in early 2020 up to October 2024, over 102 individual County Lines have been closed in Norfolk. Over that same period, 209 people have been charged in connection with running drugs supply lines in Norfolk with a total of 563 years of prison sentences given by Crown Court judges in Norfolk. Drugs, cash and weapons are regularly recovered during enforcement activity. Cash seizures currently total over £200,000 in the five years. Norfolk Constabulary is currently considering a number of options around the structure of the existing team to ensure it continues to build on the significant achievements of the last five years beyond April 2025 when the central funding to the Constabulary ceases.
- 2.3.3 **Diversion:** There are four diversionary roles at risk due to the additional funding uncertainty, which include a conditional caution and early intervention worker and specialist women's criminal justice worker. The two early intervention workers who work in a Police Investigation Centre, engaged with over 260 children in custody over the last 12 months, with only 11 children declining support.
- 2.3.4 **Treatment:** Supplemental grant funding has funded 32 additional drug and alcohol treatment staff, increasing the number of people accessing drug and alcohol treatment by approximately 600 places. Loss of funding would reduce the current workforce and result in caseload sizes increasing by more than 50 people per worker, making an average caseload size of up to 130 per Recovery Coordinator.
- 2.3.5 **Recovery:** Grant funding has supported recovery with an additional 30 posts created in a number of organisations providing improved access to housing, physical and mental health care, employment, education and social activities. In the past 12 months, housing related support has been delivered to over 370 people, helping to find solutions to a wide range of housing issues, and recovery support has been provided to over 440 people including specialist support for young people aged 18 to 25.

Officer Contact

If you have any questions about matters contained in this paper, please get in touch with:

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Email: diane.steiner@norfolk.gov.uk



If you need this report in large print, audio, Braille, alternative format or in a different language please contact 0344 800 8020 or 0344 800 8011 (textphone) and we will do our best to help.

Appendix A – NDAP Terms of Reference

Norfolk Drugs and Alcohol Partnership (NDAP) Strategy Group

Terms of Reference

Updated June 2024

1. Context and Role of the Strategy Group

Preventing and combating the harm caused by drug and alcohol misuse is an issue requiring concerted action from a range of partners. At a local level, success is reliant on these partners working together to understand our population and their needs; particularly how substance misuse causes harm in our area, any specific challenges in our local system and the changes that are needed to address them.

The NDAP will comprise:

- A **Strategy Group** to provide senior strategic leadership, agree priorities based on identified needs and review progress
- a **NDAP Programme Group** to provide leadership and direction; whilst bringing together local partners to deliver against identified priorities, supported by focused task and finish groups (see appendix B). The Programme group is closely aligned to the **Serious Violence Duty Group** to work across both agendas, and recognising the frequent overlap of both issues and partners involved in tackling them, and to streamline partnership working

The Strategy Group will report to the Norfolk and Waveney Health and Wellbeing Board.

The Strategy Group will coordinate action and provide oversight across alcohol misuse and the three priorities of the 10-year national drugs strategy¹ with accountability for delivery against the National Combating Drugs Outcomes Framework.

2. Principles

The Strategy group will operate under the following guiding principles:

1. A partnership of equals – to seek consensus and make joint decisions, including working through difficult issues, where appropriate
2. A collective model of accountability – partners hold each other mutually accountable for shared and individual organisational contributions to objectives
3. Improving outcomes for communities and ‘at risk’ groups
4. Collaboration and integration – a culture of broad collaborations and integration at every level of the system to improve outcomes and reduce duplication and inefficiency
5. Co-production and inclusivity – create a learning system which makes decisions based on evidence and insight
6. A commitment to creating meaningful and effective data collection and monitoring metrics through a dedicated working group
7. As a collective, partners recognise each organisation’s sovereign responsibilities and differing pressures and government drivers
8. The partnership will not seek to replicate existing structures/partnerships, but to influence or challenge them as appropriate.

3. Membership

The core member organisations of the Strategy Group are:

- Local Authority (including expertise in substance misuse, housing, employment, education, social care and safeguarding)
- NHS (including strategic mental and physical health leads, clinicians and provider reps)

- Jobcentre Plus
- Substance misuse treatment providers
- Norfolk Constabulary
- Office of Police and Crime Commissioners Norfolk
- The Probation Service
- Service user voice – representing people with lived experience including families/carers
- Secure estate
- VCSE sector representatives
- District Councils

In addition to these organisations, partnerships are also expected to engage and work with:

- Primary, junior, secondary and further education settings
- Housing, providers of supported housing and homelessness services
- Youth Offending Service
- Coroner's offices
- Fire and Rescue Authority
- Office for Health Improvement and Disparities regional team.

4. Appointment of Chair

The Chair of the Strategy Group will be the **Senior Responsible Owner (SRO)**, who will:

- build and foster strong relationships in the system
- have a collaborative leadership style
- be committed to innovation and transformation
- have expertise in delivery of health and care outcomes
- be able to influence and drive delivery and change.

The Strategy Group will appoint a **Vice Chair** from its membership and review annually.

In addition to the SRO the partnership may wish to consider the following three roles:

- **Partnership lead** – a named lead for overseeing delivery of local programmes and co-ordinating partnership working
- **Public involvement lead** – a named lead to ensure the voices of the public are heard, people with lived experience, or family/carers impacted by substance misuse
- **Data and digital lead** – a named lead on data, data protection, information governance and outcomes measurement.

5. Duties and Responsibilities

The Strategy group will:

- Be rooted in the needs of people, communities, and places across all ages (e.g. children and young people, families, adults)
- Conduct a joint needs assessment, reviewing local drug and alcohol data and evidence
- Agree a local drug and alcohol strategy delivery plan
- Ensure partners agree a local performance framework to monitor the implementation and impact of local plans
- Implement and support an integrated and co-ordinated programme of monitoring, metrics and data collection to report on the key priorities outlined in *From Harm to Hope* as appropriate to the population of Norfolk
- Review progress, reflecting on local delivery of the strategy, current issues and priorities
- Support integrated approaches and subsidiarity

- Take an open and inclusive approach to strategy development and leadership, involving communities and partners to utilise local data and insights
- Provide a forum for agreeing collective objectives, enabling place-based partnerships and delivery to thrive alongside opportunities to address substance misuse in Norfolk.

At times, official sensitive, restricted, provisional or confidential data and information will be shared in NDAP meetings – members should safeguard the information or data accordingly and refrain from sharing such data/information without seeking permission.

6. Authority, Accountability, Reporting and Voting Arrangements

The Strategy Group will report to the Health and Wellbeing Board.

The aim will be for decisions of the Strategy Group to be achieved by consensus decision making. Voting will not be used, except as a tool to measure support, or otherwise, for a proposal. In such a case, a vote in favour would be non-binding. The SRO will work to establish consensus as the basis for decisions, recognising that organisations will be operating within their own individual guidance and constraints.

Meetings of the Strategy Group will not be open to the public.

Minutes of the meeting will be taken and approved by members of the Strategy Group, along with maintaining an action and risk log.

Disagreements and unresolvable conflicts of interest shall be referred to the Health and Wellbeing Board who will have oversight and scrutiny of the Strategy Group.

7. Attendance

Members should commit to attend meetings. Where a member is unable to attend, they may nominate a named deputy to attend meetings in their absence and must notify the Secretariat.

Attendance will be recorded within the minutes of each meeting and monitored annually.

8. Notice and Frequency of Meeting

Meetings will be held four times a year but more frequently if required for specific matters. Meetings will primarily be held virtually, with occasional ad hoc face to face meetings where useful.

An annual schedule of meetings will be prepared and distributed to all members. Where the date or time of a meeting needs to be changed, notice shall be sent electronically to members at least five working days before the meeting.

Agendas and all supporting papers will be sent out at least five working days before the meeting.

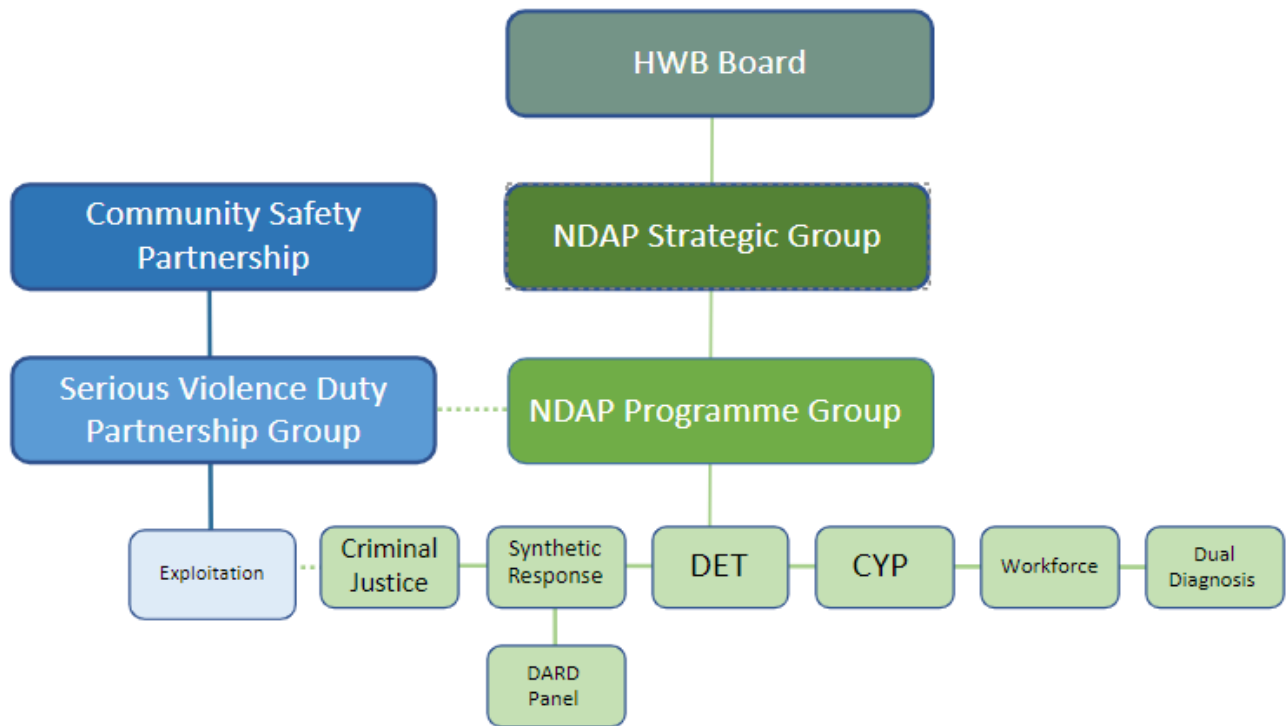
9. Working groups

To support the Strategy Group to deliver its outcomes, a NDAP Programme Group has been established which will report progress to the Strategy Group. Any task and finish group established by the NDAP Programme Group will not be static and may be stood down when not actively working on or tasked with delivering projects.

10. Review

The Strategy Group will review these terms of reference on an annual basis.

Appendix B – Norfolk Drug and Alcohol Partnership Governance Structure



Key:
 NDAP – Norfolk Drug & Alcohol Partnership
 HWB – Health & Wellbeing Board
 DET – Data and Emerging Trends
 CYP – Children and Young People
 DARD – Drug and Alcohol Related Death

Appendix C – Updates on NDAP workstreams

Dual Diagnosis:

Purpose: to develop pathways that support engagement, treatment and recovery for people experiencing both mental health and substance misuse issues

Update:

- A draft pathway has been designed and a clinical workshop in September began the process of obtaining clinical agreement across primary care, CGL and the Norfolk and Suffolk Foundation Trust (NSFT)
- Work has begun on a data collection protocol, with a number of gaps in current data identified
- Regular focus groups have been held with experts by experience. Further integration is planned once an NCC commissioned lived experience contract is implemented in November
- Development of a co-produced NSFT co-occurring conditions approach is underway, which will act as a guideline to help inform the implementation of the pathway.

Prison to Community Continuity of Care (CoC)

Purpose: to ensure that those moving between prison and community treatment do not fall through the gaps at a particularly vulnerable time

Update:

- To assess strengths and identify development opportunities within the prison to community system, system partners held a series of workshops to undertake OHID's self-assessment process. This has ensured that activities are informed by national best practice
- Pathways and process maps have been created and developed by the CoC partnership
- Data audits have been undertaken to understand who is not attending services and why, and weekly data match meetings between prison and community providers have been established and adopted as business as usual
- A new prison in-reach role has been created and recruited to
- New resources have been co-developed by providers to support smooth transfer of care
- A four-stage referral form has been developed and implemented between prison and community providers to ensure accurate information sharing and alerts between services.

Workforce Development

Purpose: to identify if staff have access to appropriate training and if gaps are found, to develop appropriate packages of training

Update:

- Training audit completed
- A countywide rolling programme of training has been implemented with a number of system partners. The first four sessions between April and July focused on substance misuse in adults, young people and pregnancy, with the aim of raising awareness of societal substance misuse, understanding the risks, and learning about the support available. CGL led on the first four sessions supported by colleagues from The Matthew Project and Children's Services. Each session was attended by an average of 27 professionals from all parts of health and social care. Feedback was very positive and led to follow up contact with CGL from partner agencies requesting bespoke training for their teams.

- As part of the Norfolk Safeguarding Children Partnership Neglect toolkit launch, CGL delivered a workshop at each of the three launch events, which were attended by over 100 delegates. The workshop was well received by attendees and feedback was extremely positive
- There have been three sessions of Blue Light training on working with people with complex needs affected by alcohol, including older people. The training is for people working with complex cases where alcohol is involved but not the primary issue. Each session was attended by an average of 20 professionals from a wide range of organisations and feedback was positive.

Project ADDER Expansion

Purpose: to implement best practice on enforcement, treatment and recovery from the Greater Norwich ADDER pilot to the rest of the county and including alcohol and recreational drugs

Update:

- ADDER and supplemental funded criminal justice staff were merged to form a countywide criminal justice team. This included expansion of Buvidal (a prolonged-release opioid partial agonist / antagonist), psychological treatment provision and service user support/recovery funds.
- This priority has now been fully completed as of April 2024.

Work with OHID

Purpose: to increase performance related to treatment-related elements of the national drug strategy.

Update:

- Via regular meetings with partners and OHID, we have developed an action plan to drive improvements across 23 thematic areas
- Now 10 months into delivery against our action plan, progress is reflected in the data and has been noted by OHID:
 - Numbers in drug and alcohol treatment increased from 4359 (September 2023 Baseline) to 4,722 (June 2024 NDTMS data) – though the number of opiate users remains steady, a picture seen nationally (and which, in some areas, has decreased)
 - ATR and DRR targets in Norfolk have been exceeded
 - Rates of successful transitions from prison to community treatment services have increased, while treatment progress measures have consistently remained higher than the national average.

Reducing Drug and Alcohol Related Deaths (DARD)

Purpose: to reduce the number of drug and alcohol related deaths in Norfolk.

Update:

- The real time surveillance system ('QES') for suspected DARD now up and running after delays due to technical issues. It links to data on suspected suicides given overlap between the two. Work isnongoing for partners to enter their data
- Six multi-agency DARD Panel meetings held to date to learn lessons, feeding up to NDAP and to the ICB Learning from Deaths Forum (LFDF) and leading to task and finish groups as appropriate e.g. on barriers to the homeless community accessing treatment

- A deep dive into the data is underway due to increasing rates of DARDs. Initial data shows a large proportion of deaths are linked to co-morbidities (physical health issues often related to long-term substance misuse). Specifically, there seems to be an increase in deaths related to cardio-pulmonary diseases especially in the Great Yarmouth area
- Reviews of deaths in service (CGL) seem to show a recent increase in the number of alcohol related deaths of service users that had only very recently been referred into specialist service and have died before any meaningful treatment could be initiated. This has been raised at the ICB LFDF and an action identified for primary care to consider early referrals
- New synthetics group set up (see below).

Synthetic Response Group

Purpose: to identify and mitigate new risks from synthetic substances, including synthetic opioids.

Update:

- Review completed of the Local Drug Information System ('drug alerts') to ensure maximum and relevant distribution amongst all partner agencies in Norfolk
- A four element Synthetic Response Plan has been developed with all relevant partners
- Review planned of current harm reduction interventions and measures (including naloxone provision) in relation to the increased risks posed by synthetic substances
- Provision of naloxone in custody is underway with Police and CGL – governance and funding will be explored by Public Health, CGL and Police
- Development underway of the use of technology to provide in-cell harm reduction messaging whilst in detention. Suitable overdose and naloxone information is currently being considered for both adults and children in the custody environment
- New piece of work looking how better to engage with licencing agencies and festival organisers ahead of next year's Norfolk festival programme in line with OHID/ADPH* best practice to reduce harm (*Associate of Directors of Public Health)
- Work is ongoing to identify gaps in knowledge and training in the wider workforce around overdose awareness, to provide training where appropriate.

Data and Emerging Trends Group

Purpose: To bring together operational data on the presenting issues facing the partnership.

Update:

- Group established to share data and experiences of emerging trends of drug use and experiences within services, to raise awareness to whole partnership
- Identified ketamine as a substance that was increasing in prevalence – collected data and added clinicians from the Norwich and Norfolk University Hospital (NNUH) ketamine clinic to the group
- Ketamine clinic clinicians have now presented at both NDAP Programme and Strategic Groups to raise awareness and share data from their clinic
- Ketamine task and finish group established to look at interventions and awareness raising in relation to ketamine
- Information shared on drug trends within the secure estate to support those who work with those on their release
- Discussions around the increased prevalence of synthetic opiates and unusual presentations of some service users to professionals.

Ketamine Task and Finish Group

Purpose: to address increasing negative impacts from misuse of ketamine in the county, including often severe altered bladder function, through awareness raising and targeting unmet need.

Update:

- Identified through the Data and Emerging Trends group that there was a need to establish a group specifically to respond to ketamine
- Collaborating with the ketamine clinic at NNUH, to ensure that there was an established referral pathway for both CGL and Unity
- Collecting and analysing data from the partnership on those who use ketamine (NNUH, drugs services) to ensure that we can appropriately target key messages and support.

Exploitation

Purpose: to strengthen and enhance the county's multi-agency response to exploitation to identify and reduce vulnerability of those at risk of / or being exploited, and to increase exploitation awareness of key stakeholders, professionals and public

Update:

- Exploitation sits across both NDAP and the Serious Violence Duty (SVD) Programme Group
- An Exploitation Strategic Group has been established to provide a countywide response to all forms of exploitation, which will include cuckooing and other exploitation related to County Lines
- First Exploitation Strategic Group is planned for November 2024, with key stakeholders invited.

Appendix D – update from the Suffolk Combating Drugs Partnership – for information only

Suffolk Combating Drugs Partnership (SCDP) update for the Health and Wellbeing Board:

- The overall number of adults entering drug and alcohol treatment in Suffolk continues to increase, although due to increased resources, numbers in treatment for opiate / crack use are increasing but at a slower rate than those in treatment for alcohol, despite the increased resource. Work is underway to address this including increased outreach and placing recovery workers within the criminal justice system – prisons, courts, Police Investigation Centres and probation – as well as seeking increased referrals from other partners.
- Suffolk are also piloting an initiative that tests the use of assertive outreach with Adult Social Care (ASC) Service Teams in Waveney who have reported concerns relating to increasing demand and complexity of people accessing ASC services with drug and alcohol use as a factor in some cases. The focus is on engagement, stabilisation and bringing people into treatment. Social Care professionals are being offered training on substance use to enhance their confidence in conducting conversations and making appropriate referrals to the service.
- Local Suffolk intelligence suggests that there has been a shift away from opiate use and increased use of non-opiates such as ketamine and cocaine. Suffolk is leading a regional task and finish group on opiates, as other areas also report challenges in increasing the number of opiate users in treatment. Suffolk Public Health are in discussions with the Office for Health Improvement and Disparities (OHID) regarding drug prevalence estimates and targets in light of the local context and intelligence picture.
- Work is underway to increase the numbers of young people in treatment, with some positive early results.
- The Suffolk partnership is also taking action to respond to the threat of synthetic opioids in line with national guidance – for example through issuing drug alerts, improving the sharing of local intelligence and looking to extend naloxone provision.

Report title: Better Care Fund 2024-2025 Quarterly Reports (Q1, Q2)

Date of meeting: 04 December 2024

Sponsor

**(HWB member): Ian Wake, Executive Director, Adult Social Services,
Norfolk County Council**

Reason for the Report

The Health and Wellbeing Board (HWB) holds the responsibility for overseeing and signing off the Better Care Fund (BCF), plans each year and for signing of each of the quarterly reports requested by the national Better Care Team. We include Q1 report and Q2 reports for sign-off.

Report summary

The Norfolk Better Care Fund Team welcomes the opportunity to share the recent quarterly reports with the Board and provides information to support the Board to fulfil its responsibility of signing off both reports. We are pleased to share that the schemes are working to key national and local metrics, supporting key programmes of work across the prevention and hospital discharge.

The quarter one report is attached for sign-off by the Board and this short report focusses on our Additional Discharge Fund spend and activity. The quarter two report is also attached for sign-off. This quarter we have been asked for data on spend to date and metrics on all of our schemes. In this report we confirm that we have met all four National Conditions, and three of the key metrics. It also updates our Discharge and Capacity actual data against the projections we made in the 2024/25 return.

Recommendations

The HWB is asked to:

- a) Agree and sign-off the BCF Q1 and Q2 reports.
- b) Support a presentation of the Q3 report at the next meeting of the Health and Wellbeing Board.

1. Background

- 1.1 The Better Care Fund (BCF) is a nationally mandated programme, launched in 2013 with the aim of joining up health and care services, so that people can manage their own health and wellbeing and live independently.
- 1.2 The BCF is a priority for our HWB and a key element of joint working, focusing on some of the most important integration priorities in our Integrated Care System (ICS). Partners utilise the BCF to fund and develop critical services that support the health and wellbeing of our population, including care from the provider market, key health and care operational teams, and community-based support.
- 1.3 The BCF is made up of a number of elements:
 - Core BCF (NHS Minimum Contribution)
 - Improved BCF (iBCF)
 - Disabled Facilities Grant (DFG)
 - Additional Discharge Fund (ADF)

- 1.4 The BCF pools a statutory minimum contribution of funding between the Integrated care Board (ICB) and the Local Authority (LA). Funding is fully allocated each year on a programme of jointly agreed schemes, the majority of which are long term commissioning commitments. Should a decision be made to include a new service in the BCF, then an existing service needs to be decommissioned or alternatively funded. This is unless an agreement is reached to include additional discretionary funding from the ICB or LA within the BCF.
- 1.5 We work together to agree the allocations between the ICB and the LA of the minimum NHS contribution and the annual joint BCF plan, both of which are signed off and governed by the HWB.
- 1.6 The Board is responsible for signing off the annual plans and quarterly reports. The 24/25 plan was signed off by the Board at the September 2024 meeting.

2. BCF Quarterly Reports

2.1 The Quarter One Report

- 2.1.1 The quarter one report (see appendix 1) focusses on the Additional Discharge Fund. It shows that we are on target for both our spend and activity against the Additional Discharge Fund.
- 2.1.2 The report is formed of three tabs:
 - **1. Guidance:** This tab offers guidance on completing the report.
 - **2. Cover:** This tab shows who is submitting the report, when it is going to Health and Wellbeing Board, and has validation boxes, which are green when the report is completed.
 - **3. Spend and Activity:** This tab focusses on the 13 schemes that we fund via the Additional Discharge Fund. It asks for the actual expenditure to date, the outputs delivered to date where required, and whether there have been any implementation issues.
- 2.1.3 Activity and expenditure profiles are in line with original profiles submitted in the 2024-25 planning return that was approved by HWB in June 2024.

2.2 The Quarter Two Report

- 2.2.1 The quarter two report (see appendix 2) looks at the National Conditions, our Capacity and Demand figures, our performance against metrics and our spend and output activity across all four income elements of the BCF. The report confirms that we are meeting our National Conditions, and that our outputs and spend are on track.
- 2.2.2 The report is formed of six tabs:
 - **1. Guidance:** This tab offers guidance on completing the report.
 - **2. Cover:** This tab shows who is submitting the report, when it is going to Health and Wellbeing Board, and has validation boxes, which are green when the report is completed.
 - **3. National Conditions:** This tab asks us to verify that we have met the BCF National Conditions, which we confirm.
 - **4. Metrics:** This tab looks at the four national metrics, and our performance against them.
 - **5.1 C&D Guidance and Assumptions:** This tab offers guidance on completing the next.

- **5.2 C&D H1 Actual Activity:** This tab looks at our actual Capacity and Demand activity for across intermediate care services, both for hospital discharge and step up from the community.
- **6a Expenditure Guidance:** This tab offers guidance on completing the next.
- **6b Expenditure:** This tab looks at all of our BCF spend. It asks for the actual expenditure to date, the outputs delivered to date where required, and whether there have been any implementation issues.

2.2.3 Activity and expenditure profiles are in line with original profiles submitted in the 2024-25 planning return that was approved by HWB in June 2024.

2.2.4 As part of the Quarter Two Report, we have reviewed our demand and capacity estimates based on activity levels in the year to date and found that discharge activity is higher than profiled across discharge pathways 1-3. Much of the difference relates to priority activity from July to September to reduce escalation beds, with capacity moved to local community provision. More detailed modelling work is being completed with stakeholders in each hospital system as part of winter planning.

Officer Contact

If you have any questions about matters contained in this paper, please get in touch with:

Name: Edward Fraser

Tel: 01603 223122

Email: edward.fraser@norfolk.gov.uk



If you need this report in large print, audio, Braille, alternative format or in a different language please contact 0344 800 8020 or 0344 800 8011 (textphone) and we will do our best to help.

Better Care Fund 2024-25 Quarter 1 Reporting Template

1. Guidance for Q1

Overview

The Better Care Fund (BCF) reporting requirements are set out in the BCF Planning Requirements document for 2023-25, which supports the aims of the BCF Policy Framework and the BCF programme; jointly led and developed by the national partners Department of Health and Social Care (DHSC), Ministry of Housing, Communities and Local Government (MHCLG), NHS England (NHSE), working with the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS). The addendum to the Policy Framework and Planning Requirements published in March 2024 provides further information on the reporting requirements for 24-25.

The key purposes of BCF reporting are:

- 1) To confirm the status of continued compliance against the requirements of the fund (BCF)
- 2) To confirm actual income and expenditure against BCF plans, actual outputs against planned, and progress against metrics
- 3) To identify areas of challenge and good practice to inform national conversations around support requirements
- 4) To enable the use of this information for national partners to inform future planning frameworks and for local areas to inform improvements

The information submitted within reports should be used by ICBs, local authorities, HWBs and service providers to understand and improve both planning processes and the integration of health, social care and housing.

Q1 reporting will only focus on the Discharge Fund.

Requirement

BCF reports submitted by local areas are required to be signed off by HWBs, including through delegated arrangements as appropriate, as the accountable governance body for the BCF locally. Aggregated reporting information will be published on the NHS England website.

Note on entering information into this template

Throughout the template, cells which are open for input have a yellow background and those that are pre-populated have a blue background and those that are not for completion are in grey, as below:

Data needs inputting in the cell

Pre-populated cells

Not applicable - cells where data cannot be added

Note on viewing the sheets optimally

To more optimally view each of the sheets and in particular the drop down lists clearly on screen, please change the zoom level to between 90% - 100%. Most drop downs are also available to view as lists within the relevant sheet or in the guidance tab for readability if required.

The row heights and column widths can be adjusted to fit and view text more comfortably for the cells that require narrative information.

Please **DO NOT** directly copy/cut & paste to populate the fields when completing the template as this can cause issues during the aggregation process. If you must 'copy & paste', please use the 'Paste Special' operation and paste 'Values' only.

The details of each sheet within the template are outlined below.

Checklist (2. Cover)

1. This section helps identify the sheets that have not been completed. All fields that appear as incomplete should be complete before sending to the BCF team.
2. The checker column, which can be found on the individual sheets, updates automatically as questions are completed. It will appear 'Red' and contain the word 'No' if the information has not been completed. Once completed the checker column will change to 'Green' and contain the word 'Yes'
3. The 'sheet completed' cell will update when all 'checker' values for the sheet are green containing the word 'Yes'.
4. Once the checker column contains all cells marked 'Yes' the 'Incomplete Template' cell (below the title) will change to 'Template Complete'.
5. Please ensure that all boxes on the checklist are green before submitting to england.bettercarefundteam@nhs.net and copying in your Better Care Manager.

2. Cover

1. The cover sheet provides essential information on the area for which the template is being completed, contacts and sign off. Once you select your HWB from the drop down list, relevant data on metric ambitions and spend from your BCF plans for 2023-24 will prepopulate in the relevant worksheets.
2. HWB sign off will be subject to your own governance arrangements which may include a delegated authority.

3. Please note that in line with fair processing of personal data we request email addresses for individuals completing the reporting template in order to communicate with and resolve any issues arising during the reporting cycle. We remove these addresses from the supplied templates when they are collated and delete them when they are no longer needed.

3. Spend and activity

The spend and activity worksheet will collect cumulative spend and outputs for Q1 for schemes against planned values and scheme types.

Once a Health and Wellbeing Board is selected in the cover sheet, the spend and activity sheet in the template will prepopulate data from the 24-25 BCF plans.

You should complete the remaining fields (**highlighted yellow**) with incurred expenditure and actual numbers of outputs delivered in Q1.

- Actual expenditure to date in column J. Enter the amount of spend to date on the scheme.

- Outputs delivered to date in column L. If a unit is shown in column L for a scheme, enter the number of outputs delivered to date. For example, for a reablement and/or rehabilitation service, the number of packages commenced. If no unit is attached, enter NA.

For reporting of outputs, the collection only relates to scheme types that include outputs. These are shown below:

Scheme Type

Assistive technologies and equipment

Home care and domiciliary care

Bed based intermediate care services

Home based intermediate care services

DFG related schemes

Residential Placements

Workforce recruitment and retention

Carers services

Units

Number of beneficiaries

Hours of care (unless short-term in which case packages)

Number of placements

Packages

Number of adaptations funded/people supported

Number of beds/placements

Whole Time Equivalent gained/retained

Number of Beneficiaries

- **Implementation issues in columns N and O** - If there have been challenges in delivering or starting a particular service (for instance staff shortages, or procurement delays) please answer yes in column P and briefly describe the issue and planned actions to address the issue in column Q. If you answer no in column P, you do not need to enter a narrative in column Q.

3. Spend and activity (new schemes)

At the top of tab 3, in cell I3, there is a hyperlink leading you to the "add new schemes" section.

For any additional Discharge Fund schemes that have been introduced in Q1, please fill in the details of these schemes in the "add new schemes" section.

If no new schemes have been introduced since the 24-25 plan then this can be left blank.

Better Care Fund 2024-25 Quarter 1 Reporting Template

2. Cover

Version 1.0

Please Note:

- The BCF quarterly reports are categorised as 'Management Information' and data from them will be published in an aggregated form on the NHSE website. This will include any narrative section. Also a reminder that as is usually the case with public body information, all BCF information collected here is subject to Freedom of Information requests.

- At a local level it is for the HWB to decide what information it needs to publish as part of wider local government reporting and transparency requirements. Until BCF information is published, recipients of BCF reporting information (including recipients who access any information placed on the Better Care Exchange) are prohibited from making this information available on any public domain or providing this information for the purposes of journalism or research without prior consent from the HWB (where it concerns a single HWB) or the BCF national partners for the aggregated information.

- All information will be supplied to BCF partners to inform policy development.

- This template is password protected to ensure data integrity and accurate aggregation of collected information. A resubmission may be required if this is breached.

Health and Wellbeing Board:	Norfolk	
Completed by:	Nick Clinch	
E-mail:	nicholas.clinch@norfolk.gov.uk	
Contact number:	01603 223329	
Has this report been signed off by (or on behalf of) the HWB at the time of submission?	No	
If no, please indicate when the report is expected to be signed off:	Wed 04/12/2024	<< Please enter using the format, DD/MM/YYYY

Checklist

Complete:

Yes
Yes
Yes
Yes
Yes
Yes

When all questions have been answered and the validation boxes below have turned green you should send the template to england.bettercarefundteam@nhs.net saving the file as 'Name HWB' for example 'County Durham HWB'.



	Complete:
2. Cover	Yes
3. Spend and activity	Yes
3. Spend and activity (new schemes)	Yes

[<< Link to the Guidance sheet](#)

^^ Link back to top

3. Spend and activity (Discharge Fund only)

[Add new schemes](#)

[existing schemes](#)

Selected Health and Wellbeing Board:

Norfolk

Checklist												Yes	Yes	Yes	Yes
Scheme ID	Scheme Name	Brief Description of Scheme	Scheme Type	Sub Types	Source of Funding	Planned Expenditure	Actual Expenditure to date	Planned outputs	Outputs delivered to date (estimate if unsure) (Number or NA)	Unit of Measure	Have there been any implementation issues?	If yes, please briefly describe the issue(s) and any actions that have been/are being implemented as a result.			
82	Home Support Enhanced Discharge Incentive Scheme	Increased rate for Home Care Providers and additional reabling home support for	Home Care or Domiciliary Care	Short term domiciliary care (without	Local Authority Discharge Funding	£1,988,000	£715,619	380	137	Hours of care (Unless short-term in which case it is packages)	No				
83	Evolve - Discharge Supported Living Scheme	Mental Health - 6 units for discharge	Housing Related Schemes		Local Authority Discharge Funding	£114,423	£24,108		NA		No				
84	Provider: CAB and Carers Matters Norfolk: Carers hardship support	Advice and support services for carers	Carers Services	Carer advice and support related to Care Act duties	Local Authority Discharge Funding	£35,000	£0	520	154	Beneficiaries	No				
86	Provider NCC: staffing costs to administer ADF	Costs associated with distributing / reporting on the funding (1%)	Enablers for Integration	Programme management	Local Authority Discharge Funding	£34,822	£8,706		NA		No				
87	Discharge Hubs	To facilitate the Discharge Process	High Impact Change Model for Managing Transfer of Care	Multi-Disciplinary/Multi-Agency Discharge	Local Authority Discharge Funding	£1,200,000	£300,000		NA		No				
52	Q1 beds	Intermediate pathway beds with various private providers during the spring months.	Bed based intermediate Care Services (Reablement, rehabilitation, wider short-	Bed-based intermediate care with rehabilitation	ICB Discharge Funding	£2,968,775	£1,082,102	52	138	Number of placements	No				
53	Home First Hubs	Locality Priority Schemes with NCH&C & NCC	High Impact Change Model for Managing Transfer of Care	Other	ICB Discharge Funding	£3,588,659	£782,381	-	NA		No				
54	Bridging the Gap	Reablement in a Person's Own Home. Service models are being developed and hours of	Home Care or Domiciliary Care	Domiciliary care packages	ICB Discharge Funding	£1,782,642	£407,753	-	NA	Hours of care (Unless short-term in which case it is packages)	Yes	Not currently commissioning in this format - this project is not commissioned to capture hours and packages			
8901	Community Based Support	Community and VCSE support for Hospital Discharge and Admission Avoidance	Community Based Schemes	Low level support for simple hospital discharges	Local Authority Discharge Funding	£497,755	£59,923	-	NA		No				
8902	Expanded Reablement Capacity	Additional reablement capacity to support people with complex needs, including	Home-based intermediate care services	Reablement at home (to support discharge)	Local Authority Discharge Funding	£1,829,000	£290,100	400	64	Packages	No				
8701	Social Care Worker Resource	Additional social worker resource to support D2A process including within	High Impact Change Model for Managing Transfer of Care	Early Discharge Planning	Local Authority Discharge Funding	£1,032,000	£192,709	-	NA		No				
88	Workforce retention	Home Care rate increase to support providers in their retention work	Workforce recruitment and retention	Improve retention of existing workforce	Local Authority Discharge Funding	£2,376,435	£594,000	-	NA	WTE's gained	Yes	This scheme does not capture outputs for WTE roles, as it provides retention of existing staff posts.			
9101	Norfolk & Waveney Community Support Service	The scheme offers short term support for people on leaving hospital or in the community	Community Based Schemes	Other	Local Authority Discharge Funding	£150,000	£0	-	NA		No				

Better Care Fund 2024-25 Q2 Reporting Template

1. Guidance

Overview

The Better Care Fund (BCF) reporting requirements are set out in the BCF Planning Requirements document for 2023-25, which supports the aims of the BCF Policy Framework and the BCF programme; jointly led and developed by the national partners Department of Health (DHSC), Ministry for Housing, Communities and Local Government (MHCLG), NHS England (NHSE). Please also refer to the Addendum to the 2023 to 2025 Better Care Fund policy framework and planning requirements which was published in April 2024. Links to all policy and planning documents can be found on the bottom of this guidance page.

As outlined within the BCF Addendum, quarterly BCF reporting will continue in 2024 to 2025, with areas required to set out progress on delivering their plans. This will include the collection of spend and activity data, including for the Discharge Fund, which will be reviewed alongside other local performance data. The primary purpose of BCF reporting is to ensure a clear and accurate account of continued compliance with the key requirements and conditions of the fund, including the Discharge Fund. The secondary purpose is to inform policy making, the national support offer and local practice sharing by providing a fuller insight from narrative feedback on local progress, challenges and highlights on the implementation of BCF plans and progress on wider integration.

BCF reporting is likely to be used by local areas, alongside any other information to help inform HWBs on progress on integration and the BCF. It is also intended to inform BCF national partners as well as those responsible for delivering the BCF plans at a local level (including ICB's, local authorities and service providers) for the purposes noted above.

In addition to reporting, BCMs and the wider BCF team will monitor continued compliance against the national conditions and metric ambitions through their wider interactions with local areas.

BCF reports submitted by local areas are required to be signed off by HWBs, or through a formal delegation to officials, as the accountable governance body for the BCF locally. Aggregated reporting information will be published on the NHS England website.

Note on entering information into this template

Please do not copy and paste into the template

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Data needs inputting in the cell

Pre-populated cells

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4. Once the checker column contains all cells marked 'Yes' the 'Incomplete Template' cell (below the title) will change to 'Template Complete'.
5. Please ensure that all boxes on the checklist are green before submission.

2. Cover

1. The cover sheet provides essential information on the area for which the template is being completed, contacts and sign off. Once you select your HWB from the drop down list, relevant data on metric ambitions and capacity and demand from your BCF plans for 2023-24 will prepopulate in the relevant worksheets.
2. HWB sign off will be subject to your own governance arrangements which may include a delegated authority.
3. Question completion tracks the number of questions that have been completed; when all the questions in each section of the template have been completed the cell will turn green. Only when all cells are green should the template be sent to:
england.bettercarefundteam@nhs.net
(please also copy in your respective Better Care Manager)
4. Please note that in line with fair processing of personal data we request email addresses for individuals completing the reporting template in order to communicate with and resolve any issues arising during the reporting cycle. We remove these addresses from the supplied templates when they are collated and delete them when they are no longer needed.

3. National Conditions

This section requires the Health & Wellbeing Board to confirm whether the four national conditions detailed in the Better Care Fund planning requirements for 2023-25 (link below) continue to be met through the delivery of your plan. Please confirm as at the time of completion.

<https://www.england.nhs.uk/wp-content/uploads/2023/04/PRN00315-better-care-fund-planning-requirements-2023-25.pdf>

This sheet sets out the four conditions and requires the Health & Wellbeing Board to confirm 'Yes' or 'No' that these continue to be met. Should 'No' be selected, please provide an explanation as to why the condition was not met for the year and how this is being addressed. Please note that where a National Condition is not being met, an outline of the challenge and mitigating actions to support recovery should be outlined. It is recommended that the HWB also discussed this with their Regional Better Care Manager.

In summary, the four national conditions are as below:

National condition 1: Plans to be jointly agreed

National condition 2: Implementing BCF Policy Objective 1: Enabling people to stay well, safe and independent at home for longer

National condition 3: Implementing BCF Policy Objective 2: Providing the right care in the right place at the right time

National condition 4: Maintaining NHS's contribution to adult social care and investment in NHS commissioned out of hospital services

4. Metrics

The BCF plan includes the following metrics:

- Unplanned hospitalisations for chronic ambulatory care sensitive conditions,
- Proportion of hospital discharges to a person's usual place of residence,
- Admissions to long term residential or nursing care for people over 65,
- Emergency hospital admissions for people over 65 following a fall.

Plans for these metrics were agreed as part of the BCF planning process outlined within 24/25 planning submissions.

This section captures a confidence assessment on achieving the locally set ambitions for each of the BCF metrics.

A brief commentary is requested for each metric outlining the challenges faced in achieving the metric plans, any support needs and successes in the first six months of the financial year.

Data from the Secondary Uses Service (SUS) dataset on outcomes for the discharge to usual place of residence, falls, and avoidable admissions for the first quarter of 2024-25 has been pre populated, along with ambitions for quarters 1-4, to assist systems in understanding performance at local authority level.

The metrics worksheet seeks a best estimate of confidence on progress against the achievement of BCF metric ambitions. The options are:

- on track to meet the ambition
- Not on track to meet the ambition
- data not available to assess progress

You should also include narratives for each metric on challenges and support needs, as well as achievements. Please note columns M and N only apply where 'not on track' is selected.

- In making the confidence assessment on progress, please utilise the available metric data along with any available proxy data.

Please note that the metrics themselves will be referenced (and reported as required) as per the standard national published datasets.

5. Capacity & Demand Actual Activity

Please note this section asks for C&D and actual activity for total intermediate care and not just capacity funded by the BCF.

Activity

For reporting across 24/25 we are asking HWB's to complete their actual activity for the previous quarter. Actual activity is defined as capacity delivered.

For hospital discharge and community, this is found on sheet "5.2 C&D H1 Actual Activity".

5.1 C&D Guidance & Assumptions

Contains guidance notes as well as 4 questions seeking to address the assumptions used in the calculations, changes in the first 6 months of the year, and any support needs particularly for winter and ongoing data issues.

5.2 C&D H1 Actual Activity

Please provide actual activity figures for April - September 24, these include reporting on your spot purchased activity and also actuals on time to treat for each service/pathway within Hospital Discharge. Actual activity for community referrals are required in the table below.

Actual activity is defined as delivered capacity or demand that is met by available capacity. Please note that this applies to all commissioned services not just those funded by the BCF.

Expenditure

Please use this section to complete a summary of expenditure which includes all previous entered schemes from the plan.

The reporting template has been updated to allow for tracking spend over time, providing a summary of expenditure to date alongside percentage spend of total allocation.

Overspend - Where there is an indicated overspend please ensure that you have reviewed expenditure and ensured that a) spend is in line with grant conditions b) where funding source is grant funding that spend cannot go beyond spending 100% of the total allocation.

Underspend - Where grant funding is a source and scheme spend continues you will need to create a new line and allocate this to the appropriate funding line within your wider BCF allocation.

Please also note that Discharge Fund grant funding conditions do not allow for underspend and this will need to be fully accounted for within 24/25 financial year.

For guidance on completing the expenditure section on 23-25 revised scheme type please refer to the expenditure guidance on 6a.

Useful Links and Resources

Planning requirements

<https://www.england.nhs.uk/wp-content/uploads/2023/04/PRN00315-better-care-fund-planning-requirements-2023-25.pdf>

Policy Framework

<https://www.gov.uk/government/publications/better-care-fund-policy-framework-2023-to-2025/2023-to-2025-better-care-fund-policy-framework>

Addendum

<https://www.gov.uk/government/publications/better-care-fund-policy-framework-2023-to-2025/addendum-to-the-2023-to-2025-better-care-fund-policy-framework-and-planning-requirements>

Better Care Exchange

<https://future.nhs.uk/system/login?nextURL=%2Fconnect%2Eti%2Fbettercareexchange%2FgroupHome>

Data pack

<https://future.nhs.uk/bettercareexchange/view?objectId=116035109>

Metrics dashboard

<https://future.nhs.uk/bettercareexchange/view?objectId=51608880>

Better Care Fund 2024-25 Q2 Reporting Template

2. Cover

Version 3.6 [unlocked]

Please Note:

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- At a local level it is for the HWB to decide what information it needs to publish as part of wider local government reporting and transparency requirements. Until BCF information is published, recipients of BCF reporting information (including recipients who access any information placed on the BCE) are prohibited from making this information available on any public domain or providing this information for the purposes of journalism or research without prior consent from the HWB (where it concerns a single HWB) or the BCF national partners for the aggregated information.
- All information will be supplied to BCF partners to inform policy development.
- This template is password protected to ensure data integrity and accurate aggregation of collected information. A resubmission may be required if this is breached.

Health and Wellbeing Board:	Norfolk	
Completed by:	Edward Fraser	
E-mail:	edward.fraser@norfolk.gov.uk	
Contact number:	01603 223122	
Has this report been signed off by (or on behalf of) the HWB at the time of submission?	No	
If no, please indicate when the report is expected to be signed off:	Wed 04/12/2024	<< Please enter using the format, DD/MM/YYYY

Checklist	
Complete:	
	Yes
	Yes
	Yes
	Yes
	Yes
	Yes

Better Care Fund 2024-25 Q2 Reporting Template

3. National Conditions

Selected Health and Wellbeing Board:

Norfolk

Has the section 75 agreement for your BCF plan been finalised and signed off?	No
If it has not been signed off, please provide the date section 75 agreement expected to be signed off	12/02/2024
If a section 75 agreement has not been agreed please outline outstanding actions in agreeing this.	Awaiting approval from Norfolk County Council Cabinet on 02/12/2024

Confirmation of Nation Conditions		
National Condition	Confirmation	If the answer is "No" please provide an explanation as to why the condition was not met in the quarter and mitigating actions underway to support compliance with the condition:
1) Jointly agreed plan	Yes	
2) Implementing BCF Policy Objective 1: Enabling people to stay well, safe and independent at home for longer	Yes	
3) Implementing BCF Policy Objective 2: Providing the right care in the right place at the right time	Yes	
4) Maintaining NHS's contribution to adult social care and investment in NHS commissioned out of hospital services	Yes	

Checklist
Complete:
Yes
Yes
Yes
Yes
Yes
Yes
Yes

Better Care Fund 2024-25 Q2 Reporting Template

4. Metrics

Selected Health and Wellbeing Board:

Norfolk

National data may be unavailable at the time of reporting. As such, please utilise data that may only be available system-wide and other local intelligence.

Metric	Definition	For information - Your planned performance as reported in 2024-25 planning				For information - actual performance for Q1	Assessment of progress against the metric plan for the reporting period	Challenges and any Support Needs <i>Please describe any challenges faced in meeting the planned target, and please highlight any support that may facilitate or ease the achievements of metric plans - ensure that if you have selected data not available to assess progress that this is addressed in this section of your plan</i>	Achievements - including where BCF funding is supporting improvements. <i>Please describe any achievements, impact observed or lessons learnt when considering improvements being pursued for the respective metrics</i>	Variance from plan <i>Please ensure that this section is completed where you have indicated that this metric is not on track to meet target outlining the reason for variance from plan</i>	Mitigation for recovery <i>Please ensure that this section is completed where a) Data is not available to assess progress b) Not on track to meet target with actions to recovery position against plan</i>
		Q1	Q2	Q3	Q4						
Avoidable admissions	Unplanned hospitalisation for chronic ambulatory care sensitive conditions (NHS Outcome Framework indicator 2.3i)	186.5	168.5	195.8	189.0	186.7	On track to meet target	Urgent and emergency care pressures remain high in Norfolk and Waveney. The UCCH is already having a positive impact on improving the capacity of services across the system and will be monitored going into	The N&W Unscheduled Care Coordination Hub (UCCH) went live in August 2023. UCCH enables ambulance and Urgent Care Response (UCR) resources to discuss cases on the stack as a multi-disciplinary team	N/A - on track to meet target	N/A - on track to meet target
Discharge to normal place of residence	Percentage of people who are discharged from acute hospital to their normal place of residence	93.3%	93.3%	93.3%	93.3%	92.49%	On track to meet target	Issues with capacity within NFS and care market to respond promptly to support hospital discharge has been a challenge but the new Caring for Better Outcomes (CFBO) service has started to improve this.	The Norfolk & Waveney Community Support Service offers short-term, temporary practical support for individuals and aims to link clients with services, groups and support networks in their community.	N/A - on track to meet target	N/A - on track to meet target
Falls	Emergency hospital admissions due to falls in people aged 65 and over directly age standardised rate per 100,000.				1,495.1	352.5	On track to meet target	There is a considerable focus on falls prevention and response across the system. There is work underway to ensure that the falls prevention and response pathways are aligned, robust and coherent and offer	There is a Norfolk and Waveney ICS Falls work programme with three workstreams. The aim is to share learning, innovation and expertise across the system to continually improve the falls offer for the population of	N/A - on track to meet target	N/A - on track to meet target
Residential Admissions	Rate of permanent admissions to residential care per 100,000 population (65+)				531	not applicable	Not on track to meet target	This is an ambitious target. A growing elderly population combined with increasing complexity of need will remain a challenge despite the focus and initiatives aimed at supporting people in their own homes.	Links have been made with Integrated Community Equipment Service (ICES) showing that an increased use of the service has resulted in people being able to stay in their own homes for longer.	This ambitious target has not allowed us to achieve the necessary changes to meet it.	We will continue to make an increased use of our ICES, Community Support Services and other Community Networks to turn a corner on this metric.

Complete:

Yes
Yes
Yes
Yes

Better Care Fund 2024-25 Q2 Reporting Template

5. Capacity & Demand

Selected Health and Wellbeing Board:

Norfolk

5.1 Assumptions

<p>1. How have your estimates for capacity and demand changed since the plan submitted in June? Please include any learnings from the last 6 months.</p> <p>We have reviewed our demand and capacity estimates based on activity levels YTD and found that discharge activity is higher than profiled across discharge pathways 1-3. Much of the difference relates to priority activity from July to September to reduce escalation beds, with capacity moved to local community provision. We are making no changes to our general profiles at this time, whilst we complete more detailed modelling work with stakeholders in each hospital system as part of winter planning.</p>	<p>Checklist Complete:</p> <p>Yes</p>
<p>2. How have system wide discussions around winter readiness influenced any changes in capacity and demand as part of proactive management of winter surge capacity?</p> <p>Initial system modelling had already profiled an increase in activity levels over Winter. This has informed our commissioning and operational planning with plans to bring additional capacity online by the end of October. This includes, for example, greater reablement capacity through our in house reablement service and the home care market, through expansion to our Caring for Better Outcomes model. In each hospital system, detailed discussions are underway about opportunities to expand capacity to meet any remaining gaps.</p>	<p>Yes</p>
<p>3. Do you have any capacity concerns or specific support needs to raise for the winter ahead?</p> <p>Confirmation about the continuation of the ADF into 2025-26 as soon as possible is essential to ensure continuity of services over Winter (many contracts expire 31st March 2025). Expansion of this funding to include additional resource to support admission avoidance is required to change the demand curve and enable expansion of prevention and community services in line with wider national strategy.</p>	<p>Yes</p>
<p>4. Where actual demand exceeds capacity for a service type, what is your approach to ensuring that people are supported to avoid admission to hospital or to enable discharge?</p> <p>Our demand and capacity plans include operational work programmes to maximise the effectiveness of existing resources through changes to policy/process. We are confident this will release capacity into the system. Where demand exceeds capacity, spot purchasing arrangements are in place to maintain flow and support admission avoidance / enable discharge. Our priority remains to develop sufficient commissioned services and we have made strong progress in the YTD against this ambition.</p>	<p>Yes</p>

Guidance on completing this sheet is set out below, but should be read in conjunction with the separate guidance and q&a document

5.1 Guidance

The assumptions box has been updated and is now a set of specific narrative questions. Please answer all questions in relation to both hospital discharge and community sections of the capacity and demand template.

You should reflect changes to understanding of demand and available capacity for admissions avoidance and hospital discharge since the completion of the original BCF plans, including

- actual demand in the first 6 months of the year
- modelling and agreed changes to services as part of Winter planning
- Data from the Community Bed Audit
- Impact to date of new or revised intermediate care services or work to change the profile of discharge pathways.

Hospital Discharge

This section collects actual activity of services to support people being discharged from acute hospital. You should input the actual activity to support discharge across these different service types and this applies to all commissioned services not just those from the BCF.

- Reablement & Rehabilitation at home (pathway 1)
- Short term domiciliary care (pathway 1)
- Reablement & Rehabilitation in a bedded setting (pathway 2)
- Other short term bedded care (pathway 2)
- Short-term residential/nursing care for someone likely to require a longer-term care home placement (pathway 3)

Community

This section collects actual activity for community services. You should input the actual activity across health and social care for different service types. This should cover all service intermediate care services to support recovery, including Urgent Community Response and VCS support and this applies to all commissioned services not just those from the BCF. The template is split into these types of service:

- Social support (including VCS)
- Urgent Community Response
- Reablement & Rehabilitation at home
- Reablement & Rehabilitation in a bedded setting
- Other short-term social care

Better Care Fund 2024-25 Q2 Reporting Template

5. Capacity & Demand

Selected Health and Wellbeing Board:

Norfolk

Actual activity - Hospital Discharge		Prepopulated demand from 2024-25 plan						Actual activity (not including spot purchased capacity)						Actual activity through only spot purchasing (doesn't apply to time to service)					
Service Area	Metric	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24
Reablement & Rehabilitation at home (pathway 1)	Monthly activity. Number of new clients	548	485	604	487	577	538	500	502	479	642	579	655	0	0	0	0	0	0
Reablement & Rehabilitation at home (pathway 1)	Actual average time from referral to commencement of service (days). All packages (planned and spot purchased)	3	3	3	3	3	3	3	3	3	3	3	3						
Short term domiciliary care (pathway 1)	Monthly activity. Number of new clients	0	0	0	0	0	0	0	0	0	0	0	0	48	55	46	47	44	33
Short term domiciliary care (pathway 1)	Actual average time from referral to commencement of service (days) All packages (planned and spot purchased)	7	7	7	7	7	7	7	7	7	7	7	7						
Reablement & Rehabilitation in a bedded setting (pathway 2)	Monthly activity. Number of new clients	223	183	237	209	239	207	175	168	148	230	230	212	0	0	0	0	0	0
Reablement & Rehabilitation in a bedded setting (pathway 2)	Actual average time from referral to commencement of service (days) All packages (planned and spot purchased)	15	15	15	15	15	15	15	15	15	15	15	15						
Other short term bedded care (pathway 2)	Monthly activity. Number of new clients.	0	0	0	0	0	0	0	0	0	0	0	0	48	30	47	34	18	29
Other short term bedded care (pathway 2)	Actual average time from referral to commencement of service (days) All packages (planned and spot purchased)	15	15	15	15	15	15	15	15	15	15	15	15						
Short-term residential/nursing care for someone likely to require a longer-term care home placement (pathway 3)	Monthly activity. Number of new clients	91	83	99	76	90	92	0	0	0	0	0	0	91	96	63	103	73	86
Short-term residential/nursing care for someone likely to require a longer-term care home placement (pathway 3)	Actual average time from referral to commencement of service (days) All packages (planned and spot purchased)	15	15	15	15	15	15	15	15	15	15	15	15						

Actual activity - Community		Prepopulated demand from 2024-25 plan						Actual activity:					
Service Area	Metric	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24
Social support (including VCS)	Monthly activity. Number of new clients.	103	103	103	103	103	103	193	200	209	209	207	245
Urgent Community Response	Monthly activity. Number of new clients.	3041	3011	3118	2890	2900	3128	2090	2140	2036	2310	2049	1893
Reablement & Rehabilitation at home	Monthly activity. Number of new clients.	1034	1036	1328	1326	1326	1332	343	391	343	389	374	379
Reablement & Rehabilitation in a bedded setting	Monthly activity. Number of new clients.	9	10	7	8	6	11	9	10	7	8	6	11
Other short-term social care	Monthly activity. Number of new clients.	0	0	0	0	0	0	0	0	0	0	0	0

Checklist

Complete:

- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes
- Yes

- Yes
- Yes
- Yes
- Yes

Further guidance for completing Expenditure sheet

Schemes tagged with the following will count towards the planned **Adult Social Care services spend** from the NHS min:

- **Area of spend** selected as 'Social Care'
- **Source of funding** selected as 'Minimum NHS Contribution'

Schemes tagged with the below will count towards the planned **Out of Hospital spend** from the NHS min:

- **Area of spend** selected with anything except 'Acute'
- **Commissioner** selected as 'ICB' (if 'Joint' is selected, only the NHS % will contribute)
- **Source of funding** selected as 'Minimum NHS Contribution'

2023-25 Revised Scheme types

Number	Scheme type/ services	Sub type	Description
1	Assistive Technologies and Equipment	1. Assistive technologies including telecare 2. Digital participation services 3. Community based equipment 4. Other	Using technology in care processes to supportive self-management, maintenance of independence and more efficient and effective delivery of care. (eg. Telecare, Wellness services, Community based equipment, Digital participation services).
2	Care Act Implementation Related Duties	1. Independent Mental Health Advocacy 2. Safeguarding 3. Other	Funding planned towards the implementation of Care Act related duties. The specific scheme sub types reflect specific duties that are funded via the NHS minimum contribution to the BCF.
3	Carers Services	1. Respite Services 2. Carer advice and support related to Care Act duties 3. Other	Supporting people to sustain their role as carers and reduce the likelihood of crisis. This might include respite care/carers breaks, information, assessment, emotional and physical support, training, access to services to support wellbeing and improve independence.
4	Community Based Schemes	1. Integrated neighbourhood services 2. Multidisciplinary teams that are supporting independence, such as anticipatory care 3. Low level social support for simple hospital discharges (Discharge to Assess pathway 0) 4. Other	Schemes that are based in the community and constitute a range of cross sector practitioners delivering collaborative services in the community typically at a neighbourhood/PCN level (eg: Integrated Neighbourhood Teams) Reablement services should be recorded under the specific scheme type 'Reablement in a person's own home'
5	DFG Related Schemes	1. Adaptations, including statutory DFG grants 2. Discretionary use of DFG 3. Handyperson services 4. Other	The DFG is a means-tested capital grant to help meet the costs of adapting a property; supporting people to stay independent in their own homes. The grant can also be used to fund discretionary, capital spend to support people to remain independent in their own homes under a Regulatory Reform Order, if a published policy on doing so is in place. Schemes using this flexibility can be recorded under 'discretionary use of DFG' or 'handyperson services' as appropriate
6	Enablers for Integration	1. Data Integration 2. System IT Interoperability 3. Programme management 4. Research and evaluation 5. Workforce development 6. New governance arrangements 7. Voluntary Sector Business Development 8. Joint commissioning infrastructure 9. Integrated models of provision 10. Other	Schemes that build and develop the enabling foundations of health, social care and housing integration, encompassing a wide range of potential areas including technology, workforce, market development (Voluntary Sector Business Development: Funding the business development and preparedness of local voluntary sector into provider Alliances/ Collaboratives) and programme management related schemes. Joint commissioning infrastructure includes any personnel or teams that enable joint commissioning. Schemes could be focused on Data Integration, System IT Interoperability, Programme management, Research and evaluation, Supporting the Care Market, Workforce development, Community asset mapping, New governance arrangements, Voluntary Sector Development, Employment services, Joint commissioning infrastructure amongst others.
7	High Impact Change Model for Managing Transfer of Care	1. Early Discharge Planning 2. Monitoring and responding to system demand and capacity 3. Multi-Disciplinary/Multi-Agency Discharge Teams supporting discharge 4. Home First/Discharge to Assess - process support/core costs 5. Flexible working patterns (including 7 day working) 6. Trusted Assessment 7. Engagement and Choice 8. Improved discharge to Care Homes 9. Housing and related services 10. Red Bag scheme 11. Other	The ten changes or approaches identified as having a high impact on supporting timely and effective discharge through joint working across the social and health system. The Hospital to Home Transfer Protocol or the 'Red Bag' scheme, while not in the HICM, is included in this section.
8	Home Care or Domiciliary Care	1. Domiciliary care packages 2. Domiciliary care to support hospital discharge (Discharge to Assess pathway 1) 3. Short term domiciliary care (without reablement input) 4. Domiciliary care workforce development 5. Other	A range of services that aim to help people live in their own homes through the provision of domiciliary care including personal care, domestic tasks, shopping, home maintenance and social activities. Home care can link with other services in the community, such as supported housing, community health services and voluntary sector services.
9	Housing Related Schemes		This covers expenditure on housing and housing-related services other than adaptations; eg: supported housing units.
10	Integrated Care Planning and Navigation	1. Care navigation and planning 2. Assessment teams/joint assessment 3. Support for implementation of anticipatory care 4. Other	Care navigation services help people find their way to appropriate services and support and consequently support self-management. Also, the assistance offered to people in navigating through the complex health and social care systems (across primary care, community and voluntary services and social care) to overcome barriers in accessing the most appropriate care and support. Multi-agency teams typically provide these services which can be online or face to face care navigators for frail elderly, or dementia navigators etc. This includes approaches such as Anticipatory Care, which aims to provide holistic, co-ordinated care for complex individuals. Integrated care planning constitutes a co-ordinated, person centred and proactive case management approach to conduct joint assessments of care needs and develop integrated care plans typically carried out by professionals as part of a multi-disciplinary, multi-agency teams. Note: For Multi-Disciplinary Discharge Teams related specifically to discharge, please select HICM as scheme type and the relevant sub-type. Where the planned unit of care delivery and funding is in the form of integrated care packages and needs to be expressed in such a manner, please select the appropriate sub-type alongside.
11	Bed based intermediate Care Services (Reablement, rehabilitation in a bedded setting, wider short-term services supporting recovery)	1. Bed-based intermediate care with rehabilitation (to support discharge) 2. Bed-based intermediate care with reablement (to support discharge) 3. Bed-based intermediate care with rehabilitation (to support admission avoidance) 4. Bed-based intermediate care with reablement (to support admissions avoidance) 5. Bed-based intermediate care with rehabilitation accepting step up and step down users 6. Bed-based intermediate care with reablement accepting step up and step down users 7. Other	Short-term intervention to preserve the independence of people who might otherwise face unnecessarily prolonged hospital stays or avoidable admission to hospital or residential care. The care is person-centred and often delivered by a combination of professional groups.

12	Home-based intermediate care services	<ol style="list-style-type: none"> 1. Reablement at home (to support discharge) 2. Reablement at home (to prevent admission to hospital or residential care) 3. Reablement at home (accepting step up and step down users) 4. Rehabilitation at home (to support discharge) 5. Rehabilitation at home (to prevent admission to hospital or residential care) 6. Rehabilitation at home (accepting step up and step down users) 7. Joint reablement and rehabilitation service (to support discharge) 8. Joint reablement and rehabilitation service (to prevent admission to hospital or residential care) 9. Joint reablement and rehabilitation service (accepting step up and step down users) 10. Other 	Provides support in your own home to improve your confidence and ability to live as independently as possible
13	Urgent Community Response		Urgent community response teams provide urgent care to people in their homes which helps to avoid hospital admissions and enable people to live independently for longer. Through these teams, older people and adults with complex health needs who urgently need care, can get fast access to a range of health and social care professionals within two hours.
14	Personalised Budgeting and Commissioning		Various person centred approaches to commissioning and budgeting, including direct payments.
15	Personalised Care at Home	<ol style="list-style-type: none"> 1. Mental health /wellbeing 2. Physical health/wellbeing 3. Other 	Schemes specifically designed to ensure that a person can continue to live at home, through the provision of health related support at home often complemented with support for home care needs or mental health needs. This could include promoting self-management/expert patient, establishment of 'home ward' for intensive period or to deliver support over the longer term to maintain independence or offer end of life care for people. Intermediate care services provide shorter term support and care interventions as opposed to the ongoing support provided in this scheme type.
16	Prevention / Early Intervention	<ol style="list-style-type: none"> 1. Social Prescribing 2. Risk Stratification 3. Choice Policy 4. Other 	Services or schemes where the population or identified high-risk groups are empowered and activated to live well in the holistic sense thereby helping prevent people from entering the care system in the first place. These are essentially upstream prevention initiatives to promote independence and well being.
17	Residential Placements	<ol style="list-style-type: none"> 1. Supported housing 2. Learning disability 3. Extra care 4. Care home 5. Nursing home 6. Short-term residential/nursing care for someone likely to require a longer-term care home replacement 7. Short term residential care (without rehabilitation or reablement input) 8. Other 	Residential placements provide accommodation for people with learning or physical disabilities, mental health difficulties or with sight or hearing loss, who need more intensive or specialised support than can be provided at home.
18	Workforce recruitment and retention	<ol style="list-style-type: none"> 1. Improve retention of existing workforce 2. Local recruitment initiatives 3. Increase hours worked by existing workforce 4. Additional or redeployed capacity from current care workers 5. Other 	These scheme types were introduced in planning for the 22-23 AS Discharge Fund. Use these scheme descriptors where funding is used to for incentives or activity to recruit and retain staff or to incentivise staff to increase the number of hours they work.
19	Other		Where the scheme is not adequately represented by the above scheme types, please outline the objectives and services planned for the scheme in a short description in the comments column.

Scheme type	Units
Assistive Technologies and Equipment	Number of beneficiaries
Home Care or Domiciliary Care	Hours of care (Unless short-term in which case it is packages)
Bed based intermediate Care Services	Number of placements
Home-based intermediate care services	Packages
Residential Placements	Number of beds
DFG Related Schemes	Number of adaptations funded/people supported
Workforce Recruitment and Retention	WTE's gained
Carers Services	Beneficiaries

See next sheet for Scheme Type (and Sub Type) descriptions

Better Care Fund 2024-25 Q2 Reporting Template

To Add New Schemes

6. Expenditure

Selected Health and Wellbeing Board:

Running Balances	2024-25			
	Income	Expenditure to date	Percentage spent	Balance
DFG	£9,988,855	£9,988,855	100.00%	£0
Minimum NHS Contribution	£81,533,291	£39,113,863	47.97%	£42,419,428
IBCF	£39,618,564	£19,811,282	50.01%	£19,807,282
Additional LA Contribution	£0	£0		£0
Additional NHS Contribution	£0	£0		£0
Local Authority Discharge Funding	£9,257,435	£4,505,938	48.67%	£4,751,497
ICB Discharge Funding	£8,340,076	£4,297,349	51.53%	£4,042,727
Total	£148,738,221	£77,717,287	52.25%	£71,020,934

<< Link to summary sheet

Comments if income changed

Required Spend

This is in relation to National Conditions 2 and 3 only. It does NOT make up the total Minimum ICB Contribution (on row 33 above).

	2024-25		
	Minimum Required Spend	Expenditure to date	Balance
NHS Commissioned Out of Hospital spend from the minimum ICB allocation	£23,124,650	£18,890,863	£4,233,787
Adult Social Care services spend from the minimum ICB allocations	£40,243,713	£25,852,828	£14,390,885

Checklist Column complete: Yes No

Scheme ID	Scheme Name	Brief Description of Scheme	Scheme Type	Sub Types	Please specify if 'Scheme Type' is 'Other'	Planned Outputs for 2024-25	Outputs delivered to date (Number or NA if no plan)	Units	Area of Spend	Please specify if 'Area of Spend' is 'other'	Commissioner	% NHS (if Joint Commissioner)	% LA (if Joint Commissioner)	Provider	Source of Funding	Previously entered Expenditure for 2024-25 (£)	Expenditure to date (£)	Comments
1	Norfolk Advice Network and Advocacy	Provider: Age UK, Equal Lives. To provide a single point of contact for information.	Integrated Care Planning and Navigation	Care navigation and planning			NA		Social Care		Joint	12.0%	88.0%	Charity / Voluntary Sector	Minimum NHS Contribution	£262,571	£131,376	
2	A Social Impact Bond for Carers	Provider: Carers Matter Norfolk. To support carers to maintain	Carers Services	Carer advice and support related to Care Act duties		2244	1770	Beneficiaries	Social Care		Joint	12.0%	88.0%	Private Sector	Minimum NHS Contribution	£1,496,906	£748,453	
76	DOLS	Deprivation of Living Safeguards	Care Act Implementation Related Duties	Other	Deprivation of Living Safeguards		NA		Social Care		LA			Local Authority	IBCF	£248,000	£124,000	
9	ICES (Integrated Community Equipment)	Provider: Medequip. Provides equipment to aid independence at home.	Assistive Technologies and Equipment	Community based equipment		39322	19318	Number of beneficiaries	Social Care		Joint	92.0%	8.0%	Private Sector	Minimum NHS Contribution	£7,777,996	£3,692,144	Cost and volume activity below YTD plan. LA spend for service for first 6 months.
10	Integrated Care Coordinators	Provider: Norfolk County Council. ICC roles work with health and social care	Integrated Care Planning and Navigation	Care navigation and planning			NA		Primary Care		Joint	89.0%	11.0%	Local Authority	Minimum NHS Contribution	£656,367	£324,556	
20	Norfolk First Response	Provider: Norfolk County Council. Reablement Services offering six weeks reablement	Home-based intermediate care services	Reablement at home (accepting step up and step down users)		6827	4490	Packages	Social Care		Joint	12.2%	87.8%	Local Authority	Minimum NHS Contribution	£10,821,868	£5,363,231	
21	Rapid Response (part of Swifts and Nightwows)	Provider: Norfolk County Council rapid response service for people with short	Urgent Community Response				NA		Social Care		Joint	25.0%	75.0%	Local Authority	Minimum NHS Contribution	£1,700,598	£723,060	
56	District Direct	Provider: District and Borough Councils. Ensures District Council	High Impact Change Model for Managing Transfer of Care	Housing and related services			NA		Acute		Joint	0.3%	99.7%	Local Authority	Minimum NHS Contribution	£162,400	£78,520	
60	Out of hospital / Short Term offer	Bed based short term offer and hospital social work teams	Community Based Schemes	Multidisciplinary teams that are supporting independence, such as			NA		Social Care		LA			Local Authority	Minimum NHS Contribution	£8,197,927	£4,098,964	
61	Brokerage	Brokerage Team Staff - increased capacity to support placements out of hospital	Enablers for Integration	Joint commissioning infrastructure			NA		Social Care		LA			Local Authority	Minimum NHS Contribution	£34,826	£17,413	
62	Social Care and Health Partnership Commissioning	Joint Commissioning Team across NCC and the ICB	Enablers for Integration	Joint commissioning infrastructure			NA		Social Care		LA			Local Authority	Minimum NHS Contribution	£261,192	£130,596	
63	Integrated Quality Team	Joint Quality Team across NCC and the ICB	Enablers for Integration	Joint commissioning infrastructure			NA		Social Care		LA			Local Authority	Minimum NHS Contribution	£272,075	£136,038	
64	LD, MH and Autism Packages of Care	Care services for people with LD, MH and Autism	Home Care or Domiciliary Care	Domiciliary care packages		138610	68994	Hours of care (Unless short-term in which case it is packages)	Social Care		LA			Local Authority	Minimum NHS Contribution	£3,532,499	£1,766,250	

65	BCF Health and Wellbeing Partnership Funds	Provider: Norfolk's Health and Wellbeing Partnerships. To support place based	Enablers for integration	Joint commissioning infrastructure			NA		Social Care		LA		Private Sector	Minimum NHS Contribution	£643,248	£43,485	
67	Disabled Facilities Grant	Spend on DFG's by our district and borough councils	DFG Related Schemes	Adaptations, including statutory DFG grants		1500	208	Number of adaptations funded/people supported	Social Care		LA		Local Authority	DFG	£9,988,855	£9,988,855	Output figure (adaptations funded) is for Q1 only.
70	ASC Core Care Services (underlying spend)	Covering market pressures	Home Care or Domiciliary Care	Domiciliary care packages		602155	301055	Hours of care (Unless short-term in which case it is packages)	Social Care		LA		Private Sector	IBCF	£14,524,000	£7,262,000	
77	Enhancement to Social Care Capacity 2018	Additional Social Work Capacity	Care Act Implementation Related Duties	Other	Additional Social Work		NA		Social Care		LA		Local Authority	IBCF	£2,640,000	£1,320,000	
81	The Old Maltings service provision	Housing with Care service	Housing Related Schemes				NA		Social Care		IA		Private Sector	IBCF	£179,000	£89,500	
82	Practice Educator Lead	Practice Educator Lead to support good practice.	Enablers for integration	Workforce development			NA		Social Care		IA		Local Authority	IBCF	£54,000	£27,000	
84	Technology for agile working	Support agile working for SW Teams	Enablers for integration	Workforce development			NA		Social Care		IA		Local Authority	IBCF	£34,000	£17,000	
85	Winter Pressures Project Support	Coordinating Winter Planning for ASC	Enablers for integration	Programme management			NA		Social Care		IA		Local Authority	IBCF	£51,000	£25,500	
38	Eating Matters	Eating Matters provides counselling in the community for people suffering with mild	Prevention / Early Intervention	Risk Stratification			NA		Community Health		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£161,288	£76,782	
40	West Norfolk Carers Project	Independent charity supporting unpaid family carers and providing a carer's	Carers Services	Other	Information, advice and guidance	164	294	Beneficiaries	Social Care		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£20,334	£15,680	Of those, 176 were new in Q2
43	Wellfamily Services (West Norfolk)	Well Family is a one-stop health and wellbeing service comprising a suite of health-	Prevention / Early Intervention	Risk Stratification			NA		Community Health		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£84,693	£47,781	
44	St. Martin's Hub	Provides emergency accommodation and support for rough sleepers in	Housing Related Schemes				NA		Mental Health		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£69,298	£0	
45	West Norfolk Disability Information	Provides a range of information and support to individuals with disabilities,	Integrated Care Planning and Navigation	Care navigation and planning			NA		Social Care		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£14,698	£6,820	
46	GP / Medical cover - Int Care Beds (West	GP medical cover to bed-based intermediate care services to help people	Community Based Schemes	Multidisciplinary teams that are supporting independence, such as	Medical cover for IC beds		NA		Primary Care		NHS		Private Sector	Minimum NHS Contribution	£21,306	£21,308	
48	Transport Plus	Provides transport to enable access to health, social care and wellbeing services using	Community Based Schemes	Other	Transport		NA		Other		NHS		Local Authority	Minimum NHS Contribution	£41,383	£19,583	
49	West Norfolk Community Action Norfolk	CAN is the leading organisation for engagement with the voluntary,	Enablers for integration	Voluntary Sector Business Development			NA		Primary Care		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£44,377	£20,795	
50	West Norfolk Community Transport	Provides day to day management of a bank of drivers, including recruitment	Community Based Schemes	Other	Transport		NA		Other		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£28,861	£13,391	
79	MH Capacity (evolve and practitioners)	MH Capacity	Care Act Implementation Related Duties	Other	MH Capacity		NA		Social Care		LA		Local Authority	IBCF	£235,000	£117,500	
82	Home Support Enhanced Discharge	Increased rate for Home Care Providers and additional reablement home support for	Home Care or Domiciliary Care	Short term domiciliary care (without reablement input)		380	338	Hours of care (Unless short-term in which case it is packages)	Social Care		LA		Private Sector	Local Authority Discharge	£1,988,000	£1,347,541	
83	Evolve - Discharge Supported Living Scheme	Mental Health - 6 units for discharge	Housing Related Schemes				NA		Social Care		LA		Private Sector	Local Authority Discharge	£114,423	£49,658	
84	Provider: CAB and Carers Matters Norfolk: Carers	Advice and support services for carers	Carers Services	Carer advice and support related to Care Act duties		520	260	Beneficiaries	Social Care		LA		Charity / Voluntary Sector	Local Authority Discharge	£35,000	£0	
86	Provider NCC: staffing costs to administer ADF	Costs associated with distributing / reporting on the funding (1%)	Enablers for integration	Programme management			NA		Social Care		LA		Local Authority	Local Authority Discharge	£34,822	£17,411	
87	Discharge Hubs	To facilitate the Discharge Process	High Impact Change Model for Managing Transfer of Care	Multi-Disciplinary/Multi-Agency Discharge Teams supporting discharge			NA		Social Care		LA		Local Authority	Local Authority Discharge	£1,200,000	£600,000	
4	Dementia / Alzheimer's Support Service	DSS is a three tier step-up / down system providing: information, Advice &	Integrated Care Planning and Navigation	Care navigation and planning		0	NA		Mental Health		NHS		Charity / Voluntary Sector	Minimum NHS Contribution	£1,317,116	£629,318	
7	HomeWard (Norwich)	HomeWard provides urgent short term care, nursing and therapy support. The MDT	Home-based intermediate care services	Rehabilitation at home (accepting step up and step down users)		24	12	Packages	Community Health		NHS		NHS Community Provider	Minimum NHS Contribution	£1,679,786	£854,386	
90	Independent Mental Health Advocacy and	Independent Mental Health Advocacy and Independent Mental Capacity Advocate	Integrated Care Planning and Navigation	Care navigation and planning			NA		Social Care		LA		Charity / Voluntary Sector	Minimum NHS Contribution	£907,662	£453,831	
37	Social Prescribing	A community wellbeing service that focus' on improving wellbeing. A free	Prevention / Early Intervention	Social Prescribing			NA		Social Care		NHS		Private Sector	Minimum NHS Contribution	£2,321,816	£1,092,411	

11	Intermediate Spot Purchase Beds	Accomodation based commissioning.	Bed based Intermediate Care Services (Reablement,	Bed-based intermediate care with rehabilitation (to support discharge)		306	156	Number of placements	Community Health	NHS			Private Sector	Minimum NHS Contribution	£1,940,830	£735,166	Phasing difference, expecting higher costs in H2 months
13	Community Access Team (CAT)	CAT manages transfers of care into NCHC's intermediate care units for	High Impact Change Model for Managing Transfer of Care	Multi-Disciplinary/Multi-Agency Discharge Teams supporting discharge			NA		Community Health	NHS			NHS Community Provider	Minimum NHS Contribution	£1,121,191	£570,269	
14	Medical Loans Service	Provider: British Red Cross. Short term loans of equipment to aid	Assistive Technologies and Equipment	Community based equipment		4861	1932	Number of beneficiaries	Community Health	NHS			Charity / Voluntary Sector	Minimum NHS Contribution	£144,791	£72,374	3353 pieces of equipment (wheelchairs 1577, toileting 672, other 324 and accessories 780) for 1932 users
16	Norfolk Medicines Support Service (NMSS)	NMSS supports vulnerable individuals with practical, user-friendly solutions to	Personalised Care at Home	Physical health/wellbeing			NA		Community Health	NHS			Local Authority	Minimum NHS Contribution	£326,035	£166,628	
17	Equal Lives	A disability rights organisation supporting people to empower themselves to live	Integrated Care Planning and Navigation	Care navigation and planning			NA		Social Care	NHS			Local Authority	Minimum NHS Contribution	£160,520	£75,961	
51	Learning Disability Beds	Accomodation-based CHC commissioning. Difficult to calculate give the varied	Residential Placements	Learning Disability		0	0	Number of beds	Community Health	NHS			Private Sector	Minimum NHS Contribution	£626,209	£314,705	
52	Q1 beds	Intermediate pathway beds with various private providers during the spring months.	Bed based Intermediate Care Services (Reablement,	Bed-based intermediate care with rehabilitation (to support discharge)		52	276	Number of placements	Community Health	NHS			Private Sector	ICB Discharge Funding	£2,968,775	£2,316,345	The ICB is spending further in Norfolk and Waveney for P2 beds and MDT support which explains why the cost is higher than
53	Home First Hubs	Locality Priority Schemes with NCH&C & NCC	High Impact Change Model for Managing Transfer of Care	Other	Hub staffing	0	NA		Community Health	NHS			Local Authority	ICB Discharge Funding	£3,588,659	£1,362,044	Central and West localities expenditure phasing is expected to increase during the winter period
54	Bridging the Gap	Reablement in a Person's Own Home. Service models are being developed and	Home Care or Domiciliary Care	Domiciliary care packages		0	0	Hours of care (Unless short-term in which case it is packages)	Community Health	NHS			NHS	ICB Discharge Funding	£1,782,642	£618,960	Central and West localities expenditure phasing is expected to increase during the winter period
26	Neuro Cardiac & Pulmonary Support Services	Specialist community nurses providing neurological, cardiac & pulmonary support	Personalised Care at Home	Physical health/wellbeing			NA		Community Health	NHS			NHS Community Provider	Minimum NHS Contribution	£547,766	£278,609	
27	Specialist Nursing Teams	Specialist Nursing Teams to support people in the community	Personalised Care at Home	Physical health/wellbeing			NA		Community Health	NHS			NHS Community Provider	Minimum NHS Contribution	£552,592	£281,064	
29	Norfolk and Norwich SEND (Special)	The Special Educational Needs and Disabilities (SEND) Support scheme provides	Prevention / Early Intervention	Risk Stratification			NA		Community Health	NHS			Charity / Voluntary Sector	Minimum NHS Contribution	£17,539	£8,185	
30	Norfolk Deaf Association	Norfolk Deaf Association (NDA) delivers community-based support to individuals	Prevention / Early Intervention	Risk Stratification			NA		Community Health	NHS			Charity / Voluntary Sector	Minimum NHS Contribution	£275,760	£198,658	
31	Community Stroke Support (West)	Provides a range of community stroke support services in the West.	Prevention / Early Intervention	Risk Stratification			NA		Community Health	NHS			Charity / Voluntary Sector	Minimum NHS Contribution	£132,041	£61,252	
32	Together	Service for people with serious mental health problems provided by	Community Based Schemes	Multidisciplinary teams that are supporting independence, such as			NA		Mental Health	NHS			Local Authority	Minimum NHS Contribution	£422,177	£197,426	
34	Discharge Practitioner Services	Funding of practitioners to support multi-agency discharge teams.	High Impact Change Model for Managing Transfer of Care	Multi-Disciplinary/Multi-Agency Discharge Teams supporting discharge			NA		Social Care	NHS			Local Authority	Minimum NHS Contribution	£135,555	£36,692	
1901	Norfolk Hospice Tapping House (NHTH) - West	Specialist palliative and end of life care provider for people living with life-	Community Based Schemes	Other	Hospice care, community outreach and	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£788,985	£340,860	
1902	Swaffham & Litcham Home Hospice (social)	Swaffham & Litcham Home Hospice is a non-medical organisation giving free	Community Based Schemes	Other	Palliative and end of life wellbeing and practical	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£86,024	£27,295	
39	Acute Psychiatric Liaison QEH and JPUH - East	The Acute Psychiatric Liaison service works with individuals with mental health conditions	Prevention / Early Intervention	Risk Stratification	0	0	NA		Mental Health	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£155,770	£110,462	
4201	Nursing support for Glaven Day Centre	This scheme provides funds for a nurse on site at Glaven Day Centre (North Norfolk) as	Prevention / Early Intervention	Risk Stratification	0	0	NA		Community Health	NHS	0.0%		Private Sector	Minimum NHS Contribution	£64,921	£5,515	Column U shows incorrect figure. Expenditure is planned at £11,803
4202	Complex Community Support Outreach	Community outreach service for individuals living with complex health/social care	Community Based Schemes	Other	Outreach support for individuals with	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£11,803	£30,389	Column U shows incorrect figure. Expenditure is planned at £64921
4701	ASD / ADHD / Asperger's Pre-Diagnostic Support	The ASD & ADHD pre-diagnostic support service offers assistance for the	Prevention / Early Intervention	Risk Stratification	0	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£215,257	£97,887	
4702	Autism Service (Norfolk)	The Autism Service in Norfolk provides pre-assessment support, assessment,	Prevention / Early Intervention	Risk Stratification	0	0	NA		Community Health	NHS	0.0%		NHS Community Provider	Minimum NHS Contribution	£109,391	£52,076	
301	Community Nursing and Therapy (CN&T)	Community nurses, therapists and clinical support staff provide physical health	Community Based Schemes	Multidisciplinary teams that are supporting independence, such as	0	0	NA		Community Health	NHS	0.0%		NHS Community Provider	Minimum NHS Contribution	£8,686,818	£4,418,357	
302	Community Nursing and Therapy (CN&T)	Community nurses, therapists and clinical support staff provide physical health	Community Based Schemes	Multidisciplinary teams that are supporting independence, such as	0	0	NA		Community Health	NHS	0.0%		NHS Community Provider	Minimum NHS Contribution	£2,838,976	£1,436,335	
3601	SOS Bus - Kings Lynn	The SOS bus is a first point of contact, support and first aid for people experiencing	Prevention / Early Intervention	Risk Stratification	0	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£41,577	£18,738	
3602	Late Night Safe Space - Norwich	The Norwich SOS Bus provides a safe space for people socialising in Norwich	Prevention / Early Intervention	Risk Stratification	0	0	NA		Other	NHS	0.0%		Charity / Voluntary Sector	Minimum NHS Contribution	£89,675	£40,415	

8	West Norfolk Rapid Assessment and Frailty Team	The Rapid Assessment and Frailty Team (RAFT) at the Queen Elizabeth hospital help	High Impact Change Model for Managing Transfer of Care	Multi-Disciplinary/Multi-Agency Discharge Teams supporting discharge	0	0	NA		Community Health	NHS	0.0%		NHS Community Provider	Minimum NHS Contribution	£2,133,629	£1,085,223	
35	Social care and ICC support to 3x mid Norfolk GP	The provision of social care and ICC resources to support mid Norfolk 3x GP Practices	Prevention / Early Intervention	Risk Stratification	0	0	NA		Primary Care	NHS	0.0%		Local Authority	Minimum NHS Contribution	£147,122	£79,133	
24	Weight Management Scheme - Tier 3	Tier 3 Weight Management scheme to support people at risk of further health	Prevention / Early Intervention	Risk Stratification	0	0	NA		Community Health	NHS	0.0%		NHS	Minimum NHS Contribution	£531,874	£203,203	
33	Central Norfolk NEAT	Central Norfolk NEAT is a multi-agency, multi-disciplinary single point of	Integrated Care Planning and Navigation	Assessment teams/joint assessment	0	0	NA		Other	NHS	0.0%		NHS Community Provider	Minimum NHS Contribution	£682,367	£344,391	
91	Norfolk & Waveney Community	The scheme offers short term support for people on leaving hospital or in the community	Community Based Schemes	Other	Simple discharge and community support to avoid	0	NA		Social Care	Joint	83.0%	17.0%	Charity / Voluntary Sector	Minimum NHS Contribution	£494,460	£208,198	
5	Great Yarmouth Community Hub	The community Hub supports a multi-agency approach with 20+ system partners	Integrated Care Planning and Navigation	Care navigation and planning	0	0	NA		Social Care	NHS	0.0%		Local Authority	Minimum NHS Contribution	£13,313	£6,250	
92	Caring for Better Outcomes	NCC Home support framework, aims to increase reablement capacity to	Home Care or Domiciliary Care	Domiciliary care to support hospital discharge (Discharge to Assess pathway 1)	0	380	255	Hours of care (Unless short-term in which case it is packages)	Social Care	LA	0.0%		Local Authority	Minimum NHS Contribution	£1,293,278	£0	Spend is done on performance outcomes. Awaiting first invoice for the year.
6401	LD, MH & Autism Packages of care	Care services for people with LD, MH & Autism. Number of placements dependent on	Residential Placements	Other	MH, LD & Autism residential care	14728 bed weeks	156	Number of beds	Social Care	LA	0.0%		Private Sector	Minimum NHS Contribution	£14,211,952	£7,105,976	Units reported in placements
8901	Community Based Support	Community and VCSE support for Hospital Discharge and Admission	Community Based Schemes	Low level support for simple hospital discharges (Discharge to Assess	0	0	NA		Social Care	LA	0.0%		Charity / Voluntary Sector	Local Authority Discharge	£497,755	£235,952	
8902	Expanded Reablement Capacity	Additional reablement capacity to support people with complex needs, including	Home-based Intermediate care services	Reablement at home (to support discharge)	0	400	200	Packages	Social Care	LA	0.0%		Local Authority	Local Authority Discharge	£1,829,000	£595,652	
8701	Social Care Worker Resource	Additional social worker resource to support D2A process including within	High Impact Change Model for Managing Transfer of Care	Early Discharge Planning	0	0	NA		Social Care	LA	0.0%		Local Authority	Local Authority Discharge	£1,032,000	£471,724	
88	Workforce retention	Home Care rate increase to support providers in their retention work	Workforce recruitment and retention	Improve retention of existing workforce	0	0	0	WTE's gained	Social Care	LA	0.0%		Local Authority	Local Authority Discharge	£2,376,435	£1,188,000	
7001	ASC Core Care Services (underlying spend	Covering market pressures	Residential Placements	Other	Covering Market Pressures	245	245	Number of beds	Social Care	LA	0.0%		Private Sector	IBCF	£21,586,564	£10,793,282	360 service users
7901	Autism Diagnostic Service	Contribution to service which assess for autism and its short term support including	Care Act Implementation Related Duties	Other	Autism support	0	NA		Social Care	LA	0.0%		Local Authority	IBCF	£67,000	£35,500	
9101	Norfolk & Waveney Community	The scheme offers short term support for people on leaving hospital or in the community	Community Based Schemes	Other	Simple discharge and community support to avoid	0	NA		Social Care	LA	0.0%		Charity / Voluntary Sector	Local Authority Discharge	£150,000	£0	

Report title: Becoming a 'Marmot Place': West Norfolk's work with the Institute of Health Equity

Date of meeting: 04 December 2024

Sponsor

**(HWB member): Cllr Jo Rust, Cabinet Member for People & Communities, Borough Council of King's Lynn and West Norfolk
Stuart Lines, Director of Public Health, Norfolk County Council**

Reason for the Report

To update the Board, as requested by the Chair, on the commissioning of the University of College London (UCL) Institute of Health Equity (IHE) led by Professor Sir Michael Marmot and for the Borough Council of King's Lynn and West Norfolk to become a Marmot Place.

Report summary

The Borough Council of King's Lynn and West Norfolk (BCKLWN) have identified that long standing and persistent health inequalities within the Borough must be a priority. There have been and continue to be efforts to reduce these inequalities but there is a need to accelerate actions, prioritise the major drivers of poor health and inequalities and strengthen partnerships for health equity.

To support the prioritisation of action on health inequalities and on successful implementation in the Borough, the University College of London Institute of Health Equity (IHE) will work with partners across King's Lynn and West Norfolk to identify key issues and based on best available evidence to develop actions and partnerships relevant to the local context. In common with over 40 other local authorities and partners, King's Lynn and West Norfolk will become a 'Marmot place', meaning that reducing health inequalities through the social determinants of health will be at the heart of its decision making.

The work will comprise four areas, completed over two years:

- Assessment of health equity system and data on health inequalities and key social determinants of health.
- Development of recommendations, action plans and monitoring systems.
- Exploring and collaborating with partners across the whole system.
- Advocacy and commitments across the whole system.

Recommendations

The HWB is asked to:

- a) Note the work of the West Norfolk Marmot team.
- b) Advocate with system partners to ensure the advisory board and steering group are appropriately supported.

1. Background

1.1 In late 2023 colleagues from the Borough Council, Norfolk County Council public health and the Norfolk & Waveney Integrated Care Board (ICB) agreed to investigate the possibility of working with the Institute of Health Equity (IHE) to become a Marmot place. Following discussions with the IHE and other areas already progressing through the Marmot work

papers were taken through the appropriate governance processes for each organisation and approved in early 2024.

2. Addressing Health Inequity in West Norfolk

- 2.1 The Marmot review 2010 and the 10-year on review identified eight principles to reduce health inequalities, they are:
- Give every child the best start in life.
 - Enable all children, young people and adults to maximise their capabilities and have control over their lives.
 - Create fair employment and good work for all.
 - Ensure a healthy standard of living for all.
 - Create and develop healthy and sustainable places and communities.
 - Strengthen the role and impact of ill health prevention.
 - Tackle racism, discrimination and their outcomes.
 - Pursue environmental sustainability and health equity together.
- 2.2 The focus of the Norfolk & Waveney integrated care conference in October 2024 was health inequalities and prevention. The Integrated Care System (ICS) was encouraged at this event to provide courageous leadership and commit to reducing health inequalities in Norfolk. To achieve this goal, building an evidence base, providing evidence-based recommendations and working with communities to deliver services collaboratively was a key driver to deliver. Delegates were also reminded of the recent findings of the Darzi report providing a focus on prevention and the importance of place-based working and providing local services for communities.
- 2.3 The challenges posed at the conference align closely with the ambition of Marmot places and the work will provide the strongest commitment to reducing health inequalities for the residents of West Norfolk. The work will align with the key priorities set out in the ICS health inequalities framework for action.
- 2.4 Usually, the work to become a Marmot place is led by public health teams in unitary and two-tier settings. However, it has been agreed between the three parties that the Borough Council will be the lead authority for this work, with the strong partnership support of the public health team and the ICB. This arrangement recognises the two-tier arrangements in Norfolk and the role of the West as a distinct place in delivering health equity in its area.
- 2.5 The work with the IHE will take place over two years and will comprise of four areas:
- Assessment of the health equity system and data on health inequalities and key social determinants of health.
 - Development of recommendations, action plans and monitoring systems.
 - Exploring and collaborating with partners across the whole system.
 - Advocacy and commitments across the whole system.
- 2.6 The IHE have recognised the rurality of West Norfolk and our ageing population and will address the impact of these two demographics on health equity in West Norfolk.
- 2.7 Governance will consist of an advisory board of senior leaders from relevant partners, including the Borough Council, ICB, public health, other public services (housing and education) and voluntary, community and business sector partners. There will be 4 to 5 meetings chaired by Professor Sir Michael Marmot. Additionally, there will be a steering group of partners from across the system who will meet regularly to initiate, deliver and lead actions. A steering group has already been formed over the summer, which has undertaken preparatory work to enable this project to start promptly in October. Membership of this group may extend on advice from the IHE about what has worked in other areas.

- 2.8 The work of the advisory board and steering group will report into the West place board and West Norfolk health & wellbeing partnership to ensure opportunities to learn and share best practice across the ICS.
- 2.9 The outputs of the work with the IHE will be, at the end of year one, a data pack showing how well needs are currently being met in order to reduce inequalities. There will be a short summary report with recommendations and indicators in accordance with the eight Marmot principles. In year two of the work programme the full report will be produced with final recommendations. These products will be shared widely across the Norfolk system and other 'places' will benefit from the learning and recommendations made in the West of Norfolk.
- 2.10 Next steps - the IHE will initially be involved with this work for two years, but this is a long-term piece of work that aims to provide systemic change in the West of Norfolk to improve health equity across all sectors, including housing, education, early years, health care, business and the economic sector. Reducing deprivation and mitigating its impacts is the central theme for all Marmot Places.
- 2.11 By focussing on the eight Marmot principles, the outcomes of the work in the West of Norfolk will include system change and culture shifts - via strong governance, accountability, leadership, partnerships, networks, training/capacity building and advocacy.

Officer Contact

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Report title: Launching the Norfolk & Waveney Health Inequalities Commitment

Date of meeting: 04 December 2024

Sponsor

(ICP member): Stuart Lines, Director of Public Health, Norfolk County Council

Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board

Reason for the Report

To update the Integrated Care Partnership on progress being made to implement the actions detailed in the Integrated Care System (ICS) Health Inequalities Strategic Framework for Action and ask the Integrated care Partnership (ICP) members to pledge their organisation's Commitment to implementation and to provide oversight to the uptake.

Report summary

The ICS Health Inequalities Strategic Framework for Action outlines 10 key actions for its first year of implementation. This report provides an update on progress around these actions, which are being overseen by a newly established ICS Health Inequalities Strategic Steering Group.

At the ICS Conference in October 2024 a 'Health Inequalities Commitment' was launched which asked organisations and partners from across the system to commit to a number of actions to further strengthen system action on addressing health inequalities. This report details these actions as well as how organisations can pledge their support and get involved in future developments.

Recommendations

The ICP is asked to:

- a) Support the Health Inequalities Commitments.
- b) Members are asked to take the Health Inequalities Commitment back to their respective organisations and pledge to support the proposed actions.
- c) Oversee uptake of the Norfolk & Waveney Health Inequalities Commitment.
- d) Support the development of a system improvement plan based on the consolidated results of the organisational self-assessments.

1. Background

- 1.1 In June 2024 the Integrated Care Partnership endorsed the ICS Health Inequalities Strategic Framework for Action and agreed to provide oversight to its implementation, with emphasis on the 10 actions identified for the first 12 months.
- 1.2 In September 2024 the Integrated Care Partnership agreed a change to its Terms of Reference to enable the creation of a sub-group, the ICS Health Inequalities Steering Group, which will be Chaired by the Norfolk Director of Public Health, Stuart Lines.
- 1.3 The ICP have requested a regular progress report from the ICS Health Inequalities Steering Group as a standing item of the meeting, to provide updates on progress, drive collective change and enable further action.

2. Health Inequalities Strategic Framework for Action

- 2.1 The ICS Health Inequalities Strategic Framework for Action sets out 10 actions required in the first year of implementation. These are:
- **Communications and Pledges** – We will continue our ‘Health Inequalities Conversation’ and roll out a programme which includes commitments and accountability.
 - **Governance** – We will identify named Senior Responsible Officers/Leaders, Organisational Leads, Clinical leads and Health Inequalities Champions
 - **VCSE Integration** – We will further develop the VCSE Assembly, integrate the VCSE sector into all parts of our planning and decision making and support volunteering
 - **Action plans** – We will produce action plans for each of our building blocks, using existing assets and with our place and system structures working closely together.
 - **Self- assessment** – We will assess where we are, what good looks like, what we need to do next. We will include action for anchor organisations.
 - **Organisational development** – Including a suite of tools and training, a learning centre to share good practice and case studies, and a health inequalities champion network.
 - **Resources** – Mapping the flow of health inequalities resources and spend across organisations to further develop the business case for investment.
 - **Intelligence** – Implement our Population Health Management Strategy, so that we get better at collecting and using data and insights.
 - **Monitoring** – A Health Inequalities Outcomes Framework developed with clear metrics and targets identified to keep us on track.
- 2.2 The ICS Health Inequalities Steering Group is overseeing progress against these 10 actions and can report progress is being made against each, as highlighted in Appendix 1.
- 2.3 At the ICS Conference on 16th October 2024 the Norfolk & Waveney Health Inequalities Commitment was launched, details of which are included in the attached. This asks colleagues to commit to 4 key actions, as highlighted below:
1. To lead your organisations to act and address inequalities by developing a network of health inequalities advocates and identifying a **Health Inequalities Lead** in your organisation.
 2. To **connect with communities** by prioritising listening to seldom-heard voices and meaningfully engaging with underserved groups.
 3. To equip your teams and services to be accessible for all by undertaking a **self-assessment** (so that we may develop a useful Resource Hub based on what the system needs), addressing data gaps and undertaking a workforce training needs analysis.
 4. By **embedding** addressing health inequalities in all you do and report progress on your actions, share best practice and become a ‘Health Literacy Friendly’ organisation.
- 2.4 To support organisations to fulfil these commitments the ICS Health Inequalities Steering Group, via its Coordination Group, will develop a number of practical tools and resources, including:
- A Health Inequalities Advocates and Leaders Programme, including a network to bring colleagues from across the system together to share and learn.
 - A self-assessment tool that we **ask all ICS organisations to undertake** so that we can establish a ‘baseline’, understand where we are now, where we have good practice and how much impact we have had. This includes a short version for small organisations, such as those in the VCSE sector.
 - A system improvement plan, based on the findings of the self-assessment.

- An ICS Resource Hub based on the findings of the self-assessment i.e. what our system needs to drive improvements.
- A clear VCSE Assembly structure that supports wider sector engagement and influence as well as a Community Voices programme and other engagement tools that can support us to listen to our seldom-heard voices.
- Guidance and support around ‘health literacy’.

2.5 At the ICS Conference colleagues were asked to rate several statements to capture a baseline ‘temperature check’ of our start position in relation to knowledge of the Health Inequalities Strategic Framework for Action and the Commitments, as illustrated below:

Health Inequalities Temperature Check



- 2.6 This ‘temperature check’ highlights a strong belief that we can make a difference but demonstrates that there are improvements to be made around the understanding of the Health Inequalities Strategic Framework for Action across all agencies, developing the tools we need to take action and sharing knowledge and good practice.
- 2.7 Positively, many organisations have indicated that they are already taking action around the Commitments, suggesting there is much we can learn from each other if we can establish the forums and mechanisms to communicate and collaborate.
- 2.8 Members of the ICP are asked to express their Commitment to addressing Health Inequalities and participate in the self-assessment process. Communications on how to identify advocates and join the Health Inequalities Advocate and Leaders Network will follow. Details can be found in Appendix 2.

Officer Contact

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ICS Health Inequalities Strategic Framework for Action

Work Programme & Progress Report As at Nov 2024

ICS HI Framework Programme Summary

Headline Scope and Priorities

Nov 2024

Programme	Health Inequalities Framework - 10 priority actions	SROs	Stuart Lines, Director Public Health, NCC Mark Burgis, Exec Director Patient & Communities	Overall Prog RAG
		Programme Lead/s	Shelley Ames, Head of HI & VCSE Partnering	

What have we achieved since last report (time period)	Key Programme Milestones (for this time period)
<ul style="list-style-type: none"> Development and launch of Health Inequalities Commitments at ICS Conference Recruitment of new VCSE Assembly Chair - Tim Gardiner Review of TOR for Health Improvement Transformation Group and Health Inequalities Oversight Group, TOR for Living and Working Conditions Group in development. 	Launch of Health Inequalities Commitment at ICS Conference
Activities planned for next reporting period	
<ul style="list-style-type: none"> Launch of HI Commitments and monitoring/reporting plan Launch of HI Advocate programme & first Health Inequalities Advocates Network Development of action plans for healthcare inequalities and health improvement (lifestyle) Finalisation of governance arrangements - Living and Working Conditions 	

Key Programme Risks (Description)	Mitigation Action	Issues to be escalated	RAG
Buy-in to Health Inequalities Commitments	Launching at ICS Conference and seeking Exec Level support. ICS HI Steering Group and SRO's to support onward advocacy and monitor uptake, reporting to ICP as required.		AMBER
System governance structures connecting to place-based governance structures and effecting change	Frequent reporting and communication with HWP and Place Board Chairs - communications plan to be developed.		AMBER

Decisions to be made/ escalated to board

HI Framework Programme Summary

Headline Scope & Exception Reporting DD Mon Year

Project Ref	Project Title	Key project milestones (with dates)	Progress / Comments / Escalation	Key project risks (with mitigation actions / support requested)	Project Lead	Planned Comp	Current RAG
	Communications & Pledges	<ul style="list-style-type: none"> Development of ICS Health Inequalities Commitment - Oct 2024 Launch of HI Commitment at ICS Conference - Oct 2024 Monitoring of commitment sign up - ongoing Progress report to ICP - Mar 25 	<ul style="list-style-type: none"> Commitment developed and agenda item for conference planned 	<ul style="list-style-type: none"> Uptake amongst system partners - monitoring of uptake reported to ICP 	PG/NJ	Oct 24	GREEN
	Governance	<ul style="list-style-type: none"> ICP TOR changed to include sub-group for health inequalities. ICP agreed overall accountability - Jun 24 ICS Steering Group & Coordination Group established - Aug 24 HIOG & HITG reporting to steering group - Nov 24 Establish Living & Working Conditions Group - Dec 24 Ongoing quarterly progress reporting to ICP 	<ul style="list-style-type: none"> Governance structures agreed by ICP and supported by system partners 	<ul style="list-style-type: none"> Effective implementation via governance structures - i.e. enabling leadership, accountability and action 	SA	Dec 24	GREEN
	VCSE integration	<ul style="list-style-type: none"> Recruitment of new VCSE Assembly Chair - Oct 2024 Formal relaunch of VCSE Assembly with comms plan - Jan 2025 		<ul style="list-style-type: none"> Improve understanding of role and function of Assembly VCSE Assembly empowered to effect change 	SA	Ongoing	GREEN
	Action plans	<ul style="list-style-type: none"> Actions plans developed for each of 4 work pillars - Apr 2025 	<ul style="list-style-type: none"> HITG, HIOG and coordination group plans developed 	<ul style="list-style-type: none"> Living & Working Conditions Group not yet established Connectivity to place-based structures 	SA	Apr 25	AMBER
	Self - Assessment	<ul style="list-style-type: none"> Develop self-assessment process - Oct 24 Launch at ICS Conference - Nov 24 Monitor uptake and report to ICP - Mar 25 System baseline report and improvement plan - Apr 25 		<ul style="list-style-type: none"> Uptake amongst system partners - ICB and Public Health to provide completion support where possible. 	PG	Apr 25	GREEN

ICS HI Framework - Programme Summary

Headline Scope & Exception Reporting Oct 24

Project Ref	Project Title	Key project milestones (with dates)	Progress / Comments / Escalation	Key project risks (with mitigation actions / support requested)	Project Lead	Planned Comp	Current RAG
	Organisational development	<ul style="list-style-type: none"> Self-assessment to provide insights into system OD requirements - Mar 25 Resource Hub plan - Apr 25 		<ul style="list-style-type: none"> Insights gathered by self-assessment insufficient to develop Hub Resources required to develop Hub 	SA/NJ	Oct 25	
	Resources	<ul style="list-style-type: none"> Flow of resources to be mapped against structures - Jan 25 		<ul style="list-style-type: none"> Access to resource/financial information to understand full financial picture 	TBC	Apr 25	N/S
	Intelligence	<ul style="list-style-type: none"> Data dashboard for each programme area to be developed - Apr 25 		<ul style="list-style-type: none"> Narrowing priorities to support development of dashboards Duplication risk Utilisation of dashboards once developed 	JR/TW	Apr 25	
	Monitoring	<ul style="list-style-type: none"> Outcome framework for each action plan to be developed - Apr 25 			SA/SM	Apr 25	N/S
	Participation	<ul style="list-style-type: none"> Discussions with ICS Steering Group about system roll out of Community Voices and resourcing strategy - Nov 24 Paper to ICP planned for March 2024 to outline community engagement potential 		<ul style="list-style-type: none"> Adoption of Community Voices by ICS partners Resources 	AK	Apr 25	

ICS HI Framework - Programme Summary

Headline Scope & Exception Reporting Oct 24

Project Ref	Project Title	Key project milestones (with dates)	Progress / Comments / Escalation	Key project risks (with mitigation actions / support requested)	Project Lead	Planned Comp	Current RAG
	Living & Working Conditions	<ul style="list-style-type: none"> Initial scoping workshop - Aug 2024 Scope resources/support offer for group across system partner - Oct 2024 Follow up workshop - Nov 2024 Develop TOR - Dec 2024 Launch group - Jan 2025 	<ul style="list-style-type: none"> Principles developed by group, further work underway to determine functions and membership 	<ul style="list-style-type: none"> Cross-sector agreement on function and purpose Adding value to existing work underway 	SA/JS/MH	Oct 25	Yellow
	Health Improvement Transformation Group	<ul style="list-style-type: none"> Review of TOR - Sep 24 Agreement on key work programme areas Development of action plans - Dec 24 	<ul style="list-style-type: none"> Priority work programme areas agreed as smoking, physical activity, food and diet and behaviour change. 	<ul style="list-style-type: none"> Access to resource/financial information to understand full financial picture 	SL/TW	Apr 25	Green
	Healthcare Inequalities Oversight Group	<ul style="list-style-type: none"> Data dashboard for each programme area to be developed - Apr 25 	<ul style="list-style-type: none"> Priority work programme areas agreed as Core20plus5, Inclusion Health, Health Literacy, Access and Support, NHS Anchors 	<ul style="list-style-type: none"> System engagement 	TW/SM	Apr 25	Green



Health Inequalities: Post ICS Conference Pack 2024

Introduction

The Norfolk and Waveney ICS Health Inequalities Strategic Framework for Action sets out 10 Actions which will drive activity over the coming 12 months. The ICS Conference 2024 was an opportunity to launch a key programme of work – the *Health Inequalities Commitments* - which will form the cornerstone of system activity in the coming years.

This information pack will provide some more detail around:

- **The Health Inequalities Commitments**
- **ICS Self-Assessment**
- **Health Inequalities Leads and Advocates Programme**

We know that our system partners are already tackling health inequalities in a multitude of different ways – we hope that these opportunities are able to enhance and support existing work and find ways for us to work together to achieve even more.

Health Inequalities Commitments

The framework for action's *10 Actions* promised to roll out a programme which sets out a series of commitments and accountability for the system. We recognise that what we achieve in the first 12 months will lay the foundations for the system's future work, so we have developed a set of commitments which will strengthen our starting position and allow us to bring together our collective knowledge and expertise.

The commitments themselves are broken down into four key actions which include an ask of system partners and an offer from the ICS to support partners.

How can I sign up?

Signing up to the *following* commitments is easy – all you need to do is complete this form by scanning the **QR code** to the right or visiting: <https://www.smartsurvey.co.uk/s/TT5EY6/>. If you consent, we will add your contact email to a mailing list so we can share latest updates and information to support you in your work. It is important to note that even if you feel you are already doing a lot of this work, we would encourage you to still sign up. It will help us in our understanding of the system as we progress, but importantly, we and all our system partners will be able to learn from you.



Lead

We ask you to *lead your organisation to act and address health inequalities.*

You will:

- Develop a network of Health Inequalities Advocates
- Identify a Health Inequalities Lead

We will:

- Provide a Health Inequalities Advocates and Leaders' Programme
- Provide a clear governance structure, with clear accountability
- Give access to an ICS Resource Hub with training and support opportunities

Connect

We ask you to *connect with communities.*

You will:

- Prioritise listening to seldom-heard voices
- Meaningfully engage with underserved group

We will:

- Further develop our VCSE Assembly
- Offer Community Voices and other engagement tools as part of the ICS Resource Hub
- Make sure engagement is prioritised

Equip

We will ask you to *equip teams and services to be accessible for all.*

You will:

- Undertake an organisational self-assessment
- Address data gaps - know our communities
- Undertake a workforce training needs analysis

We will:

- Provide a self-assessment tool & self-assessment report to enable you to benchmark yourself and identify areas for improvement
- Develop an ICS improvement plan
- Provide an opportunity to match with peer organisations and access to a peer network of Health Inequalities Advocates.

Embed

We will ask you to *embed addressing health inequalities in all you do.*

You will:

- Report progress on your actions
- Share best practice and learn together
- Become a health literacy friendly organisation

We will:

- Provide opportunities to come together to share and learn
- Provide guidance and support around 'health literacy'
- Roll out and promote this health inequalities commitment

Self-Assessment

As an Integrated Care System, we are asking organisations to use this self-assessment tool to understand how much progress we have made in how we help people who are often at a disadvantage because of the way organisations work. We want to understand what we are already doing, where there might be gaps and opportunities and how we might address these. This will form a system improvement plan and feed into the development of the *ICS Resources Hub*. Importantly, this report will be yours to help your organisation baseline your own activity and support your own organisation's improvement plan.

To sign up to hear more about the assessment when it launches, you can scan the **QR code** or visit:

<https://www.smartsurvey.co.uk/s/TT5EY6/> . The assessment itself will open on **1st November** be open until the **31st January 2025** as we would like as many organisations to complete it as possible. We will then produce a system report which will be shared after **April 2025**.



Health Inequalities Leaders & Advocates Programme

Establishing leadership and activity at different levels is essential in influencing change across the system. We are fortunate as an ICS to have some excellent examples of work taking place with our communities and population. To help us bring this all together and create spaces where we can support one another in our shared vision to tackle health inequalities.

If you are interested in becoming a *Health Inequalities Lead* in your organisation or a *Health Inequalities Advocate* you can complete a simple expression of interest here:

<https://www.smartsurvey.co.uk/s/TT5EY6/> or scan the **QR code**. We are planning on bringing together all of those who are interested together in an event in **December 2024**, including any existing advocates/champion role so we can begin to explore what these networks look like.



Contact Details

The wider programmes of work relating to the *10 Actions* are in development, and more information will be shared in due course. In the meantime, if you have any questions please do reach out to: nwicb.healthinequalitiesconversation@nhs.net.

Report title: Update on driving integration through system wide training opportunities

Date of meeting: 04 December 2024

Sponsor

**(ICP member): Ian Wake, Executive Director, Adult Social Services, Norfolk County Council
Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board**

Reason for the Report

This is a standing item presenting an update to the Integrated Care Partnership (ICP) on integration opportunities through system wide training, education and leadership opportunities.

Report summary

This report provides an update on current activities taking place within the Integrated Care System (ICS) and highlights progress on the further areas for development in system training, education, and leadership that were identified following the initial ICP development session on the 31 January 2024.

Recommendations

The ICP is asked to:

- a) Consider the update on ongoing activities taking place across the ICS in respect of system leadership, educational and training opportunities.

1. Background

- 1.1 Norfolk and Waveney ICS recognises the need to provide opportunities for system wide leadership and training programmes.
- 1.2 Professionals/employees in partner organisations need a shared understanding of:
 - Practice
 - Processes/responsibilities across partners
 - How we engage with service users/patients
- 1.3 Joint training and leadership opportunities foster a shared leadership culture, which is essential for delivering better quality services and achieving cost efficiencies.
- 1.4 In previous updates to the ICP, challenges were identified in the following areas:
 - a. System level work in the health and social care environment is focused on and shaped by NHS partners, with some social care and County Council input. This could be strengthened by input from VCSE, district or other stakeholder involvement, and would allow the development of a system forum for collaboration on OD initiatives in which all stakeholders are represented.
 - b. There are several wide-ranging initiatives across the system, driven mainly through local, system or national requirements. The approach would be strengthened by an overarching strategic plan that supports integration across all system partners.

- c. Whilst some of the initiatives described above are currently funded through pre-existing arrangements, the financial challenges facing all partners mean that limited progress is likely for the foreseeable future on key strategic approaches.
- d. Whilst there is an ambition to pool and share learning resources, it is proving challenging to put this into practice
- e. The ICP advocated for more collaborative efforts between partners in securing funding for integrated training and development opportunities.
- f. The ICP previously supported recommendations for development and delivery of a system training transformation programme over the next three years including:
 - 1. The development of a system “skills passport”
 - 2. A systemwide approach to leadership and management development which is a key enabler of a “One Workforce” approach
 - 3. The development of an approach to pooling training resources including all ICS partners.
 - 4. Longer term exploration of a system wide Learning Management platform (recognising the data governance, financial and organisational challenges that this would entail).
- g. There was a recognition of the need for a more balanced approach in future updates concerning social care, ensuring that both Adult and Children’s Services are equally represented, and the Norfolk Strategic Social Care Network meeting would be a key forum for addressing this effectively.
- h. The ICP advocated for more collaborative efforts between partners in securing funding for integrated training and development opportunities.

2. Joint Learning, Leadership and Development/Education Updates

2.1 Norfolk Economic Strategy and Norfolk Employment & Skills Board

- 2.1.1 The new (draft) economic growth strategy for Norfolk (which will be known as the “Local Growth Plan” builds on the Norfolk & Suffolk Economic Strategy and other local strategies. The strategy will be an overarching document for Norfolk, to encompass thematic, place based and sector strategies to help grow the local economy and support the people who live and work in Norfolk.
- 2.1.2 Among the key priorities within the strategy is the focus on People and Skills. This priority emphasizes the development and enhancement of skills across the workforce to ensure that staff are well-equipped to meet the evolving demands of the health and social care sectors and aims to support collaboration, efficiency and skills system leadership.
- 2.1.3 The Norfolk Employment & Skills Board (E&S Board) is the representative group retaining oversight in the application of the Adult Skills devolution funding in Norfolk and leading on wider strategic adult skills discussion and the implications of future skills investment & programmes (devolved & non-devolved.) The E&S board will be responsible for the delivery of the strategic objectives outlined in the local growth plan and Strategic Skills plan.
- 2.1.4 An initial meeting with the strategy manager for the Adult Education Budget will take place on the 15th October 2024 to explore the opportunity to align the ICP recommendations on system leadership with the work of the E&S board, and explore the potential for joint funding opportunities for system leadership, education and training.

2.1.5 An update will be provided to the ICP in early 2025 on the progress of these discussions.

2.2 NHS Digital Skills passport

2.2.1 Conversations continue to take place with the ICB innovation team and with the ICS clinical education forum about developing a skills passport between NHS organisations in the first instance, with a view to confirming a minimum viable product that can potentially be developed for third party users.

2.2.2 There is also a national conversation being led by NHS England on the Digital Skills passport. The NHS Digital Staff Passport service is currently piloting the service with a limited number of NHS trusts, carefully selected based on critical eligibility criteria. The pilot focuses on two specific staff groups:

- Temporary movers, who remain employed by their current NHS employer and will work at another NHS trust for an agreed period.
- Postgraduate doctors in training, who rotate between trusts as part of their training programme.

2.2.3 NHS Trusts in the East of England region are not included in the pilot at this time.

2.3 Volunteering for Health Programme: Digital Learning Academy Initiative

2.3.1 The Integrated Care Board (ICB), Norfolk County Council (NCC), and other partners have successfully secured funding from NHS England, NHS Charities Together and CW+ for the 'Volunteering for Health' programme across Norfolk and Waveney. This programme encompasses several objectives, one of which is the establishment of a 'Digital Learning Academy' for volunteers and volunteer managers.

2.3.2 The Digital Learning Academy will serve as an online portal providing accessible training for all volunteers and volunteer managers. The training content, which is currently under discussion, aims to address the needs of Voluntary, Community, and Social Enterprise (VCSE) organisations that often struggle to access standard training modules such as safeguarding and cyber security. Additionally, the academy will offer training on volunteer management.

2.3.3 It is anticipated that once the platform is operational, there will be opportunities to incorporate additional modules to meet further training requirements.

2.3.4 It is expected that the management of this platform will mirror the arrangements in place with Norfolk's 'Get InVOLved' volunteer recruitment portal. The portal is well used and trusted by VCSE and Public Sector partners, and managed by Voluntary Norfolk and The Empowering Communities Partnership. Building on this existing arrangement will allow for collaboration and an efficient management structure.

2.4 Social Care Institute for Practice Excellence Board

2.4.1 Following a review in early 2024, the purpose of the SCIFE Board has been revised. The Board has been renamed to the "Norfolk Strategic Social Care Network" and will now focus on the following key areas:

- Sharing Key Service Updates: Providing regular updates on social care services.
- Discussing Opportunities for Collaboration: Identifying and exploring opportunities for joint working.
- Agreeing on Actions to Address Service Barriers: Formulating and agreeing on actions to overcome barriers within services.

2.4.2 The next meeting is scheduled for November 2024, and an update will be provided to the ICP on joint learning opportunities and development across both adult and children's social care where identified.

3. Updates on other joint training opportunities

3.1 Norfolk & Waveney Learning Opportunities: Fortnightly Online Learning Sessions

3.1.1 Norfolk & Waveney Learning Opportunities provide a complimentary fortnightly online learning hour, accessible to all staff, including clinical and non-clinical personnel, social care workers, healthcare professionals, and students. These sessions are strategically designed to coincide with the health and social care events calendar and are delivered by experts in their respective fields.

3.1.2 The sessions cover a wide range of topics, such as Learning Disabilities, Mental Health awareness, and physical health education. Each session is eligible for Continuing Professional Development (CPD) credits, with certificates issued upon completion of a post-session evaluation. Training is advertised via an interactive poster and is shared on internal NHS learning platforms and websites.

3.1.3 These learning opportunities have garnered significant popularity within the Health and Social Care sectors, reflecting their value and relevance.

3.2 Digital Placement System: Educators Update

3.2.1 Currently, the ICB lacks comprehensive oversight regarding NHS student placement capacity. To address this issue, the development of a Digital Placement System is underway.

3.2.2 This system aims to provide a detailed overview of the following:

- **Potential Placement Capacity:** Identification of available placement opportunities.
- **Actual Placement Offers:** Tracking of placements that have been offered.
- **Placements Utilised:** Monitoring of placements that have been filled.

3.2.3 Additionally, the system will feature links to quality markers for each placement host. This will facilitate the identification of gaps in placement areas and support the enhancement of placement quality.

3.3 Norfolk Initiative for Coastal and rural Health Equalities (NICHE)

3.3.1 The Norfolk Initiative for Coastal and rural Health Equalities (NICHE), Anchor Institute, is a co-ordinated programme of activity to establish effective workforce intelligence networks across the Norfolk and Waveney Integrated Care System, for sustainable workforce optimisation, supporting effective system level transformation.

3.3.2 NICHE uses embedded research, education and evaluation to achieve system transformation, through exploring new approaches to measurement, integrated workforce development and linking partners to shared knowledge for enhanced innovation.

3.3.3 NICHE will provide a coordinated approach to evidencing the value, benefits, outcomes and impacts of research, evaluation and innovation for the East of England, and beyond.

4. Next steps

- 4.1 The ICP is requested to note the update on system leadership, educational and training opportunities within the ICS, with particular attention to early signs of progress in the development of digital skills passports, the potential of the Employment and Skills board to bring together wider system conversations on skills development and a forum for developing joint funding bids and the potential creation of a portal for a system learning management system via the Digital Learning Academy.

Officer Contact

If you have any questions about matters contained in this paper, please get in touch with:

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Report title: Driving Integration Through Digital, Data and Technology

Date of meeting: 04 December 2024

Sponsor

**(ICP member): Ian Wake, Executive Director of Adult Social Services, Norfolk County Council
Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board**

Reason for the Report

This paper is to provide an update on how we continue to work collaboratively as a system and some of the progress that has been made since our last update in September. It also includes a proposed roadmap of areas we would like to cover over the year ahead.

Report summary

This report provides an update on the work we have progressed on the Shared Care Record (ShCR) since we last updated in September and also a proposed roadmap of area’s that we consider would be helpful to share with the partnership.

Recommendations

The ICP is asked to:

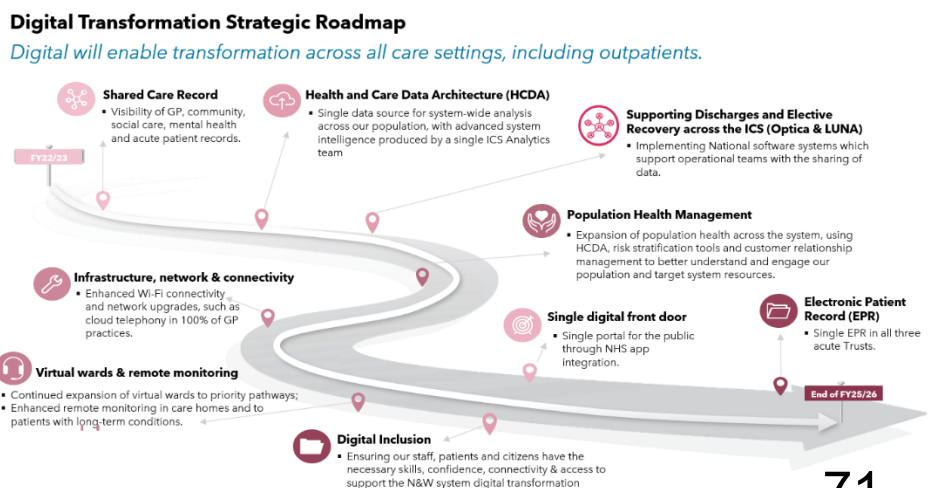
- a) Note the updates on the progress taken around the collaboration as a system and raise any potential gaps or priorities to further inform the plan.
- b) Review, comment, and advise on the progress taken with the Shared Care Record.
- c) Review, comment and advise on the proposed items to be discussed at future meetings.

1. Background

1.1 This paper is brought to the ICP to update on how we are working collaboratively as a system to enable data sharing and what we are doing to drive integration through our digital, data and technology systems (DDaT). The report provides a detailed update on the Norfolk and Waveney Shared Care Record and suggestions we can cover at future meetings.

2. Update on the Digital Overview

2.1 Following the September meeting, we have amended the ICS Digital Transformation Roadmap to reflect the work we are doing around Digital Inclusion and have included this below.



- 2.2 Cloud telephony has been installed in the majority of GP Practices in Norfolk & Waveney, giving the opportunity for patients to opt for a call back from the practice rather than waiting in a queue. Practices have more lines and more reporting via dashboards, so they can see call volumes, numbers waiting and other information that allows them to manage their staff resources.
- 2.3 The GP Practice infrastructure programme is progressing well, with resilient networks installed in all practices. The new connections are faster and practices are seeing benefits in improved performance of clinical systems. Wi-fi for GP premises will be switched on from the end of October in a phased approach, giving access throughout GP Practice premises for all practice staff, patients and any visiting staff.
- 2.4 The first step of an ICS wide intranet will go live by the end of October. The intranet will be live first in primary care – GP Practices, Pharmacy, Optometry and Dentists, and in Care Homes before being rolled out across the ICS.
- 2.5 The campaign to encourage sign up to the NHS App continues with many events taking place across the area. The NHS App uptake in Norfolk and Waveney is 55% which is lower than the East of England average of 58% and the national average of 61%. With the new wi-fi connections being available in GP Practices, there will be renewed campaigns to increase the uptake. The council's Digital Inclusion Team is also working closely with colleagues from the NHS to ensure we are helping those who need some digital support.
- 2.6 40 Care Homes have the remote monitoring technology deployed and staff are confident in taking observations. Linked GP Practices have access to the observations on a dashboard. Development work is underway to enable a direct link between the GP Clinical System and the dashboard and it is hoped that this will improve use of the observations.
- 2.7 A project is underway with James Paget Hospital and a number of care homes to electronically track Red Bags when care home residents are admitted to hospital. The Red Bag scheme is designed to ensure that care home residents have all notes and personal belongings with them when they go to hospital, and that they return to the home with the same belongings. There is an issue currently with bags going missing resulting in a loss of personal items and it is hoped that electronic tracking will resolve this.
- 2.8 Developments in Robotic Process Automation are releasing time in GP Practices. A bot to process repeat prescription requests has been developed and is working in around 20 practices across Norfolk and Waveney. The bot is trained to follow the protocols devised by the Medicines Management Team in the processing of repeat prescription requests and will manage all compliant requests, leaving more complicated requests for controlled drugs or patients requiring review to the practice staff.
- 2.9 Since September 2024 NCC has been running a number of proof of concepts using Microsoft Co-Pilot. This has identified a number of areas in Adults and Childrens where we will continue our focus on specific used cases. We will look to update the ICP on these areas at a future meeting.

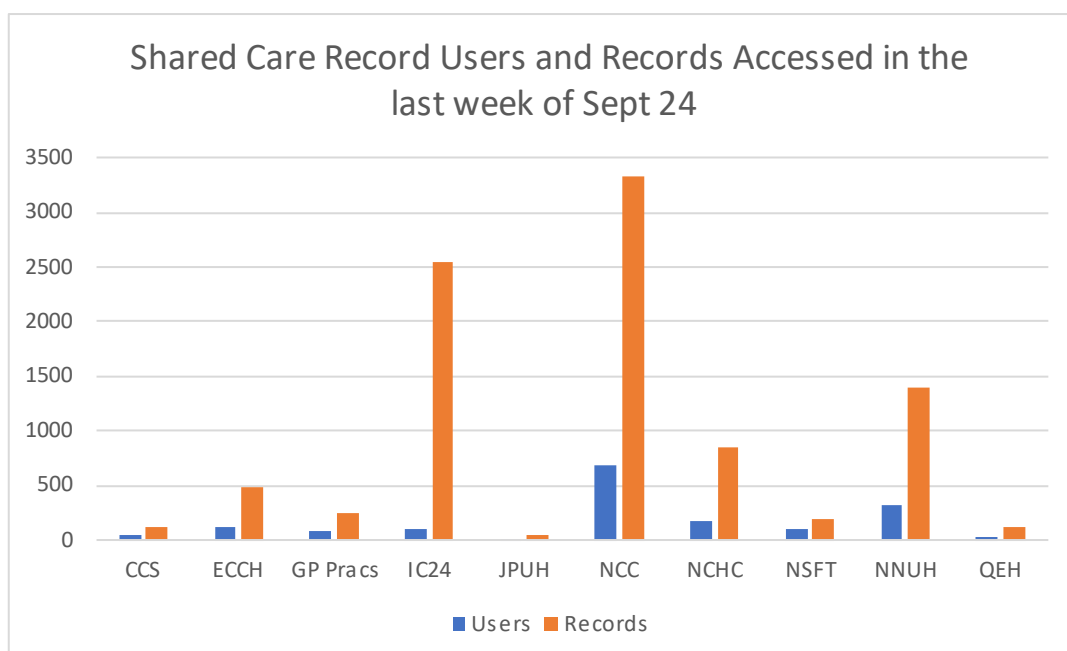
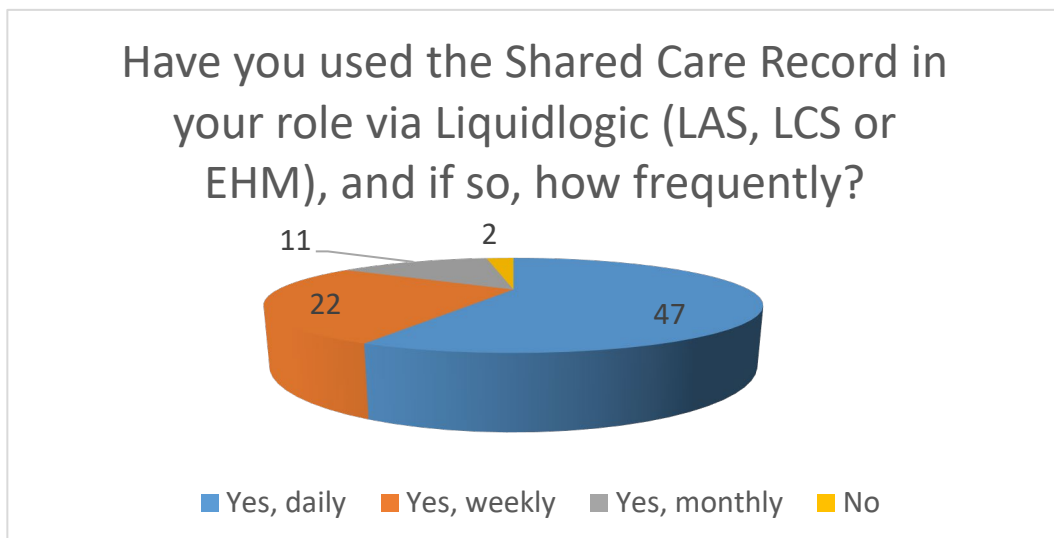
3. Deep Dive into the Shared Care Record (ShCR)

- 3.1 Phases 1 and 2 of the Norfolk & Waveney Shared Care Record (NWShCR) Project are complete and the record is accessible in Norfolk County Council, all three Acute Hospitals, the community providers, Norfolk & Suffolk Foundation Trust (NSFT), NHS 111, GP Practices and the Out of Hours Service.

- 3.2 Data is provided to the Shared Care Record by all three Acute Hospitals, NHSFT, all Norfolk & Waveney GP Practices, IC24 and Norfolk County Council Adult and Children's Services. A contract has now been put in place that will enable the flow of community data. Work is in progress for Voluntary, Community and Social Enterprise (VCSE) access via the Social Prescribing system.
- 3.3 As at the end of September 2024, the Norfolk & Waveney Shared Care Record was being accessed by an average of 1,600 staff per week, accessing the records of 9,300 patients.
- 3.4 An evaluation of the Norfolk & Waveney Shared Care Record Project has been completed, as well as two surveys by Healthwatch, one for staff and one for patients.
- 3.5 The staff survey focussed on the effectiveness of training and communication and provided a lot of useful lessons for the project team. The patients survey showed that patients were keen on the idea that Health and Social Care staff could access their record, meaning that they need tell their story only once. A small selection of user stories from staff gathered during engagement sessions has been included below along with a table showing the frequency of use by NCC staff.
- 3.6 Phase 3 of the project will begin soon, the focus of which will include work on compliance with the NHS England minimum viable standard for Shared Care Records version 2, for delivery by March 2025, and ensuring the Professional Records Standards Board core information standards are met, and:
- Working towards the NWShCR being able to support care plans.
 - End user access for Hospices, MIND Norfolk, NSFT Talking Therapies, ICB Adults and Children's Services.
 - Data interfaces from Acute Radiology, Community Services, ICB Adults and Children's Services.
 - Looking at the feasibility of cross border connections, such as joining up to the Suffolk Care Record and the Cambridgeshire and Peterborough Care Record.
 - Exploring the options for patient access to records.
- 3.7 Programme delivery and contracting mechanisms will remain the same, with oversight by a cross-organisational Board.
- 3.8 Below shows a few examples of feedback received from users of the NWShCR and the frequency of use for both NCC and ICB staff:
- 3.8.1 **Dr Tim Merchant, Regional Medical Director, Integrated Care 24:** *"I encountered a patient in urgent care with documented safeguarding concerns. However, I was able to access the relevant information, through the Norfolk and Waveney Shared Care Record. This allowed me to build a comprehensive understanding of the wider care input, ensuring that I could make informed decisions and provide appropriate support."*
- 3.8.2 **Sally-Anne Palmer, Patient Pathway Co-ordinator for cancer services:** *"I was recently introduced to the Shared Care Record (ShCR) when the NWICB came to visit. I have already identified benefits with accessing information from other hospitals, information from GPs for when our patients have had or are due their Surgery's/OPAs and to check discharge Summaries. This is going to save us a lot of time on the phone, as we can now just check the ShCR."*
- 3.8.3 **IV Specialist Nurse, Ed and Peads, Norfolk and Norwich University Hospitals:** *"I was working with a patient with suspected mental health issues. After receiving permission to access his ShCR I was able to identify this was correct. He also has a social worker appointed as his next of kin, and a safeguarding concern noted, which informed me the*

patient needed supervision. However the data within our system was incorrect, so I was able to update his next of kin and the safeguarding concerns. I would not have been privy to this information if it was not for the ShCR.”

- 3.8.4 How does the ShCR aid decision making in your role? **Assistant Practitioner (Adult Social Services)** – “Having knowledge of the person’s medical conditions is very helpful when determining what support they need.”
- 3.8.5 **Duty Parctitioner (Adult Social Services)** – “I work within a duty/crsis management role. Shared care enables safe, effective and robust decisions quickly.”
- 3.8.6 **Best Interests Assessor (Adult Social Services)** – “I would say that it gives me additional evidence in order to make informed and evidence-based decisions in my role and I would use it in addition to my own assessment of the situation, not instead of it.”
- 3.8.7 **Assistant Practitioner (Adult Social Services)** – “Often basic health history and medication information is required for me to accurately inform agencies an get a clear picture of needs especially when someone has an impairment of the mind and brain and nobody to support and helps to gather the nessasary information to pceed in a timely manner...”



4. Suggested areas for further discussion with the ICP

4.1 To ensure the partnership is aware of all of the digital activities being carried out across the ICS we are proposing that the items in the table below are considered at each meeting over the next 12 months:

Item topic to be discussed	Meeting date
Overall Digital Roadmap	included in all meetings/papers
Generative AI including Ethics and Phase 3 of the Falls Prevention Work and the impact on the ICP.	March 2025
Information Governance and sharing of data across the system	June 2025
Assistive Technology and Virtual Wards	September 2025
Data Hub and Population Health Management	December 2025

4.2 There are many other collaborative areas that we could cover so we welcome a discussion and steer around this.

Officer Contact

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Report title: Preparing for Seasonal Pressures: ICS Framework for 2024/25

Date of meeting: 04 December 2024

Sponsor

**(ICP member): Ian Wake, Executive Director, Adult Social Services, Norfolk County Council
Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board**

Reason for the Report

The winter period can impact on the health and wellbeing of our population, with health conditions that can be caused or worsened by cold weather, higher incidences of seasonal illnesses, and impact on wider social wellbeing. Our system often faces greater pressures in winter which are managed by all partners in our Integrated Care System (ICS). This report appraises of work being undertaken to support our residents, and a resilient system, to face the impact of the 2024/25 winter.

Report summary

This report appraises the ICP of significant steps to ensure preparedness this winter. In developing our plan for the winter period, we are engaging with a wide range of teams and key external partners. Engagement is a key part of providing visibility on our planning and supporting teams to prioritise winter in their workplans.

Since last winter, partners have been implementing plans that have placed our services in a strong position ahead of seasonal pressures this year, including:

- Improvements and investment in the community-based intermediate care offer that will support residents this winter, including a forecast increase in the number of people Adult Social Services will support back to their own home of c.5-10%, on top of a c.6% increase last year.
- Continued steady decrease in the number of cases on the Interim Care List to one of its lowest points since the COVID-19 pandemic, which indicates there is good capacity within the local Home Care sector.
- In advance of this winter, we have contacted over 1000 residents at high risk of a fall, and offered interventions to reduce the likelihood of a serious fall.
- Continue to deliver our unscheduled care coordination hub, supporting the ambulance service to enable the right care in the right place.
- Improving processes that support patient flow, timely access and transfer or care.
- Ensure the annual vaccination programme of COVID and seasonal flu is delivered across Norfolk and Waveney.
- Improving flow within our acute and community hospitals to maximise longer term outcomes and support with improvement in patient flow.

However, as with last year, our ICS has not experienced a summer where pressures have abated. We also face the additional challenge this winter of pressures on budgets, with the combination of additional demands and unit prices meaning we are experiencing financial pressure in the 2024/25 financial year and beyond.

Recommendations

The ICP is asked to:

- a) Comment on the draft Winter Framework for 2024/25, including the assurance it provides on preparedness for seasonal pressures.
- b) Endorse the draft Winter Framework for 2024/25.

1. Background

1.1 Although winter is not an emergency or considered an unusual event, it is recognised as a period of increased pressure due to demand both in the complexity of people's needs and the capacity demands it places on resources within health, social care, and the wider ICS. Collaborative preparation and sharing of learning between partners is key to ensuring our population are best supported when pressures arise.

2. Preparing for winter pressures

2.1 **Priorities for Winter 2024/25:** Publication of national expectations on social care during winter, by the Department of Health and Social Care (DHSC), was received on 17th September 2024. The letter outlines short-term priorities for the winter period, including:

- A 'home first' approach to support independence for as long as possible.
- A focus on ensuring high-quality care.
- Involvement of people receiving care and their families and carers.

2.2 The Association of Directors of Adult Social Services (ADASS) have emphasised the importance of care at home, intermediate care and information and advice this winter – with a focus on prevention of admission to hospital or residential care as a means of reducing pressures across health and social.

2.3 NHS England (NHSE) have also set national expectations for the winter period (16th September 2024) that will have ramifications for NHS organisations and wider ICS partners, in both the planning and delivery of support. These cover:

- Providing safe care over winter.
- Supporting people to stay well.
- Maintaining safety and patient experience.
- Using evidence based practice.

2.4 The NHS remains in a period of pressure around urgent and emergency care (UEC) and planned care provision. Alongside continued delivery of existing priorities, such as elective care including for those who have experienced a longer wait for treatment, the NHS is focussed on delivering year two of the UEC Care Recovery Plan (part of a submitted annual operating planning). As we enter the second half of the year the focus remains on:

- Delivering a 30min response for category 2 ambulance patients.
- Delivering an emergency department standard of 78% of patients being admitted, transferred or discharged within 4hrs of arrival, with a stretch to 80%.

2.5 As part of a joint analysis between Adult Social Services (ASSD) and NHS Norfolk & Waveney Integrated Care Board (ICB) looking at interventions last winter (2023/24), considerations of learning from that period include:

- Teams and services across the ICS, including ASSD, district councils and VCSE, played a critical role in supporting the local UEC system, alongside partner

organisations. Preparations should continue to promote the importance of joint working during seasonal pressures.

- There are opportunities to make more effective use of data to better target our winter planning at a Place level.
- Where schemes have been successful, consideration should be given to how they can form part of a substantive offer.
- Sustainability of, and ability to mobilise at speed, schemes is important and should be factored into longer term improvements.

2.6 **Framework for action (ASSD):** ASSD has developed a winter framework, building on previous years successful approaches. This framework reflects the following increasing priorities:

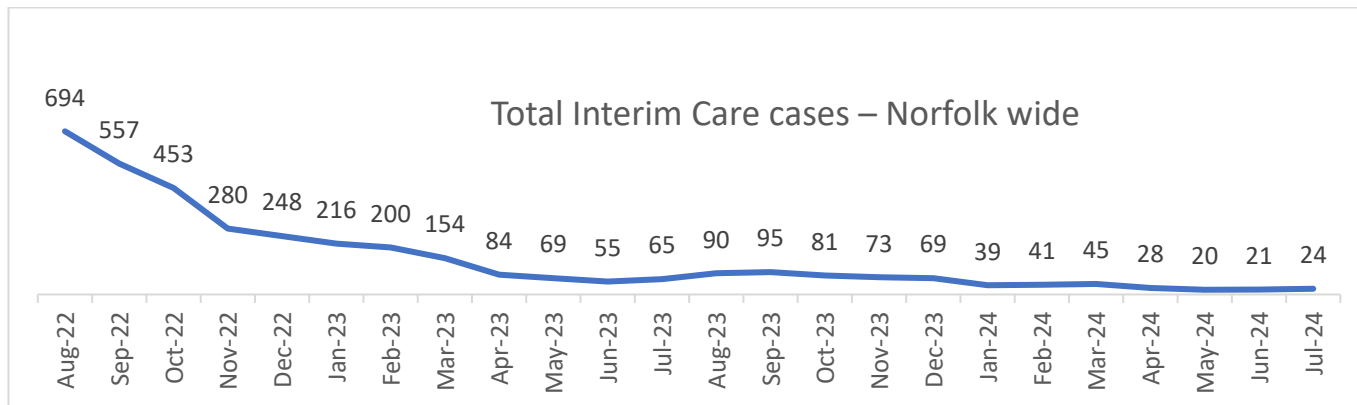
- Additional focus on intermediate care – given its vital importance to supporting people to remain at home, and return home after crisis, during winter.
- Managing demand and capacity within limited resource.
- Prioritising proactive intervention to support people to remain independent in winter.

2.7 With these refinements, the key strategic priorities for ASSD winter framework are:

- Meeting people's needs (to remain at, or return to, home).
- Resilient communities.
- Supporting our workforce, and
- Working together in winter conditions.

2.8 **Meeting People's needs:** Ensuring people can access the support they need during winter is important in delivering consistent health and wellbeing outcomes. Our winter framework will address this through:

- ASSD has an important role to play in intermediate care, as a commissioner and provider of a number of the community-based options, and in support planning and assessment in advance of leaving intermediate care. NCC also has a regional leadership role in intermediate care as co-chairs of the regional ADASS network that is working with NHSE to develop intermediate care guides for the region.
- We approach winter seeing c.90% of people being discharged from acute hospitals back to their normal place of residence, be that their own home or a residential setting where they live. Reablement support from ASSD's NFS (Norfolk First Support) service, community support and increased financial support for the Home Care market have all contributed to this success using Better Care Fund investment.
- We forecast an increase in the number of people ASSD will support back to their own home, increasing by c.5-10% from our main discharging Acute hospital, on top of c.6% increase last year. ASSD provides the majority of supported discharge via a community-based offer, meaning we play a vital role in supporting people back home during winter.
- ASSD has seen strong improvements over the year that will support people to access long term care and support when they need it. There has been a continued steady decrease in the number of cases on the Interim Care List during 2023-24 and 2024-25, which indicates there is good capacity within the local Home Care sector.



- A challenge remains that over winter, we are likely to see times of pressure and spikes in demand (volume and/or complexity of need). This is placed within a context of no additional winter funding expected this winter. In addition to improvements we have delivered over the year in anticipation of winter, ASSD will also prioritise:
 - Continued capacity brought online through Caring for Better Outcomes, which is starting to have a material impact on the percentage of people who are supported through reablement after hospital discharge.
 - Work with the 'Norfolk & Waveney Community Support' (commissioned by NCC, ICB and SCC) to ensure maximum utilisation.
 - Reducing utilisation of non-recovery short term beds, to ensure individuals are able to return home, or when they need a bed-based temporary offer they receive the appropriate intermediate care support.
 - Prioritising Mental Health - schemes to support seasonal pressures for people with mental health needs. This includes resourcing to strengthen Mental Health Act (MHA) assessments, New Approved Mental Health Professionals (AMHP) working with Psychiatric Liaison at acute hospitals, and strengthened AMHP out of hours support in ASSD's Emergency Duty Team.
 - Care Act Assessments and Reviews of Care & Support Plans – Supporting residents with care and support needs is one of the core responsibilities for practitioners working within Adult Social Services, and important to support during winter pressures as a vital element of the care and support system. Going into winter, there has been a continued focus on assessment for people who need it, with twice the number of new assessments compared to those waiting for an assessment being completed each month, and a 6.5% increase in review being completed during the last 12 months compared to the previous year. Work is underway to prioritise the longest overdue reviews and this is being driven through ASC's operational governance boards and as a result.

2.9 **Resilient communities:** Support for people in the communities in which they live will ensure that we mitigate some of the challenges we see during winter. Adult Social Services has an important role in this, with particular regard to support for carers:

- The Carers Matter Norfolk service offers Information advice, assessment and support, carers breaks, access to a health and wellbeing fund and welfare advice. Examples include sustaining additional resource from last winter in to providing advice focussing on enable carers to access additional financial support to cope with cost-of-living concerns such as heating and food resources.
- Expand the 'Tech Skills for Life' (TSfL) pilot to support unpaid carers and those receiving care and support to connect more people with information advice, guidance, activities and services.

- An important part of supporting people over winter is preventing the need for unplanned support, such as intermediate care. In advance of this winter, we have contacted over 1000 residents at high risk of a fall, and offer interventions to reduce the likelihood of a serious fall (and associated impact on their life). This is part of our 'Proactive Intervention' programme, which has been developing approaches to how we transform the way in which Norfolk offers support proactively to its residents using advanced analytics approaches and a suite of interventions to reduce falls occurring.

2.10 Supporting our workforce: Our workforce is our key asset in supporting people with their health and wellbeing, and this is more important than ever during the winter period.

Supporting our workforce, both in recruitment and in their welfare, will be addressed by:

- **Market Sustainability** - The Market Sustainability Improvement Fund (MSIF) was announced as part of the autumn statement in November 2022. The primary purpose of the fund is to support local authorities to make tangible improvements to adult social care services in their area, with a particular focus on building capacity and improving market sustainability. Funding has been received by NCC for 2023-24 and 2024-25, and is being utilised against the government identified target areas of improvement: Increasing fee rates paid to Adult Social Care providers; Increasing Adult Social Care workforce capacity and retention; Reducing Adult Social Care waiting times.

2.11 Working together in winter conditions: Winter presents a series of external challenges relating to weather, energy, and illness, which require individual and collective action:

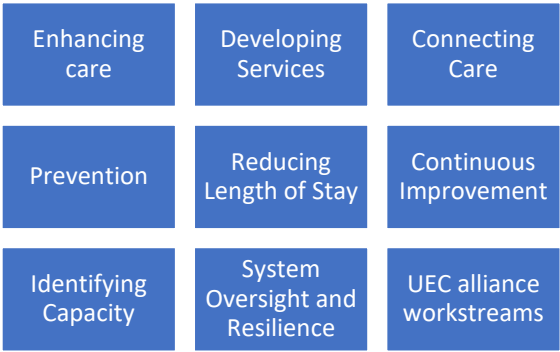
- Infection, prevention and control and promoting immunisations - protocols in place to manage and contain outbreaks of flu and COVID-19 and supporting and monitoring the care market to ensure a consistent IPAC approach. *Examples include the Integrated Quality Service supporting Public Health and Infection Control partners in promoting best practice to care providers and advising on risk reduction whilst minimising social exclusion in care settings.*
- Promoting winter immunisations with staff - joint working across health and social care to promote vaccination programmes for staff and care residents.
- Supporting those most at risk during adverse weather or energy issues - preparing for, and responding to, winter conditions including identifying and prioritising those most at risk during the colder winter period. *Examples include joining up with partner-wide resilience forum arrangements, and ensuring corporate business continuity plans and incidents management arrangements are well prepared.*

2.12 Framework for Action (NHS): For the NHS, and wider ICS partners involved in urgent and emergency care, delivery plans over the last 12 months have been developed to support this winter, leading to alternative access to healthcare, and alternatives to the emergency department if hospital care is required. Planning has also looked to increase capacity for patients on discharge pathways. Three key areas of winter planning are in place:

- 9 winter focus areas.
- UEC Board Priorities.
- 10 high impact interventions.

2.13 Winter focus area: For the NHS, the strategic focus is on responding to demand for UEC. Actions are designed to support safety and quality of patient care, with aim to get the

right care, to the right patient at the right time, through various access points. The following are the priority areas:



2.14 UEC Board priorities: Across Norfolk and Waveney, system partners have worked to meet national standards, to support patient care. The focus has enabled an improvement within our ambulance response times and our emergency department performance. It is recognised that these interim targets are still subject to variation with the focus on medium and longer-term transformation to support sustainable change. The experience within 2024/25 to date has been one of fluctuation demand patterns on urgent and emergency care, especially at our emergency departments.

2.15 The areas of focus for the delivery of winter cover build upon existing workstreams and direction set by the Urgent and Emergency Care Board, across three domains: Deterioration/accident, In-hospital and Recovery and rehabilitation.

2.16 These identified areas have enabled system wide and local alliance priorities to be progressed with support of partners, who have driven change and improvement for shared purpose and outcomes, with patients at the heart. Learning and experience, combined with data has supported a drive for improved outcomes, identifying different ways of work and ensuring effective use of our care pathways.

2.17 Ten high impact interventions: The winter approach utilises the nationally identified top 10 high impact interventions with the greatest opportunity and positive impact for our patients (see table below).

Intervention	Impact for patients and our system
Enhancing Care	<ul style="list-style-type: none"> Maximise GP front door streaming at our acute hospitals. Utilise pharmacy first to support patient care in the community working with primary care and 111. Ensure the walk-in centre supports care as an alternative to emergency department. Working with 111/OOH to ensure call answering, clinical validations and capacity is maintained.
Developing Services	<ul style="list-style-type: none"> Continue to deliver our unscheduled care coordination hub, supporting the ambulance service to enable the right care in the right place. Work with our acute hospitals to develop the same day emergency care offer for medical, surgical, and frail patients. Enabling these services to be accessed by healthcare professionals.

Intervention	Impact for patients and our system
Connecting Care	<ul style="list-style-type: none"> • Improving processes that support patient flow, timely access and transfer or care. • Supporting care homes to keep their residents well during winter, working with other agencies who support to maximise health and social care presence. • Maximise hospital and community virtual wards to provide alternatives to in patient care.
Prevention	<ul style="list-style-type: none"> • Ensure the annual vaccination programme of COVID and seasonal flu is delivered across Norfolk and Waveney. • Additionally, delivery RSV vaccinations for those whose whom are eligible. • Work with patients in care homes and with longer term conditions.
Reducing Length of Stay	<ul style="list-style-type: none"> • Improving flow within our acute and community hospitals to maximise longer term outcomes and support with improvement in patient flow.
Continuous Improvement	<ul style="list-style-type: none"> • Using data, support the identification of opportunities for improvement. This builds upon our work in tier 1 and continues into tier 2. • Using support offers from regional and national experts to achieve sustainable change.
System Oversight and Resilience	<ul style="list-style-type: none"> • Support timely ambulance handovers. • Coordinate system provider plans and escalation. • Review annual operating plans around forecast demand and activity.
UEC alliance workstream	<ul style="list-style-type: none"> • Continue with the agreed locality plans that maximise ways of working for patients.

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If you need this report in large print, audio, Braille, alternative format or in a different language please contact 0344 800 8020 or 0344 800 8011 (textphone) and we will do our best to help.

Report title: 2023/2024 Learning from Lives and Deaths: People with a Learning Disability and Autistic People (LeDeR) Annual Report

Date of meeting: 04 December 2024

Sponsor

(ICP member): Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board

Reason for the Report

This is the seventh Norfolk and Waveney (N&W) annual LeDeR report. This report covers the reporting period from 1st April 2023 to 31st March 2024. It is the responsibility of all Integrated Care Boards (ICBs) to have an established LeDeR programme within their system. ICBs must publish a LeDeR annual report describing their progress in completing reviews, provide interpretations of the collected data and detail completed and ongoing service improvements, made in response to any learning. It also provides an opportunity to reassess local priorities in response to any themes or trends.

Report Summary

Sadly, people with learning disabilities and/or autistic people continue to have a much shorter life expectancy, with the average being over 20 years younger than the general population. Mortality data presented in the LeDer annual report (see appendix A) shows that the leading single cause of death of those reviewed was aspiration pneumonia and pneumonia, followed by cancer.

The focus on respiratory health and prevention continues to be a health improvement priority for us. It is positive to note that COVID-19 and Flu vaccination uptake is performing well and that we have plans to further improve access to the pneumonia vaccine. Diagnosis and treatment of cancer was also a significant theme within the deaths reported, as the third single cause of death. This has informed work targeted work around early diagnosis of bladder cancer, including a review of referral pathways and a plan for a programme of clinical training. Wider work around addressing barriers for cervical and breast screening also continues and we must work towards better equity of access to interventions that helps catch cancers early and improve outcomes and survival rates.

Work has been undertaken to standardise and improve uptake of the NHS Annual Health Check (AHC) and completion of Health Action Plans (HAP). Practices have been able to work with the ICB Health Improvement Team to access support around improving the quality and accuracy of their patient data, developing skills and confidence, and understanding and implementing reasonable adjustments. The focus for the year ahead is to share good practice and improve how AHC and HAP are used as meaningfully as possible. Palliative and End of Life Care also continues to be a core part of the programme and there is evidence of improved practice around Do not attempt cardiopulmonary resuscitation (DNACPR) decision making, which demonstrates better planning and support around those 'big decisions' at the end of a person's life.

The team's learning into action work has been extensive and taken directly from our learning. It is worth highlighting the teams continued work within education and training. Collaborative work with University of East Anglia has generated excellent student feedback on sessions and resources that will help develop learning disability and autism education within health and social care courses, as well as with colleagues across the system to help raise awareness and shape practice for our future workforce.

Recommendations

The ICP is asked to:

- a) Agree and approve the recommendations from the LeDeR annual report and system learning.
- b) Champion advocacy and inclusion for people with a learning disability and autistic people in any discussion and/or decision that may impact their health and wellbeing.

1. Background

- 1.1 The LeDeR programme reports on deaths of people with a learning disability and/or autism aged 18 years and over. Latest figures available estimate there are approximately 1.2 million people (951,000 adults and 299,000 children) living in England, known to have a learning disability. As at the end of March 2024, 6868 people are registered with GP practices in Norfolk and Waveney out of a total population estimate of 1,032,472. Our area one of the highest percentage representations in England.
- 1.2 People with a learning disability are considerably more likely to be impacted by health inequalities, including higher levels of avoidable and premature deaths. This inequity is something we wish to address within Norfolk and Waveney, through a continuing programme of change informed by learning from LeDeR.
- 1.3 Last year our team presented the 2022/2023 Annual LeDeR Report for the first time.
- 1.4 The LeDeR programme is not mandatory so we may not have complete coverage of all deaths of people with a learning disability and/or autistic people. Our data set is small and has only been collected robustly and consistently for the last two years. As such data and trends must be interpreted with caution. Our priority is to present “the current picture” as to gaps in service quality and provision and learning which represents people’s strengths, talents, hopes and ambitions.

2. Key highlights from the LeDeR Annual report 2023 – 2024

- 2.1 The team works to achieve the national target of 95% of reviews completed within 6 months of notification. The team completed 77% (43 out of 56 reviews) of reviews within 6 months of notification in the 2023/2024 year. However, in the subsequent 6 months, due to capacity and a continued increase in notification, this has slipped considerably.
- 2.2 Better engagement means notifications have increased 29%.
- 2.3 Referrals for autistic people have increased but more work is needed.
- 2.4 There is an increased COVID, Flu and Pneumonia vaccine uptake.
- 2.5 Prevention of respiratory ill health is key; including vaccination, dental care and dysphagia management.
- 2.6 58% of deaths were coded as avoidable, because they are considered preventable or treatable.
- 2.7 The median age of death is 62 years old, which reflects the current national picture.
- 2.8 22% more people in our reviews lived to over the age of 65 years old, which is higher than last year.

- 2.9 There is more bowel cancer screening, but cervical and breast screening uptake remains low.
- 2.10 Evidence of good quality DNACPR decision making has increased from 66% to 93%.
- 2.11 Reviews show a reduced adherence to the Mental Capacity Act and Deprivation of Liberty Safeguards.
- 2.12 Epilepsy and hypertension are the two most common comorbidities.
- 2.13 Most people had a healthy BMI, but more people had a BMI >30kg/m² than last year.
- 2.14 Acute and Community Learning Disability Nurses are an invaluable resource.
- 2.15 Prevalence of ReSPECT has increased but proper and quality use of the tool requires improvement.
- 2.16 74% of people reviewed had an annual health check, which is an increase from last year.
- 2.17 Fewer people were prescribed psychotropic medications, especially for “behaviour”.
- 2.18 [Go to improvinglivesnw.org.uk to view the 2023/2024 Annual LeDer Report in detail.](https://www.improvinglivesnw.org.uk) This webpage contains the main report, an easy read version and will soon have our video version, narrated by Experts by Lived Experience from Opening Doors.

Officer Contact

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Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR)

Norfolk and Waveney Annual Report 2023-2024

Authors

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Nikki Goble - LeDeR Coordination Officer

Responsible Executive Lead

Patricia D'Orsi - Executive Director of Nursing

Forewords

Patricia D’Orsi: Executive Director of Nursing for the Norfolk and Waveney Integrated Care Board (NWICB) - Senior Responsible Officer (SRO) for the Learning Disability and Autism (LD&A) Programme Board

On behalf of NHS Norfolk and Waveney Integrated Care Board (ICB), I would like to welcome the publication of our seventh LeDeR Annual Report in Norfolk and Waveney and recognise the breadth and depth of its analysis and learning. I would like to recognise the local LeDeR Team for the skill and empathy required to undertake this work to such a high standard.

The ICB continues to be grateful for the contributions made by families, carers, and friends. The importance of ensuring that each review reflects the person at the centre of it; their character, interests and what they meant to those who knew them, is particularly powerful in the report’s section on lived experiences, which can be found on pages 50-59.

I would also like to recognise and thank staff from across the health and social care system for sharing the records and information required to complete each review to a robust and high standard, as well as the insights shared from their professional practice and from their time spent with the people and families whose experiences are central to this report. The organisations that provide health and social care are also key in taking forward learning into action and support for the programme continues to be outstanding.

Sadly, people living with learning disabilities and/or autistic people continue to have a much shorter life expectancy than the wider population and are more likely to face health inequalities that lead to poorer care access, experience, and outcomes, which can impact significantly on physical and mental health and wellbeing.

The data presented in this report shows that the leading single cause of death in Norfolk and Waveney over the past twelve months for people living with learning disabilities and/or autistic people continued to be aspiration pneumonia and other respiratory conditions. Therefore, the focus on respiratory health and prevention continues to be a health improvement priority for us; building on the work of the previous year. It is positive to note that COVID-19 and Flu vaccination uptake is performing well and that we have plans to further improve access to the pneumonia vaccine.

Diagnosis and treatment of cancer was also a significant theme within the deaths reported, as the third single cause of death. This has informed work targeted work around early diagnosis of bladder cancer, including a review of referral pathways and a plan for a

programme of clinical training. Wider work around addressing barriers for cervical and breast screening also continues and we must work towards better equity of access to interventions that helps catch cancers early and improve outcomes and survival rates.

I would like to acknowledge the work undertaken to standardise and improve uptake of the NHS Annual Health Check (AHC) and Health Action Plan (HAP). Practices have been able to work with the ICB Health Improvement Team to access support around improving the quality and accuracy of their patient data, developing skills and confidence, and understanding and implementing reasonable adjustments. The focus for the year ahead is to share good practice and improve how AHC and HAP are used as meaningfully as possible.

Palliative and End of Life Care also continues to be a core part of the programme and there is evidence of improved practice around DNACPR decision making, which demonstrates better planning and support around those 'big decisions' at the end of a person's life.

Finally, I would like to highlight the LeDeR Team's work this year within education and training. Collaborative work with University of East Anglia has generated excellent student feedback on sessions and resources that will help develop learning disability and autism education within health and social care courses, to help raise awareness and shape practice for our future workforce.

The ICB continues to be committed to ensuring that people living with learning disabilities and/or autistic people live well, and we recognise that the development of services and care pathways must be informed by people's lived experiences. I support the improvement priorities identified across the year ahead and look forward to working with the LeDeR Team to take this work forward over the year ahead, to further improve the lives of people living in Norfolk and Waveney.

Rachel Clarke: Co-ordinator for Family Voice Norfolk

My name is Rachel Clarke and I am proud to have been asked to contribute to this foreword for the second year running. I am the co-ordinator of Family Voice Norfolk (FVN), the Norfolk parent carer forum for families who have children and young people with special educational needs and/or disability aged 0-25 years. We are not a support group, nor are we an advisory and guidance service. We are a forum which gathers real-lived experiences and views of families to work in co-production to improve services within health, education, and social care.

FVN has been attending the LeDeR working groups, the Learning into Action Group, and the LeDeR Steering Group for over two years. We currently have two parent carer representatives attending these meetings, namely Laura Godfrey and myself. Both

Laura and I are parents of children and young people who have autism, learning disabilities and other conditions. Laura's son is moving into the realms of preparing for adult life where support and planning are key. My own son is in his twenties and although fully supported at home, and within adult services, we work every day towards him being able to be more independent in his way. Independence looks very different for each of our unique children and young people.

We believe that having parent carers present at the LeDeR meetings brings a different dynamic and different perspectives at times. We are able to put ourselves in the shoes of families involved and, hard as it may sometimes feel, think about the future care for adults who are autistic and/or have a learning disability, whether they be independent in their community or within a supported/residential setting. What would we expect to see from care for these adults? What would we want to see done differently in the care of adults as our young people will become adults themselves? There have been some extremely 'difficult to read' and, rightly so, emotive cases to review. Over the past year, we have been struck, at times, how young people have become 'lost' when no longer in education and less likely to be on any service's radar for support. This is something that needs addressing. It is exactly those cases where things have been 'missed', no matter at what age or stage of a person, that make the learning from the LeDeR work so vital.

As parents and carers, we want to be able to trust that, when we are no longer around for our sons and daughters, the best is done for them within the best environments. Each time we review an individual, we reflect on the importance of the annual Learning Disability Annual Health Check throughout a person's life, how crucial this can be in the early identification of emerging health problems and how important these checks are in ensuring a person is known by their primary care practice. We know there are inconsistencies in the quality of how learning disability annual health checks are conducted and we understand that there is ongoing work and training around this. Through LeDeR and the Learning into Action Group meetings we attend, we have heard about the learning from tragic deaths within residential homes and how important good housing and the support within it, is. As parents, it gives us much to think about for our young people and their adult lives.

Laura and I understand how dedicated everyone is within the meetings to make improvements, prevent recurrences of failings and to truly take learning from each case we review. We are grateful for the support and 'open ears' that are offered to us by colleagues should we find a case to be upsetting. There are times when the cases do make us think 'this person is exactly like my own'. The drive to learn from the deaths of people who are autistic or have learning disability, is tangible. There are sometimes examples of good or exceptional care. These are heartening to hear and again, learning is taken from these as examples of good and best practice. On behalf of Family Voice Norfolk, I should like to say how pleased we are to be part of the groups and the work going forward.

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1. Acknowledgments

Firstly, the team would again like to remember, and thank, all the people who have contributed to LeDeR by sharing their stories with us, following their death. It remains our greatest privilege to be given the opportunity to explore their experiences, and our primary aim is always to use all information in a compassionate and respectful way. Thanks also again go to the families, friends, and keyworkers of those we are reviewing, who contributed their time to enrich the information we had and help us find their voice.

Secondly, the LeDeR programme would not have been possible over that last year without the care, expertise and time given by health, social care, and voluntary sector colleagues. Delivering real and sustainable change takes a commitment of resource, and this has been freely given and gratefully received. Colleagues have supported the LeDeR groups and our learning into action project work. Special thanks go to our partners with lived experience for their guidance, support and challenge.

LeDeR reviews are not an investigation of a death but an assessment of a person’s experience. This aims to bring to life the circumstances leading up to the person’s death and provide a life portrait of the people we have reviewed. This can be a difficult and challenging role but has been fulfilled by a team of highly experienced and dedicated nurses and administrators, who have been central to delivering the programme.

We would also like to acknowledge with much appreciation the crucial role of the health and social care staff, who have diligently delivered high quality care to people with learning disabilities and/or autistic people over the last year.

2. Executive Summary

Welcome to the Norfolk and Waveney Integrated Care Board (NWICB) LeDeR report. This is the seventh annual report in Norfolk and Waveney on the reviews of the lives and deaths of people with a learning disability and/or autism since the inception of the LeDeR programme in England in 2017. It is the responsibility of all Integrated Care Boards (ICB) to have established a LeDeR programme within their system and implement any actions identified by the learning taken from reviews.

ICBs must publish a LeDeR annual report describing their progress in completing reviews, provide interpretations of the collected data and detail completed and ongoing service improvements made in response to any learning. It also provides an opportunity to reassess local priorities in response to any themes or trends. This report from the Norfolk and Waveney LeDeR programme demonstrates the work covered in the reporting period from 1st April 2023 to 31st March 2024. The deaths reviewed can cover a longer period dating back to early 2022. This is due to death reporting delays but also delays in the review completion.

There will be some comparison available between this and last years' annual report due to significantly more robust local data collection. Comparison will be limited between this year and last year, so extrapolations are of course limited. As such, analysis primarily describes the current situation in Norfolk and Waveney and continued work over the coming years will be able to better highlight trends and improvements.

Comparisons can be made between Norfolk and Waveney and the regional and national picture by reading this report alongside the East of England and National Reports¹. Summary findings from the Norfolk and Waveney reviews in 2023/2024 can be seen on the next page:

¹ <https://www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities>

More people have had their pneumonia, flu and COVID vaccinations than last year.

As a region we achieved 74% completion of annual health checks for those eligible, an increase on last year.

Use of ReSPECT forms has increased, but work is needed to solidify good use as an emergency care planning tool.

Evidence of good quality DNACPR decision making has increased from 66% to 93%.

The median age of death in last years reviews has increased from 57.5 years old to 62 years old.

58% of deaths were coded as avoidable, which is an increase from last year. However, we believe this is due to better MCCD completion.

Acute and community learning disability nurses are key supports for improving service access and reasonable adjustments.

Primary care are good at offering face to face appointments and we have seen improved preparation for interventions such as blood tests.

Notifications for those with autism have increased but there is room for further improvement.

Focused review gradings have demonstrated improvements in assessed quality of care and access to services.

Epilepsy and hypertension continue to be the two single leading comorbidities seen in reviews.

For the first time since 2020, we had no reviews with COVID-19 as a cause of death.

More people had bowel cancer screening last year, but uptake of breast and cervical cancer screening remains low.

Respiratory disease remains the leading cause of death, with pneumonia still the most frequent cause of death.

Overall we have had 29% more notifications this year. This is due to increased awareness of LeDeR across the system.

Of the people we reviewed, 43% died over the age of 65 years old. This is an increase from 21% last year.

Most people had a healthy BMI, but we did have more people recorded with a BMI in the obese range of <30.

Reviews this year have shown evidence of a decrease in adherence to MCA and DoLS.

Reviews this year demonstrated less people were prescribed psychotropic medications, especially for behaviour.

Prevention of respiratory illness is a priority for the whole system, including dysphagia management, dental care and vaccination.

3. Introduction and Purpose (Local and National)

3.1 What is LeDeR?

The LeDeR programme reports on deaths of people with a learning disability and/or autism aged eighteen years and over. Latest figures available estimate there are approximately 1.2 million people (951,000 adults and 299,000 children) living in England, known to have a learning disability². As at the end of March 2024, 6,868 people were registered with GP practices as having learning disability in Norfolk and Waveney, out of a total population estimate of 1,032,472³. Our area has one of the highest percentage learning disability representations in England⁴.

People with a learning disability are considerably more likely to be impacted by health inequalities, including higher levels of avoidable and premature deaths. For example, the latest data from the 2022 National LeDeR Report demonstrates the disparity in age of death for those with a learning disability. Compared with the general population, males with a learning disability die 20 years younger and females die 23 years younger⁵. This inequity is something we wish to address within Norfolk and Waveney, through a continuing programme of change informed by learning from LeDeR.

The LeDeR programme⁶ uses the national policy's definition of a learning disability. For autistic people to be included within the LeDeR programme they must have a diagnosis of autism recorded within their health records prior to their death. The child death review (CDR) process reviews the deaths of all children aged under 18 years. This is the primary review process for children with learning disabilities and autism, which is completed collaboratively with the LeDeR programme. A full explanation of the review process including national priorities for a focused review can be found in the LeDeR policy⁷.

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so may not have complete coverage of all deaths of people with a learning disability and/or autism. Comparatively, numbers are also small compared to the general population, and as such must be interpreted with caution. Data interpretation and analysis is an important

² https://www.norfolkinsight.org.uk/wp-content/uploads/2022/03/Briefing_paper_Disability_Adults_with_Learning_Disabilities_May_2018_accessible.pdf

³ <https://www.norfolkinsight.org.uk/>

⁴ [Quality Assessment Framework 2021/2022](https://www.norfolkinsight.org.uk/wp-content/uploads/2021/03/Quality_Assessment_Framework_2021/2022)

⁵ <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf>

⁶ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

⁷ Section 3/page 12 of <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

part of finding trends in poor practice and identifying gaps where improvement is needed. However, we also aim to present person focused qualitative learning which represents people's strengths, talents, hopes and ambitions.

3.2 Reporting a Death

Anyone can notify the programme of a death or person with learning disabilities and/or autism at <https://leder.nhs.uk/report>

3.3 Local Programme

Within Norfolk and Waveney, we are committed to improving services for people with learning disabilities and/or autistic people and use the framework set out in the LeDeR policy by NHS England. Data collection significantly changed for 2022/2023 and this allowed us to provide a more detailed report last year, and subsequently this year.

4. Challenges and changes to delivery of the LeDeR review programme

The success of the LeDeR programme is built on the efforts and input of the LeDeR team and the wider contribution from Integrated Care System (ICS) partners and colleagues. The team has continued to strengthen their quality of work, supported by local governance, robust escalation routes, a systemic approach to learning and creating education routes to update the wider health and social care community on learning from LeDeR. We have experienced many challenges in delivering LeDeR over the past year, capacity has been reduced in the team, while the number of notifications and number of focused reviews have both increased. This has resulted in a drop in performance.

All reviewers are reliant on the timely provision of notes from all involved services to complete a review within the 6-month target. This includes notes from acute trusts, primary care, community trusts and social care. Mostly the team will receive at least one set of notes back within 2 weeks of the request being sent. However, responses to all requests can take up to several months which significantly delays allocation and completion of reviews. Reviewers also rely heavily on talking to carers and professionals who knew the person well to get a complete picture of the person they are writing about. Care providers can sometimes be difficult to engage in this process which restricts the information available to really tell a person's story and describe their lived experience.

Due to improvements in the timeliness of reviews families are being contacted and invited to participate in the LeDeR process much sooner after the death of their loved one and we believe due to this, we are seeing more families choosing not to be part of the review. We have delayed completing reviews at the request of the family to give them more time, even if this takes the review over 6 months, as we recognise the importance of a loved one's contribution. We will also still offer families the option of receiving a copy of the completed review should they wish. Where we have a telephone number for a family member, we have implemented a

follow up phone call to every invitation letter, to try every method we have, to engage a family. However, this has not been in place long enough to gauge if it has helped.

5. Governance Arrangements

In line with the national policy, we have governance arrangements to support reviewing and signing off completed reviews. As well as clear reporting routes into the Learning Disability and Autism Programme Board and Learning from Death Forum.

5.1 Initial reviews

Initial reviews are presented at the Local Quality Assurance Panel (LQAP) which is chaired by one of the Local Area Contacts (LAC) or another suitably senior person within the Learning Disability and Autism Team within the NWICB. The panel will scrutinise the review for quality and ascertain if the recommendations address the identified learning. Initial reviews are signed off and themes and trends are presented through LeDeR's reporting programme.

5.2 Focused Reviews

Focused reviews go through the same quality assurance and scrutiny process above but are then presented at the Learning into Action Group (LIAG) for sign off which is chaired by either the NWICB LAC or the NWICB Senior Reviewer. This group is attended by key operational stakeholders who will agree the SMART recommendations, care grading, and identify any good practice of note.

5.3 Reporting Structures

LeDeR's reporting structures ensures key themes and learning are shared with senior colleagues and a wide range of stakeholders on a regular basis. This helps us review identified learning, strategic actions, and quality improvement work streams. Reports are presented to the:

- ICS Learning from Death Forum – Every 2 months.
- ICB Learning Disability and Autism Programme Board – Every 2 months.
- ICB Quality and Performance Committee – Every 2 months.
- Norfolk Safeguarding Adults Board – Every 6 months.
- Social Care Quality Improvement Programme – Every 6 months.

6. Performance

The team works to achieve 95% of reviews completed within 6 months of notification. At the end of Quarter 4 (Q4) the team has completed 77% (43 out of 56 reviews) within 6 months of notification in the 2023/2024 year.

Some reviews may take over the 6 months to enable any statutory process to be completed such as police investigations, coroner proceedings or safeguarding inquiries. It is important that LeDeR pauses and gives precedence to these to avoid prejudicing any investigations. We can put these reviews on hold, which in effect “stops the clock” so the delay doesn’t count towards the 6-month timeframe. Reviews which are considered to have exceeded the 6-month timescale included those delayed for reasons such as clinical notes not being received, capacity issues within the review team and giving families time who may not be ready to engage but want to be part of their loved one’s review.

The team have completed 56 reviews this year. Last year the ICB signed off 72 reviews. Last year we completed 7 paediatric reviews, however reviews for children and young people are no longer in scope for LeDeR nationally. To ensure our team still delivers the same contribution to this process, the ICB’s Child Death Review process has been strengthened through collaborative working. Lastly, in 2022/2023, 13 reviews were completed by an externally commissioned provider to clear our historical reviews. So, the ICB team alone has completed more reviews ($n=56$) than last year ($n=52$).

We carried forward 32 reviews from the 2023/2024 review period and this year we are carrying over 51 reviews into 2024/2025, so 60% more than last year. The team is also tasked by NHS England to convert a minimum of 35% of reviews from initial to focused. This year the team has again exceeded this target and achieved 45% of reviews being focused, a higher percentage than last year.

7. Overview of Notifications

As Figure 1 shows how the number of notifications to LeDeR has changed over the years. It is important to note that as reporting to LeDeR is not mandatory, the true number of deaths is likely to be higher. Our team have received 81 notifications in the 2023/2024 period. The team did have an additional notification for child, but as LeDeR no longer reviews those under 18 years of age, this notification has not been included in any analysis as a review did not take place. To compare the number of notifications, 2019/2020 is used due to the number of excess deaths from COVID which is also exemplified in Figure 1. Overall, our notifications have increased by 62% since pre-COVID levels with an increase of 29% on last year alone. We believe this increase reflects a higher number of autism only notifications, as well as our continuing work to raise the awareness of LeDeR in our system. We have also seen more robust reporting processes within the coroner’s court, medical examiners and mental health trusts which has meant we received notifications which previously would have been missed.

7.1 Age

The youngest reported death during 2023/2024 was 18 years of age and the oldest was 91 years. Most of our referrals were for people 65 years and over, which is an increase from last year. Overall, the representation across the age groups for men and women was very similar. This year's data shows an increase in the median age at death of notifications from 57.5 years to 63 years of age. Using the latest data from 2018 - 2020, the average age of death for the general population in Norfolk and Waveney is 79 years old for men and 84 years old for women.⁸ See Figure 2.

7.2 Gender

Relatively, we had the same number of referrals for men than women, whereas last year we had more notifications for men. See Figure 3.

7.3 Diagnosis

The majority of our referrals were for those with a diagnosis of a learning disability. A small number had a diagnosis of both a learning disability and autism, however this is likely an error in referrals and post review we would expect a higher percentage to also have an autism diagnosis. The team received 6 notifications for people with a sole autism diagnosis, compared to last year when we didn't receive any. It is thought that 1% of the population has autism which would mean approximately 10,330 people in Norfolk and Waveney. The latest standardised mortality rate for autistic people is 17 deaths per 10,000. This shows the LeDeR team what is still being missed and the continued need for communicating the importance of autism referrals will be an ongoing priority for 2023/2024. The medical examiner role for acute and community should go live this year which will aid these referrals, as well work done by Norfolk and Suffolk Foundation Trust (NSFT) who have built in notification of eligible deaths to LeDeR into their new mortality oversight processes.

7.4 Place of Death

Place of death is not a mandatory question for referral completion. At the time of writing, 7 of the notifications did not have an identifiable place of death in the referral or in the available notes. This means some of the figures could change if all information was available. However, from the information we have, most deaths referred to us in 2023/2024 happened in hospital, 52% ($n=42$) overall, and 21% ($n=17$) occurred in the person's usual residence. This means a lower percentage of people died in hospital than

⁸ https://www.norfolkinsight.org.uk/wp-content/uploads/2022/08/State-of-Norfolk-and-Waveney-health-report-2022_correctedByPAVE.pdf

last year, but so did a lower percentage die in their usual residence. The percentage of people dying in hospital is coming more in line with the general population figure of 51%⁹. See Figure 4.

7.5 Month of Death

Looking at the deaths which occurred during the reporting period Figure 5 shows how many deaths occurred by month for the notifications this year and for last year. We have excluded notifications for this year, where the death falls outside of the reporting period. For this year's notifications, 10 deaths happened before the reporting period: 3 in early 2023, 6 in 2022 and 1 in 2021.

7.6 Ethnicity

Of the notifications from 2023/2024 where the ethnicity was disclosed, 100% ($n=81$) were for white British people. The last figures we have for Norfolk and Waveney suggest 5.1% of the general population is from an ethnicity other than white British.

7.7 Leading Cause of Death

From notifications the leading single cause of death (COD) in Norfolk and Waveney was aspiration pneumonia, with all respiratory conditions including chest infections and type two respiratory failure leading across the board. This is the same as last year's notification data and is also seen in the completed reviews from this year. This profile is different to the general population where the top three COD in 2022, (the last available full year of data) for England and Wales, were Dementia and Alzheimer's Disease, followed by Ischaemic Heart Disease, then Chronic Lower Respiratory Diseases¹⁰. Again, a COD is not a mandatory question for referral completion. As such, at the time of writing, only 45 of the notifications had an identifiable COD in the referral or in the available notes. As such some of the figures may change if all COD were available.

7.8 Area of Deprivation

The Indices of Multiple Deprivation (IMD) again shows a mode score of 6 this year, which is the same as our completed reviews. The overall breakdown in representation into the higher and lower IMD areas is also very reflective of the completed reviews for 2023/2024, with more people with a learning disability and/or autism living in areas with an IMD score of 5 or less. This is still higher

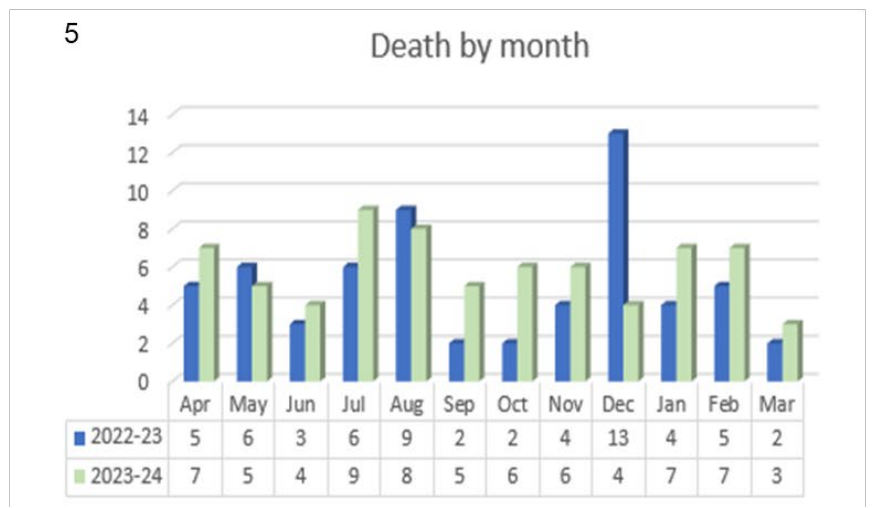
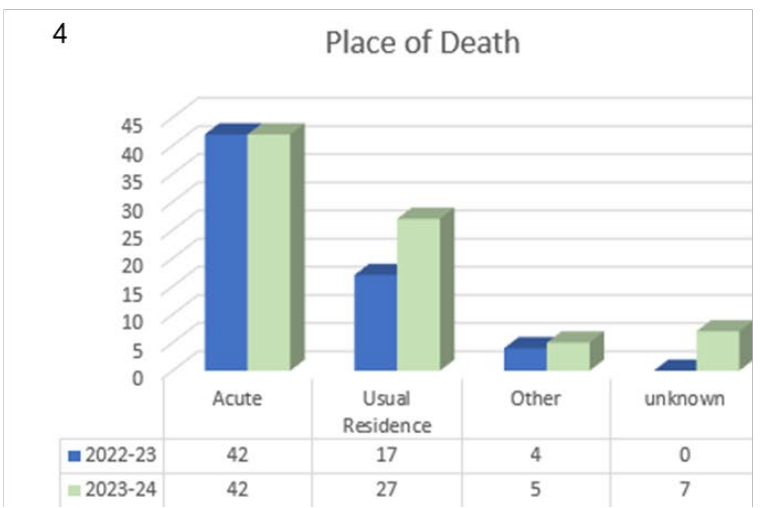
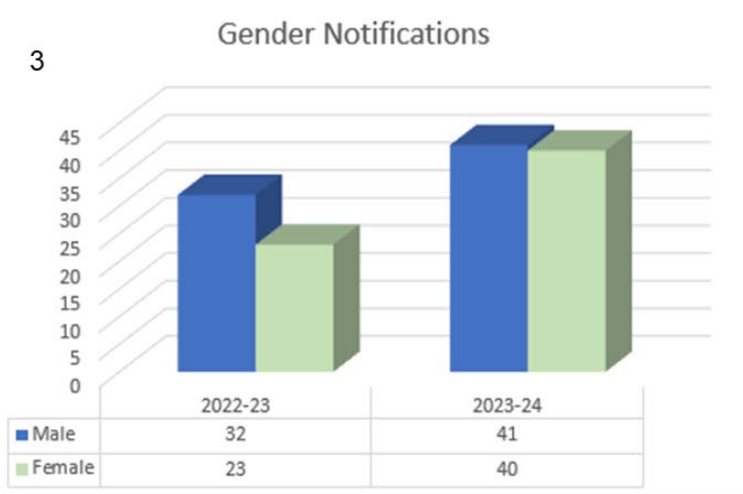
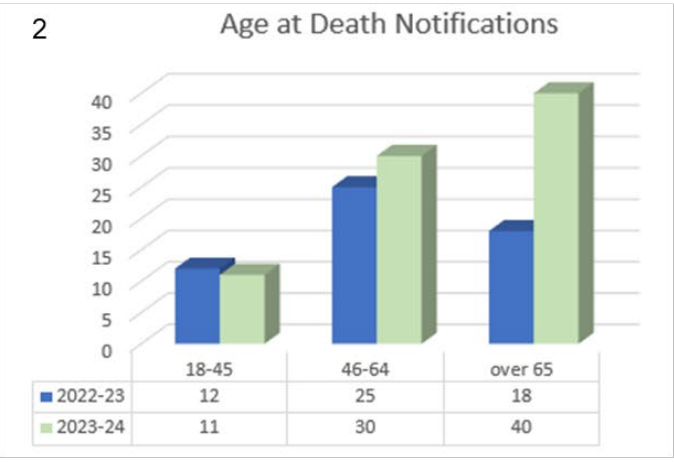
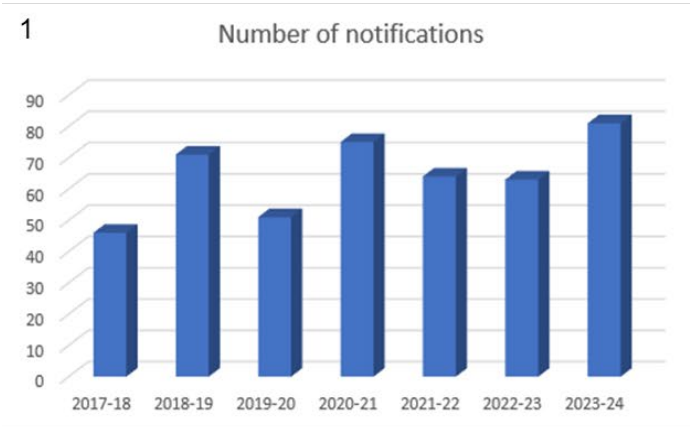
⁹ <https://fingertips.phe.org.uk/profile/end-of-life/data#page/1/gid/1938132883/pat/15/ati/221/are/nE54000022/iid/93474/age/1/sex/4/cat/-1/ctp/-1/yr/1/cid/4/tbm/1/page-options/car-do-0>

¹⁰ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2022>

than the general population where 2019 data shows 52% in Norfolk live in an area with an IMD score of 5 or less¹¹. However, we have seen a narrowing from 34% to 16%, in the difference between the top and bottom 50%.

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	10%	47	58%
2	6	7%		
3	5	6%		
4	11	14%		
5	17	21%		
6	19	23%	34	42%
7	6	7%		
8	6	7%		
9	2	2%		
10	1	1%		

¹¹ <https://www.norfolkinsight.org.uk/deprivation/reports/#/view-report/8b97d75c317745b3a6016fc0788469d1/E1000020/G3>



8. Overview of Completed Reviews

The LeDeR review performance report as at the end of March 2024 shows that 89% ($n=393$) of 444 reviews received since 2017 have been completed by the 2023/2024 year end. The table below breaks down the number of referrals received, and the number of reviews completed every year since the programme began.

Years	No of adult notifications	No of reviews completed	No of reviews carried forward
2017-18	46	3	43
2018-19	71	23	91
2019-20	51	77	65
2020-21	75	77	63
2021-22	63	85	41
2022-23	63	72	32
2023-24	80	56	51
Total	449	393	

In 2023/2024 56 initial and focused reviews have been signed off as complete. At year end (March 2024), the team have 11 reviews in progress and 40 waiting to be allocated. This includes 5 which are on hold, awaiting statutory processes to be concluded. The team have completed more reviews than previous years as discussed in section 6 but are carrying over more reviews this year and have more reviews waiting to be allocated, demonstrating the increased workload of the team.

For certain variables such as cause of death, avoidable deaths, areas of deprivation and chronic conditions all reviews have been included to get the best breadth of information possible to draw conclusions. Quality of Care grading has only been discussed with the focused reviews as the national policy does not currently require care and service provision grading for initial reviews.

8.1 Initial Reviews

Of the 56 reviews completed in 2023/2024, 30 (55%) were initial reviews.

8.2 Focused Reviews

Of the 56 reviews completed in 2023/2024, 26 (45%) were focused. Most reviews (35%) were converted to focused due to care quality concerns and 23% were converted due to professional judgement, for example if a case is particularly complex. There were

many other reasons which individually represented less than 5 reviews, including family request, ethnicity, history of being held under a section of the mental health act, autism diagnosis and local priority.

8.2.1 Quality of Care

The national policy requests that the LIAG grade the care received and the effectiveness and availability of services for all focused reviews. Only focused reviews are graded on the delivery of quality of care and accessibility and effectiveness of services. Grading is based on the information the reviewer has gathered and presented at panel. Of the 26 completed focused reviews from 2023/2024, a higher number of the reviews than last year graded the quality of care as being satisfactory or above ($n=9$). Likewise improving, 65% of reviews demonstrated care which fell short of expected good practice this year, with 10 reviews where this was judged to have impacted the person’s wellbeing. At 38%, this again is an improvement on last year. The below table shows the grading of Care for completed reviews for 2023/2024.

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	0	%
5	This was good care (it met current good practice in all areas).	5	19%
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person’s wellbeing).	4	16%
3	Care fell short of expected good practice but did not contribute to the cause of death.	7	27%
2	Care fell short of expected good practice and this significantly impacted on the person’s wellbeing and/or had the potential to contribute to the cause of death.	8	31%
1	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	2	7%

Of the 26 completed focused reviews from 2023/2024, a higher number of the reviews than last year graded the Effectiveness and Availability of Services as being satisfactory or above ($n=10$). Likewise improving, 62% fell short of expected good practice this year with 9 reviews where this was judged to have impacted the person’s wellbeing. At 35%, this again is an improvement on last year. The below table shows the grading of Availability and Effectiveness of Services for completed reviews for 2023/2024.

Rating	Standard	Number	Percentage
6	This was excellent Service Effectiveness and Availability (it exceeded current good practice).	1	4%
5	This was good Service Effectiveness and Availability (it met current good practice in all areas).	6	23%

4	This was satisfactory Service Effectiveness and Availability (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	3	11%
3	Service Effectiveness and Availability fell short of expected good practice but did not contribute to the cause of death.	7	28%
2	Service Effectiveness and Availability fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	6	23%
1	Service Effectiveness and Availability fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	3	11%

8.3 All Reviews

8.3.1 Age

The table below shows the total number of reviews in each category, since LeDeR began in Norfolk and Waveney. Overall, the 65+ age group still has the highest number of reviews. Potentially because of the 65+ age category seeing a heightened number of excess deaths due to COVID-19 in 2020/2021, due to the added mortality risk of age. Indeed, in the two years from 2021 to 2023, the 46 – 64 age group surpassed it in numbers. Yet this year we are again seeing more deaths at a higher age in both reviews and notifications. The median age of death for all reviews in 2023/2024 was 62 years old, which is an increase of 4.5 years from last year's annual report and is similar to our notification data. As stated in previous years, we are now seeing the impact of a strengthened governance and review process in that our median age of death now more closely matches that of the national picture. The latest national data from 2022 shows 85% of people in the UK population died at age 65 years and over¹², in Norfolk and Waveney 43% of reviews were for those aged 65 and over. This an increase from only 21% last year.

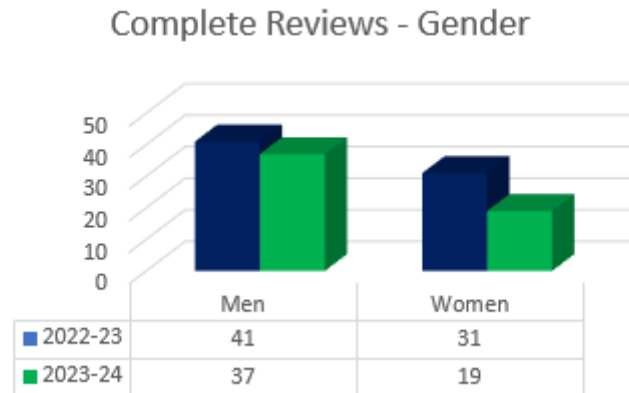
Year of death	Number of Reviews by Age Group (in years)			
	Under 18	18-45	46-64	65 and over
2017-18	0	10	17	19
2018 -19	5	9	25	32
2019-20	<5	11	19	20
2020-21	<5	21	18	33

¹² <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables>

2021-22	<5	10	27	23
2022-23	7	12	25	19
2023-24		11	21	24
Total		84	152	170

8.3.2 Gender

As with our notification data, we had a fairly even split between men and women who had an initial review. Of the 26 focused reviews, most were for men (81%), with only 5 (19%) for women. Last year there were slightly more women having a focused review. Overall, we completed 37 (66%) reviews for men and 19 (34%) reviews for women.



8.3.3 Ethnic Groups

Norfolk and Waveney general population data from 2021 shows 94.9% of people reported themselves to be white, with the broad minority groups representing 5.1% of the population. All initial reviews were for people who were white British, as any person from an ethnic minority would automatically have a focused review as per the national priorities. This year LeDeR completed 2 reviews where the person was not white British (4%). Usually, we would not report on cases numbering less than 5, to protect anonymity, but have done so in this case to highlight our current representations.

8.3.4 Diagnosis

In 2023/2024, 23 (77%) initial reviews had a learning disability diagnosis and 7 (23%) had learning disability and autism diagnosis. All autism only deaths were converted to focused as per the national priorities. Overwhelmingly most of our focused reviews were for people with learning disability only (88%), with most being for men, which is not surprising considering the larger number of men reviewed. We only completed 2 reviews for people with a sole diagnosis of autism. Usually, we would not report on cases numbering less than 5, to protect anonymity, but have done so in this case to highlight our current representations. We have seen our team has received 6 autism only notifications this year, so our expectation is that this number will be higher next year.

8.3.5 Level of Learning Disability Severity

Most initial reviews (37%) were for people with a mild learning disability, followed by moderate (33%) severe (27%) and then profound. Women had a marginally higher representation in the mild category and more men had more severe levels of learning disability, even with a number of women having had a profound learning disability. Of the 24 focused reviews with a learning disability, most were again completed for those with a mild learning disability (42%), but followed by severe (33%), then moderate (21%) then profound. Last year we had more reviews for people with a moderate learning disability, whereas this year we had more reviews for people with a mild learning disability.

Level of Learning Disability	Number	Percentage (n=54)
Mild	21	39%
Moderate	15	28%
Severe	16	30%
Profound	<5	xx%

8.3.6 Areas of Deprivation

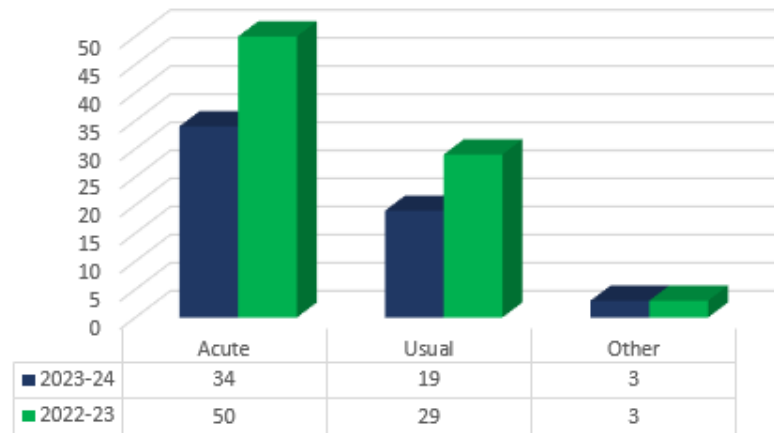
Our local data collection methods allow us to review the Indices of Multiple Deprivation (IMD) for all the completed reviews. As seen in the below table, most people reviewed lived in an area with an IMD score of 6 which is higher than last year, but areas with a rating of 10 were not represented at all in the completed reviews. Overall, as with our notifications for 2023/2024, most of the people we reviewed lived in an area scoring 5 and below on the IMD scale. This tells us people with a learning disability and autism predominantly live in areas of higher deprivation and more so than the general population. However, we have seen a narrowing from 28% to 14%, in the difference between the top and bottom 50%.

IMD Score	Number of Completed Reviews	Percentage	Number of Notifications	Percentage
1	6	11%	32	57%
2	6	11%		
3	5	9%		
4	6	11%		
5	9	16%		
6	14	25%	24	43%
7	5	9%		
8	2	4%		
9	3	5%		
10	0	0		

8.3.7 Place of Death

From our initial reviews, most people died in hospital (63%), followed by the persons usual residence, whether that be a private home, care home or supported living (33%). Our focused reviews reflect the same, with 58% dying in the acute setting. This was the same as last year. However, a reduced number of focused reviews died in combined residential services including care homes and supported living (35%). Overall, most (61%) people died in the acute setting, but at a reduced percentage to last year, and 34% died at their usual residence, which again is a reduced percentage to last year.

Place of Death - Completed reviews



Learning identified from the reviewers:

Although most of the reviews showed people dying in the acute environment, there were several cases where admission could have been avoided with earlier identification of deterioration and better end-of-life planning. Most homes express regret when they are not able to support a person to die peacefully in their home, where familiarity provides reassurances and avoids undue stress.

Appropriate support for staff, robust admission avoidance plans (where appropriate) and good symptom management plans can often mean fewer hospital admissions. Exceedingly good practice has seen some homes going above and beyond to enable a person to die at home with needs that would usually exceed the abilities of a care home. However, these cases were also very reliant on early identification of an end-of-life stage, collaborative planning from the person’s multi-disciplinary team and good support from community health services.

It is worth mentioning however end-of-life care in hospital is often managed well, with frequent use of side rooms to offer respite from the busy acute environment. The learning disability liaison nurses are integral to providing this support and are seen repeatedly to be an invaluable resource. Family and carers are often supported and encouraged to accompany the person and oversight from palliative care teams offers excellent symptom and pain management. In one case, a hospital even supported a

person's preference to die in hospital, rather than move to a Hospice, as after a prolonged admission they had become familiar and comfortable with the ward staff.

8.3.8 Accommodation

Most people who had an initial review lived independently or in the family home (37%). Supported living accommodated 33% and slightly less lived in a care home (30%). Most people who had a focused review lived in a care home (46%), increasing to 53% when combined with those living in supported living. Slightly less lived in independently or in the family home (42%). Overall, 59% ($n=33$) of people lived in residential services and 39% ($n=22$) lived independently or in the family home. This has reduced from last year where a combined 75% lived in combined residential services. However, this could be reflective of the changes in demographic of learning disability severity this year.

Learning identified from the reviewers:

Most people lived in a supported living or care/nursing home environment. Some issues have been seen such as medication errors and development of pressure areas, but this is not unique to the care of people with learning disabilities and autism. Reviewers are seeing increasing evidence of oversight and monitoring from quality teams where concerns are raised, which appears to support improvements. Reviewers still see problems with homes understanding and adhering to SALT plans, something which is especially important considering the prevalence of aspiration pneumonia.

Availability of suitable accommodation which meets a person's needs, continues to present problems, especially with discharge from hospital. Reviewers have repeatedly seen situations where a Discharge 2 Assess (D2A) bed was sourced in order to enable discharge from hospital, while waiting for a CHC assessment to agree a longer-term living arrangement. Ultimately this means repeated moves for a person, which is often anxiety provoking and presents barriers to staff building familiar and long-term trusting relationships with people which is so important to good health and wellbeing.

Independent housing also presents issues, where oversight is rare, and use of reasonable adjustments is infrequent at best. Reviewers have seen issues with repeated evictions where, despite the person having known vulnerabilities, no one was leading on housing needs or making appropriate referrals for support. Reviewers have seen cases of suspected abuse, including potential "cuckooing" and people being found to have no heating, water or electric within the property. Other reviews have shown poor property upkeep from social housing, including obvious fire risks and hazards which have not been fixed.

8.3.9 Chronic Conditions

Most people with a learning disability and/or autistic people are known to have other complex physical health complications. Analysis of the 56 completed reviews demonstrate all the people we reviewed had one or more chronic physical or mental health condition. This is thought to be due to a combination of factors more likely to occur in people with a learning disability, including congenital conditions, progressive degenerative illness, obesity and poor mobility, difficulties accessing services and many more. The table below is a list of some of the common health conditions and number of people affected, recorded from completed reviews (most people had more than one condition recorded). The single most common comorbidity is still epilepsy, which was recorded in 48% ($n=27$) of reviews. However, cardiovascular was the highest grouping of co-morbidities, with hypertension being the biggest contributor to this. The below tables show the most common single and grouping of co-morbidities. There were multiple other chronic conditions seen in less than 5 reviews which have not been listed here to protect anonymity. For the group comorbidities, the top 10 have been listed.

Single Comorbidity	Frequency	Percentage
Epilepsy	27	48%
Hypertension	14	25%
Type 2 Diabetes	10	18%
Depression	9	16%
Anxiety	8	14%
Constipation	7	13%
Cancer	6	11%
Chronic Kidney Disease	6	11%
Cerebral Palsy	6	11%

Group Comorbidity	Frequency	Percentage
Cardiovascular	34	61%
Mental Health	25	45%
Endocrine	20	36%
Continence	16	29%
Eating and Drinking	12	21%
Muscular Skeletal	12	21%
Developmental Disability	11	20%
Sensory Impairment	10	18%
Respiratory	9	16%
Skin	8	14%

Learning identified from the reviewers:

Reviewers have seen continence care presenting multiple issues over the last year, especially with management of recurrent Urinary Tract Infections (UTI) and catheter care. Often repeat UTI's are not managed appropriately. Some were not referred to urology for review and others were not prescribed the prophylactic antibiotics recommended. Poor care and monitoring of catheters have been notable. There have been repeated issues with bypassing, blockages and recurrent UTI's. Catheter

passports are not completed or used appropriately and poor practice in frequency and competency of catheter changes has led to pain, distress, urethral trauma, and incidences of urosepsis.

There are issues with early identification, diagnosis and management of mental health seen by the reviewers. Often opportunities for referrals into secondary care are lacking, even with repeated admissions for serious self-harm. Work is also needed to increase the knowledge and use of adapted assessment tools such as scales to determine depressive, anxiety and/or suicidal symptoms. Pharmacological methods for treating mental health conditions are predominantly used as first line treatment regimens with little evidence seen of any adapted therapeutic approaches such as talking therapy or Cognitive Behavioural Therapy. Little is seen in the way of outcome-based care planning for mental health and where wellbeing services are recommended, self-referral is heavily relied upon with little to no follow up.

Overall, women's health needs greater focus for people with learning disabilities. Screening is discussed later but also the consideration, recognition and management of menopause is seen to be missing. Reviewers have seen a lot of cases where skin integrity has not been considered in those with limited mobility and there have been multiple reviews which noted the need for safeguarding referrals due to the development of grade 3 and 4 pressure sores. Care homes have experienced difficulties in getting appropriate foot care for people in their care, with podiatry services offering limited reasonable adjustments to those needing home visits and complex cases.

8.3.10 Causes of Death

As part of our post review process, we collate causes of death for all reviews. In Norfolk and Waveney, a review is not signed off as complete unless the Medical Certificate of Cause of Death (MCCD) determination of COD has been seen. A MCCD indicates the sequence of conditions which lead to death, including the underlying, and in turn the leading, cause of death. The leading cause of death is taken from the first line of Part 1 of the MCCD. The World Health Organization (WHO) defines the underlying cause of death as the disease or injury that initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury. An underlying cause of death is extracted from the lowest line of Part 1 of the MCCD.

COD can be assigned one of approximately 14,200 codes according to the International Statistical Classification of Diseases and Related Health Problems: 10th Revision (ICD-10). This allows for better comparison between annual reports. Causes of death can then be grouped by code into ICD-10 chapters. Chapters are split according to general types of injury or disease (e.g., Diseases of the Respiratory system).

8.3.11 Leading Causes of Death

In comparison to last year, none of our completed reviews were a COVID related death. This is consistent with the national trend of COVID disease and disease mortality decline.

Year	COVID-19 Deaths
2020/2021	20
2021/2022	13
2022/2023	<5
2023/2024	0

The most common leading causes of death for all of the 56 reviews completed in 2023/2024 are set out in the table below. There were multiple other leading causes of death seen in less than 5 reviews which have not been listed here to protect anonymity. Our completed reviews tell us aspiration pneumonia is the most common leading cause of death for the learning disability community in Norfolk and Waveney. This has not changed from last year. Combined aspiration and other pneumonias accounted for 38% of all leading causes of death in the 56 reviews completed in 2023/2024. Cancer is now the third most common leading cause of death, with all other pneumonias now second most common. Bladder cancer was the most common cancer seen in our 2023/2024 reviews.

Leading Cause of Death	Number	Percentage
Aspiration Pneumonia	11	20%
Pneumonia	10	18%
Cancer	7	13%

The below table looks at the number of leading causes of death by ICD-10 Chapter. There were other chapters allocated to a leading cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Leading Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	24	43%
Diseases of the Circulatory System	8	14%
Neoplasms (Cancers)	7	13%

Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	5	9%
Diseases of the Nervous System	5	9%

8.3.12 Underlying Causes of Death

The two most common underlying causes of death for all the reviews completed in 2023/2024 were pneumonia at 18% ($n=10$) and then cancer at 13% ($n=7$). Some underlying causes of death may also be the leading cause of death as there may only be the first line of Part 1 completed on the MCCD. Underlying causes of death are often more varied and as such to protect anonymity only those with above 5 were listed. The below table looks at the number of underlying causes of death by ICD-10 Chapter. There were other chapters allocated an underlying cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Underlying Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	15	27%
Diseases of the Nervous System	9	16%
Neoplasms	8	14%
Diseases of the Circulatory System	7	13%

8.3.13 Avoidable Deaths

Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/Eurostat list of preventable and treatable causes of death¹³ using the underlying cause of death recorded on death certificates, for people who died younger than 75 years old. This is the same definition as used by the Office of National Statistic (ONS). Of the 51 Norfolk and Waveney reviews included in this definition 58% ($n=30$) were coded as avoidable. This is a higher percentage than last year but actually represents 2 fewer than the 32 avoidable deaths last year. Yet, this still far exceeds the avoidable death rate of the general population of 23%¹⁴.

Avoidable Causes of Death	Number	Percentage
Treatable	15	28%

¹³<https://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death.pdf>

¹⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2020>

Preventable	12	24%
Treatable and Preventable	3	6%

Appropriate classifications for causes of death are vital to ensuring these figures are accurate. ONS Guidance for the completion of MCCD¹⁵ state that physical and intellectual disabilities and congenital syndromes which are not fatal in themselves should be avoided in Part 1. Classifications in the first part of the MCCD have been better this year with COD such as “Learning Disability” being seen less, which would also account for the higher avoidable death percentage. Yet we have again seen MCCD including conditions such as Cerebral Palsy and Down Syndrome this year, which can lead to post-mortem diagnostic overshadowing.

Classification was also hindered by use of terms such as “natural causes” which should never be used and “old age” which should only be used very limited circumstances. To maintain the integrity and comparability of the data analysis, the author has strictly followed the coding process used by the regional and national team and assigned these deaths as non-avoidable as per the OECD list. However, were it open to clinical interpretation the avoidable death percentage for Norfolk and Waveney would be higher.

9. Themes, Learning and Recommendations

This section focuses on the findings from the main aspects of care provided to people with learning disabilities and, where data is available, how this compares to other areas. This includes AHC, weight management, overmedication of psychotropic medications, provision of reasonable adjustments, cancer screening programmes and MCA assessments as well as end-of-life care.

9.1 Annual Health Checks (AHCs)

Evidence shows that people with learning disabilities are more likely to experience a greater number of health conditions than the general population. They are also less likely to receive regular health checks or access routine screening¹⁶. All people with learning disabilities are entitled to an AHC. Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions. Work has been ongoing within primary care to increase the number of checks completed and their quality.

¹⁵https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1062236/Guidance_for_Doctors_completing_medical_certificates_Mar_22.pdf

¹⁶ <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/>

Performance for 2023/2024 across the different localities in Norfolk and Waveney, is measured and can be seen in the table below. Notably there is approximately a 12% difference between the best and worst performing areas. This is less than last year but still suggests inequality across the region. Again, there has been an increase in the number of AHCs completed for all people with a learning disability across the Norfolk and Waveney system. Starting in 2019/2020, 63.5% was achieved. This performance went down to 51.5% in 2020/2021, thought to be due to the impact of COVID-19. In 2021/2022, 68% was achieved, increasing to over 70% in 2022/2023 and 74% in 2023/2024.

Locality	# on Learning Disability Register (March 2024)	# of Declines	# of AHC Delivered+	% of AHC delivered*
Great Yarmouth and Waveney	1754	254	1496	75%
North Norfolk	1172	95	1027	81%
Norwich	1548	50	1102	69%
South Norfolk	1459	98	1121	72%
West Norfolk	935	113	779	74%
Total	6,868	610	5,525	74%

+Using manual adjustments & automatic reports via CQRS National (April 2023 – March 2024)

*(AHC delivered divided by Declines + Learning Disability Register Total)

Comparing this with the LeDeR reviews, out of the 54 completed for those who were eligible for regular AHCs, 85% ($n=46$) had been offered an AHC in the 12 months before they died, an increase of 11% on last year. Our post review data collection is also able to tell us that 74% ($n=40$) actually attended their AHC, in the last 12 months before they died, which is again an increase on last year. This means the percentages from LeDeR reviews, now match what we are seeing in the Primary Care and national figures.

AHCs are a foundation of preventative care for people with a learning disability, and an essential part of managing co-morbidities and reducing mortality. Last year, when discussing some of the main themes, we related this to the AHC to reflect how the attendance of a good quality AHC impacts a person's whole wellbeing. This year we are conscious we have 2 autism only reviews. As such, this year we will only review the demographic information of those with a learning disability and interventions you would expect to see at an AHC so as not to exclude anyone.

This year we have a more even distribution of people with different learning disability severities having had their AHC. For those who didn't have an annual health check, this was more likely for those with mild or moderate learning disabilities, suggesting those with more severe disabilities are being reviewed. Although positive, people with mild learning disabilities often have less health oversight and so the AHC remains an important intervention to make sure they don't fall between the gaps in services.

Level of Learning Disability	AHC Completed (n=40)	% AHC Completed	AHC not Completed (n=14)	% AHC not Completed
Mild	13	33%	8	35%
Moderate	12	30%	<5	xx%
Severe	14	35%	<5	xx%
Profound	<5	xx%	0	0

Those who had received an AHC were nearly 30% more likely to have had an annual medication review. This was higher than last year, with a 13% increase in the number of recorded medication reviews for people who had an AHC. This is an important part of healthcare in that it supports the review of chronic conditions as well as abides by STOMP principles to reduce unnecessary overmedication.

	AHC Completed (n=40)	% AHC Completed	AHC not Completed (n=14)	% AHC not Completed
Recorded Annual Medication Review	37	93%	9	64%

For those who did not have an AHC in the 12 months before they died, we only knew the BMI for 12. Nevertheless, the average BMI was less, and in the normal range, compared to those who did have an AHC. There are many variables which could impact this including the quality of AHC and the need for proactive weight management in future, the higher severity of disability, prevalence of psychotropic medications and likely higher incidence of physical disabilities and mobility issues in those who had a regular AHC.

	AHC Completed (n=40)	AHC not Completed (n=12)
Mean BMI	26.2kg/m ²	23.3kg/m ²

Learning identified from the reviewers:

There seem to be standardised annual health checks, but they appear to be predominantly used as a tick box exercise, not a thorough assessment and reflection of the person's individual situation and needs. Usually, reviews for long term conditions, such as diabetes, are reviewed in a different appointment. However, there would be a benefit to one, longer, appointment which takes a wider holistic view of all the persons health and care needs. Similarly, blood tests are also often organised after a health check, which can lead to a repeat appointment if the results are abnormal. Arranging for blood tests before an annual health check or using Point of Care Testing would allow for better information to assist in health action plans. Where reviews are done well there is a clear benefit to management of long-term conditions, but there are equally poor recordings of annual health checks where reviewers have just seen a set of observations and possibly a weight.

9.2 Health Action Plans (HAP)

A HAP identifies a person's health needs and how best they can be managed, including what the person needs to do, who will help and when this will be reviewed. Completing and providing a HAP is an essential part of a good quality AHC. A HAP is expected to include information such as:

- Health promotion activity
- Weight monitoring
- Referrals to community health, social care, acute and specialist services
- Pain management
- Sight tests
- Dental checks
- Advanced care planning
- ReSPECT paperwork

The person needs to be given a copy, as well as shared with any carers or home environments which may support them. The practice should then scan a copy into the electronic record.

Of the 40 completed reviews where there was an AHC in the last year of their life, 25 (63%) mentioned a HAP was in place. The information from data collected by the Primary Care Team for HAP completion as part of an AHC in 2023/2024 is very different as seen in the table below. Compared to this year's primary care figure of 75%, in 2021/2022 only 56% had a HAP, showing a significant improvement.

Locality	# on Learning Disability Register	# of HAP completed	Percentage*
Great Yarmouth and Waveney	1,754	1,386	79%
North Norfolk	1,172	988	84%
Norwich	1,548	1,035	67%
South Norfolk	1,459	1,063	73%
West Norfolk	935	704	75%
Total	6,868	5,176	75%

* These totals do not include the 161 LD Health Checks claimed by practices via manual adjustments to CQRS since manual adjustment claims do not capture whether a HAP was provided.

Learning identified from the reviewers:

Although many annual health checks mention a health action plan has been created, no reviewers have seen any in the notes for any reviews. Due to this it is hard to evidence the quality or how detailed or accessible these are. There is no documentation of the outcomes or health goals which have been agreed and no documented review of these outcomes in subsequent appointments. There is also no evidence any HAPs being shared with wider carers or professionals where improving health outcomes may require a collaborative approach.

9.3 Screening

It is of note that we often only receive the last 3 years of primary care notes for a review; therefore, our knowledge of historical screening is limited. So, to give as accurate portrayal of current practice as possible we have only included people who were eligible for the screening at the time of their death in the below analysis.

9.3.1 Abdominal Aortic Aneurysm (AAA) Screening

AAA screening is a way of checking if there's a bulge or swelling in the aorta, the main blood vessel that runs from the heart down through the abdomen. Screening for AAA is offered to men after they turn 65. Of the 13 reviews with these eligibility criteria, only 4 had evidence of a AAA screening being offered, despite 10 having had an AHC in their last year of life.

9.3.2 Cervical screening

Cervical screening is offered to all those with a cervix aged 25-64 years. Invitations should be sent every 3 years up to the age of 49 years and every 5 years up to the age of 64 years. Our reviews did not show any of those eligible had their cervical screening, despite, 5 of the 7 reviews eligible for cervical screening, having had an AHC in their last year of life.

9.3.3 Breast screening

All people registered with a GP as female and aged between 50 and 71 years should have breast screening offered every 3 years. Breast screening involves use of an x-ray test (a mammogram test) to identify any cancers (when too small to feel) plus any other abnormalities in a breast. Despite the low numbers of breast screening uptake as seen below, all the reviews eligible for breast screening, had an AHC in their last year of life.

9.3.4 Bowel screening

Everyone aged 60-75 years should have bowel screening. A home testing kit is sent to a person's home address every two years to collect a small stool sample to be checked for tiny amounts of blood which could be early signs of cancer. Of the 26 reviews, 21 had an annual health check in their last year of life.

The table below shows engagement with national cancer screening programmes. Bowel cancer again has the highest percentage of eligible people screened and has also increased in uptake from last year. This could be because it is the least invasive and can be done at home without having to attend an appointment. Cervical screening had the worst performance from screening of the reviews from 2023/2024, again the same as last year. However, this year we haven't seen anyone have their cervical screening, whereas last year we saw a few. The refusal rate for this intervention was again like breast cancer screening.

Attendance	Bowel (n=26)		Breast (n=10)		Cervical (n=7)	
	Number	%	Number	%	Number	%
Did not Respond	5	19%	1	10%	3	43%
Not Invited/Offered	4	15%	1	10%	0	0%
Screened	15	58%	4	40%	0	0%
Refused	2	8%	4	40%	4	57%

Learning identified from the reviewers:

Cervical screening is usually not undertaken, and it is classed as declined by patient, even when they may lack capacity. Reviewers do not see evidence of reasonable adjustments in undertaking the capacity assessments and if best interest is being considered this is not documented or evidenced. Reviewers have also still seen the screening being declined on the persons behalf as the health professionals deems the person to be not sexually active. Reviewers found breast screening to be more common, however serious service accessibility issues persist for those with atypical body formation or wheelchair users.

Reviewers have found bowel screening can often be used as an investigatory tool in response to symptoms, which may explain why the screening rates are comparatively higher to other cancers. This suggests, on the sole basis of screening, issues with access may still be present. Usually, people are reliant on their carers actioning the invite letter sent to their home and reviewers see too often evidence of care settings ignoring the invite on behalf of the resident, which demonstrates a lack of understanding of the scope of the screening programme. Whether a person has their AAA screening appears to be very much dependent on the surgery they are registered at.

Lack of attendance for screening has been seen due to a bad experiences in the past. Good input from community learning disability teams and preparation for and support in appointments would help counter this. We have seen some informative sessions on screening run by organisations in our area with the support of healthcare professionals, but attendance unfortunately has been very low considering the scale of the problem.

9.4 Vaccinations

We can look closely at the uptake of pneumonia vaccines for those eligible. Chapter 25 of The Green Book of Immunisations¹⁷ states which comorbidities meet the “high-risk” eligibility criteria for the vaccine. Despite recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report¹⁸, Learning Disability is still not included in in this.

Of the 21 reviews, where the persons leading cause of death was a pneumonia, 17 (81%) would have been eligible for a pneumonia immunisation. This is either due to their age or meeting the current high-risk criteria according to the green book. Of

¹⁷<https://www.gov.uk/government/publications/pneumococcal-the-green-book-chapter-25>

¹⁸<https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

these 17 reviews, 9 had evidence of having a pneumococcal vaccine, meaning 47% didn't. Although still not ideal, this is an improvement on last year. These figures do not include the 2 cases with a leading COD as Sepsis who both had a pneumonia as the underlying COD.

The influenza ('flu') vaccine is a safe and effective vaccine. It is offered every year by the NHS to help protect people at risk of flu and its complications. The flu vaccine is offered to everyone aged 65 and over and everyone under 65 years of age known to have a medical condition that puts them at risk of flu complications. Chapter 19 of The Green Book of Immunisations states which comorbidities meet the eligibility criteria for the vaccine¹⁹. Uptake of the flu vaccine has also improved on last year, with 86% (*n*=48) of all completed reviews having evidence that the person had a flu vaccine regularly. 46 had been immunised of the 54 who were eligible for and attended their AHC (85%). This is in contrast with only 7% (*n*=4) who had not had a regular flu vaccine but who were eligible for and attended their AHC, highlighting the importance of AHC on public health initiatives and preventative care.

The COVID-19 vaccine is a safe and effective vaccine and began distribution from December 2020. Those with a learning disability and associated co-morbidities were highlighted as being more at risk from severe COVID-19 complications and, as such, fell into the priority groups for being offered the vaccine. The first vaccines were rolled out in January 2021. All the completed reviews had a date of death after the third dose was offered from the beginning of October 2021 and 89% (*n*=50) had evidence of 3 or more covid vaccines, which again is an improvement on last year.

COVID Doses	Number
0	3
1	1
2	2
3	18
4	19
5	13

¹⁹ <https://assets.publishing.service.gov.uk/media/654cf306014cc90010677371/Green-book-chapter-19-influenza-3November2023.pdf>

Learning identified from the reviewers:
 Reviewers have continued to see good COVID vaccination coverage and continued high uptake of the yearly flu vaccination. Reviewers have suggested a higher uptake of the pneumonia vaccine which is evident in the data and good to see. However, reviewers still identify people with health co morbidities who would benefit from this vaccine, did not receive this vaccine.

9.5 Obesity/Weight Management

When a person carries excess weight or body fat it can affect their health. Evidence shows that people with learning disabilities are more likely to have a poor diet and are more likely to be underweight or obese than people in the general population²⁰. The Body Mass Index (BMI) is a measure that uses a person’s height and weight to calculate whether their weight is healthy. BMI should be used with caution for those with learning disabilities as certain co-morbidities can impact someone’s weight such as chronic constipation. It can also be difficult to accurately capture measurements for people with an atypical body shape or poor posture (postural kyphosis) which are more common with persons with a learning disability. The BMI tool is currently the most used and acceptable measure of weight and health, but some other options could include waist circumference or measuring a fold of skin. BMI categories can be seen below:

- <18 is underweight.
- Between 19 and 24.9 is healthy.
- Between 25 and 29.9 is overweight.
- >30 is obese.

Being underweight or overweight raises the risk of serious health problems and is known to have a direct impact on the person’s quality of life. The table below shows the outcome and analysis of data of BMIs recorded for the 56 reviews.

Gender	BMI (kg/m2)									
	<18	%	19-24	%	25-29	%	>30	%	Unknown	%
Males (n=37)	3	8%	16	43%	7	19%	10	27%	1	3%
Females (n=19)	3	16%	8	42%	3	16%	5	26%	0	%

²⁰ <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance>

Total (n=56)	6	10%	24	43%	10	18%	15	27%	1	2%
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In the 56 completed reviews both men and women mostly had a healthy BMI recorded. However, last year men had a higher percentage in the 19-24 range than even the overweight and obese categories combined, which is not the case this year. Yet, in a change from last year women have a lower combined percentage of people who were overweight or obese. There were again more women, as a percentage, who were underweight than men. Overall, most percentage representations in the age groups were similar to last year except the >30 group which was higher. However, we have far less reviews with unknown BMIs than last year, which may account for the change.

Learning identified by reviewers:

Although the review data shows that on average weight falls into the higher end of normal weight, where weight management is an issue, it has a big impact on wellbeing. Reviewers identified that being overweight or obese was a common issue amongst people with a learning disability and this is complicated by diet, poor mobility and/or wheelchair dependency. Obesity is leading to type 2 diabetes and then poorly managed diabetes is leading to chronic kidney disease, retinopathy, and recurrent infections. In managing weight, there seems to be a general advice for healthier lifestyle at AHCs including uptake of exercises and healthier diet. However, this is rarely adhered to or monitored, and referrals to specialist support is infrequent. Another issue seen in the lack of appropriate scales available in the community, either at GP surgeries or in care homes. Adapted scales are needed for those who require hoisting or wheelchair/sitting scales and when not available, often weights are just not done.

9.6 BMI and Psychotropic Medications

Psychotropic medicines are used for psychosis, depression, anxiety, sleep problems, epilepsy and sometimes given to people because their behaviour is seen as challenging. Weight gain can be associated with use of psychotropic medicines including antidepressants, mood stabilizers and antipsychotic drugs²¹. Of our completed reviews, 39% (n=22) had evidence of psychotropic medications being prescribed, this is a reduction of 14% on last year.

It is suggested that patients with a BMI of 25 or over should be regularly reviewed and where appropriate, supported to stop or reduce psychotropic medicines. In all our reviews recorded as being on a psychotropic medication, 50% (n=11) had a BMI

²¹ https://www.bap.org.uk/pdfs/BAP_Guidelines-Metabolic.pdf

considered overweight or obese, which is higher than last year. Again however, this may be due to better recording of BMI in our reviews.

9.7 Stopping Overmedication of People with a Learning Disability (STOMP)

STOMP²² is about helping people to stay well and have a good quality of life by stopping the overuse of medicines for those with a learning disability and/or autism, mainly comprising psychotropic medicines. Long term psychotropic use with epilepsy is expected. This is often a first line treatment and effectively managing epilepsy is essential at avoiding Sudden Unexplained Death in Epilepsy (SUDEP). However, 77% (*n*=17) of people who were prescribed psychotropics, had them for a mental health condition or to support in behavioural management, and 76% of those (*n*=13) had been on psychotropics for over 5 years.

The most common singular reason for a psychotropic being prescribed was due to a mental health diagnosis, present in 11 (50%) reviews. 27% (*n*=6) had multiple psychotropics prescribed for multiple diagnosis, mostly this was a diagnosis of epilepsy with a mental health condition and/or behaviour management. Less than 5 reviews had psychotropics prescribed for a sole diagnosis of behaviour and then epilepsy.

Most people prescribed psychotropics had a mild learning disability, followed by moderate and then severe. The table below shows the findings from completed reviews. Last year a total of 53% of reviews were prescribed psychotropic medications, this year 39% of reviews had psychotropics prescribed.

Learning Disability	Mild	Moderate	Severe	Profound
Psychotropics prescribed	9	8	5	0
Percentage	41%	37%	22%	0%

Learning from the reviewers:

Reviewers have seen many cases where antipsychotic medication was prescribed many years ago where the person does not have a mental health diagnosis and they are not open to mental health services. Meaningful medication reviews for antipsychotic medications are not satisfactory and shared care arrangements to ensure specialist reviews of mental health medications are not in

²² <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

place. It is often documented in GP records that medication reviews have taken place, but it is unclear what this involves and the quality of this review. Good practice has been seen in primary care where reviews have shown good evidence of medications being reviewed and psychotropics being stopped when they are not of benefit. The best practice in prescribing and in adherence to STOMP principles has been seen with the involvement of the community learning disability psychiatry team.

9.8 Mental Capacity Act (2005) Assessments and Restrictive Legislation

Mental Capacity Act (MCA) assessments are applied to people aged 16 years and over. The aim is to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. The MCA covers a wide range of decisions such as day to day decisions on what to wear, personal care, where to shop, to significant and serious life-changing decisions such as changing homes, major surgery, and financial management.

The MCA states²³:

- Assume a person has the capacity to make a decision themselves, unless it is proved otherwise.
- Wherever possible, help people to make their own decisions.
- Do not treat a person as lacking the capacity to make a decision just because they make an unwise decision.
- If you make a decision for someone who does not have capacity, it must be in their best interests.
- Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

It is expected that all our reviews for people with a learning disability ($n=54$) would have required a capacity assessment at some point in their care. From the reviews 61% ($n=33$) had evidence of a capacity assessment being completed, 20% ($n=11$) of reviews described adherence to the MCA as variable, and 19% ($n=10$) reviews had no evidence of a capacity assessment having been completed at all. This performance is worse than last year.

Learning from Reviewers:

Reviewers find that usually the MCA is appropriately and effectively used in acute settings, although good documentation is still an issue. The voice of the person at the centre of the decision is usually lost and consideration of their experience, feelings and values is

²³ Section 1 of <https://www.legislation.gov.uk/ukpga/2005/9/contents>

missing. It has been noticed that if the patient is deemed to lack capacity and needs a best interest meeting to make a decision, there seem to be significant delays which is detrimental to the patient. Allocation of an IMCA still takes too long, which is not good practice when a decision needs to be made for the individual. Good practice is best exemplified when the need for the MCA is identified early and a collaborative decision-making process involving all necessary professionals is undertaken. As with other areas of care, acute compliance with the MCA is most seen when learning disability liaison teams are supporting the process and advocating for the person. MCA is rarely seen in primary care, but is often referenced and documented by community care services who may be visiting home to take bloods or provide wound care etc.

9.9 Deprivation of Liberty Safeguards (DoLS)

DoLS ensure people who cannot consent to their care arrangements (i.e., in a care home or hospital) are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and in the person’s best interest. Representation and the right to challenge a deprivation are other safeguards that are part of DoLS. This safeguard is also appropriate if a person lives in supportive living or in their own home and is under ‘continuous supervision and control’. The point of the authorisation is the same as in a care home or hospital, and the same criteria apply. However, the process is slightly different. Most reviews highlighted that DoLS had not been used when it was required to safeguard a person’s liberty.

DoLS Used	Number	Percentage
Yes	10	19%
No/Not Stated	39	72%
Not Applicable	5	9%

Learning from Reviewers:
 Reviewers have seen evidence of hospitals applying for emergency DOLs, but in the community very few cases have the safeguards in place. Processes are heavily delayed due to capacity issues

9.10 End-of-Life Care

End-of-life care is also referred to as palliative care or advanced care planning. It involves conversations between people with learning disabilities, their families, and carers and those supporting them about their future wishes and priorities for care. Out of all the completed reviews, 33 (59%) had evidence of the person being on an end-of-life plan before they died, similar to last year. The length of time on an end-of-life care plan varied from a couple of days to over 6 months. A higher percentage of people

who died on an end-of-life care plan, died in the acute setting. This year we didn't have any deaths in a hospice setting, potentially as we no longer review the lives and deaths of children. There is no data available to indicate whether people's wishes were observed in all settings.

End-of-life Pathway	Place of Death							
	Acute	Percentage	Usual Residence	Percentage	Hospice	Percentage	Other	Percentage
Yes (n=33)	22	67%	11	33%	0	0%	0	0%
No (n=23)	12	52%	8	35%	0	0%	3	13%

Learning from the reviewers:

There are a growing number of cases who despite being at an end-of-life stage, end up in hospital for symptom management. With appropriate planning and support for palliative care and clear care plans this could be avoided. Reviewers have seen good examples of excellent end-of-life planning including consideration of a person's preferred place of care, with the option to die at home in familiar surroundings, but often because of a rapid decline this was not possible. Reviewers have also seen multiple issues around not having anticipatory medication and necessary paperwork in place to allow community teams to administer care, suggesting primary care need to be referred to and engaged earlier in the planning process.

9.11 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

The Recommended Summary Plan for Emergency Care and Treatment²⁴ (ReSPECT) process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. It would be reasonable to expect everyone who we reviewed to have had a ReSPECT form in place, when they died. Out of all the completed reviews 42 (75%) had evidence of a completed ReSPECT document at the time of their death which is very similar to last year, but with a slightly higher percentage of those with a ReSPECT form having died in hospital (69%). As previously mentioned, ReSPECT is a discussion which should happen as part of the AHC. According to reviews, 79% of those who had a ReSPECT document completed, had attended an AHC in the last 12 months of their life, a higher percentage than last year. Of the 33 people who were on an end-of-life plan, 97% had a ReSPECT form completed. This is compared to only 39% of those

²⁴ <https://www.resus.org.uk/respect/respect-healthcare-professionals>

who were not on an end-of-life plan. Suggesting although ReSPECT may be being better used in those at end-of-life, work is still needed to make full use of its design as an emergency care planning document.

Learning from the reviewers:

Reviewers are still seeing hospital ReSPECT forms used primarily as a DNACPR, where completion is poor, and evidence of MCA adherence is lacking. Reviewers have seen more ReSPECT forms being completed in the community which is good, but rather than review and update these on admission, they are often re-done, to a lower quality. We often see good involvement of families, but too limited consideration for adapted ways of involving the actual person in decisions being made about their care. Where there is permanent and severe impairment to the functioning of the brain, little is documented to give the person a voice and demonstrate their values or wishes have been considered. Where ReSPECT forms are used as intended, reviewers see excellent examples of a fully completed forms with clear care plan for avoiding hospital admissions, which significantly improved a person's quality of life.

9.12 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

The guidelines state that it is good practice for decisions about DNACPR to be clearly communicated to all those involved in the patient's care. It is important that healthcare professionals, patients, families and those close to patients understand that a DNACPR decision applies only to cardiopulmonary resuscitation (CPR) and not to any other element of care or treatment. A DNACPR decision must not be allowed to compromise high quality delivery of any other aspect of care. Out of all the completed reviews 43 (77%) patients had a DNACPR order in place before they died, with 93% of these being deemed appropriate according to the evidence available. This is much improved from last year.

Learning from the reviewers:

Reviewers feel that overwhelming DNACPR orders are used appropriately and, in the persons best interest, with conversations with family and key carers frequently seen as good practice. However, documentation how decisions were made continues to be poor with little evidence of adherence to the MCA.

9.13 Reasonable Adjustments

Making reasonable adjustments is a statutory duty under the Equality Act 2010. This states that all health and social care providers must make reasonable adjustments to remove any barriers, physical or otherwise, that could make it difficult for disabled people to use their services or prevent them from using them altogether.

A lack of reasonable adjustments can be a significant barrier to accessing healthcare and healthcare settings. Reasonable adjustments are not just stand-alone interventions and are woven into people’s daily care and support. Below are highlighted some of the themes seen in reviews, regarding good provision of reasonable adjustments and where practice needs improvement. Looking at the reviews examined, reasonable adjustments fell into multiple themes, which were either accommodated or not, and are summarised in the tables below.

Theme	Examples of good use of reasonable adjustments
Adapted Access	<ul style="list-style-type: none"> • Primary Care visits at home or outside of the practice to encourage engagement. • Environmental controls such as side rooms, especially used for end-of-life care. • Changing appointment times to ensure face to face contact. • Home visits by hospital staff to help prepare for interventions. • Use of hospital passports and emergency admission plans. • Clinician follow up as part of a “was not brought” policy following non-attendance at appointments. • Acute Learning Disability Liaison Teams. • District nurse visits to day centres to deliver care which wasn’t possible at home. • Supporting home between ED attendance and surgical review the following day to reduce anxiety.
Communication	<ul style="list-style-type: none"> • Information provided in clear, concise, and simple language. • Easy read care plans provided by primary care in collaboration with patients. • Plans for end-of-life care produced with the input of patient using adapted methods to gain their wishes and views. • Use of community learning disability nurses to support communicating a terminal diagnosis and provide reassurance. • Appointment invitation letters in easy read. • Provision of communication care plans. • Adapted communication which meets individual needs. • Time allowed for processing.
Familiar Carers	<ul style="list-style-type: none"> • Parent/carers are supported to stay with their children while admitted. • Using care staff to support with end-of-life care. • Involving familiar carers in best interest decision making. • Allowing community care staff into the acute care environment.

	<ul style="list-style-type: none"> • Staff are encouraged to attend appointments with people for support and advocacy. • Flexibility in visiting times for family and carers.
Bespoke Care	<ul style="list-style-type: none"> • Adequate planning and individualised care to support interventions such as blood tests. • GP overrode a person's need to attend a specialist clinic on a different site as they engaged well at surgery, and it was causing undue stress. • Non pharmaceutical methods to aid anxiety and agitation. • Flexible service provision to provide continuity of care by staff familiar to the patient. • Collaborative needs-based care planning. • Shortened hospital admissions with increased community-based follow up interventions. • Admission plans include strategies to reduce overly restrictive and restraint practices. • Care home taking on complex end-of-life care to enable a person to die in their home. • Good response to soft signs of deterioration.

Theme	Examples of poor use of reasonable adjustments
Adapted Access	<ul style="list-style-type: none"> • Lack of referrals to specialist learning disability teams due to poor diagnosis coding, delaying support. • Services requiring intensive and time-consuming advocacy from professionals to deliver reasonable adjustments including home visits. • No annual health check provided to a person as they were not able to attend the surgery and no alternative was offered or provided. • Service referral and triage processes not adapted to accommodate a person with a learning disability, meaning multiple discharges without a person being seen. • No admission plans to avoid busy and distressing environments which can impact concordance with care.
Communication	<ul style="list-style-type: none"> • Lack of access to easy read and simple language information and communication for people who require it. • Lack of adapted communication to aid and assess understanding including for invasive surgical procedures. • Where a person had refused care, additional time to communicate effectively and allow time for processing may have helped.

MCA Principles	<ul style="list-style-type: none"> • Limited use of MCA principles in decision making about cancer screening. • No reasonable adjustments used to enable a person to understand or contribute to the completion of their ReSPECT form. • DNACPR forms completed with little to no evidence or documentation of how the decision was made and how the person voice was represented. • Poor evidence of MCA principles being used to inform someone’s living situation. • Poor adaptive communication to best assess someone’s capacity when they decline important health interventions. • Best interest meetings may not always need to be strictly formalised, but documentation is required to evidence the work.
Provision of Care	<ul style="list-style-type: none"> • Frequent changes in home lead to inconsistent care and little oversight of health and wellbeing. • Referrals into our area from out of county are poor with little communication on history, needs and goals. • Lack of adaptations to service provisions have created barriers to engaging in care, especially for those with more complex social situations. • Poor collaborative working between services has resulted in gaps in care planning, highlighting deterioration and assessing risk. • Required cancer home screening processes were not supported or facilitated by community care providers. • Follow up for missed or declined screening appointments is lacking. • People are not added to learning disability lists so not invited for annual health checks. • Availability of respite facilities that can meet the needs of people with complex health needs is poor.

Use of reasonable adjustments is variable across the different reviews examined for this section. There is also evidence of variability within the same reviews and some cases showed evidence of multiple adjustments to make services more accessible and a lack of adjustments which have created barriers for people to access the care they need. Overall, there is definitely evidence of more use of reasonable adjustments than not. Last year we had several reviews where reviewers did not see any examples of reasonable adjustment being used, this year we didn’t have any. Although highly subjective, this is still perhaps a good indicator of progress. Especially as it is notable that the number of reviews with examples of missed reasonable adjustments has fallen.

Learning from reviewers:

Reasonable adjustments are hard to measure as each person's needs are different. Some are very clear and obvious whereas others are subtle. Overall, there was a prevalence in reasonable adjustments being used. This was predominantly led by learning disability specialist staff in acute and community settings. The value of these colleagues cannot be underestimated and is evidenced in the reviews. The best way to identify and communicate what adjustments are needed is by having updated care plans such as hospital passports, health action plans and ReSPECT forms. These should be electronically added to someone's file where possible. Reasonable adjustments are usually something that needs to be asked for, which isn't easy or possible for everyone. A good roll out of the Reasonable Adjustment Digital Flag will open up accessibility from the very first contact with services.

10. Safeguarding

Reviewing the deaths of people known to have a learning disability and/or autistic people helps us identify avoidable factors that lead to early deaths and supports services to improve their quality of care. This is a major step forward towards tackling inequalities within health and social care provision. As part of the review process, safeguarding is always a consideration and forms the foundation for any case discussions the team has. The national LeDeR policy provides a robust governance process for safety and abuse concerns to be highlighted, and the Norfolk and Waveney team has been structured to meet this.

A review will often be presented at multiple panels for Quality and Assurance checks and sign off. This allows the multi-agency panel the opportunity to go beyond the remit of LeDeR and promote challenge, assurance, and service improvement. In addition, the team has structured its local arrangements through guidance co-authored with the ICB designated safeguarding team and the Norfolk Safeguarding Adults Board (NSAB).

This has proceeded the agreement of appropriate safeguarding training and supervision for the LeDeR Team as per the collegiate document²⁵ and a structured process for referring for Safeguarding Adult Reviews (SAR). The Senior Nurse Manager and LAC for the LeDeR programme also presents the findings of reviews to the ICS Learning from Death Forum every quarter, to share key learning with representatives from the wider NHS providers and the ICB's Safeguarding Team.

²⁵<https://www.rcn.org.uk/Professional-Development/publications/adult-safeguarding-roles-and-competencies-for-health-care-staff-uk-pub-007-069>

Over the last year our team has had five cases go to NSAB to be considered for a SAR. For LeDeR, the basis for a SAR is to learn lessons from particularly complex or serious safeguarding adult cases, where an adult has died, and abuse or neglect has been suspected. If the referral is accepted a detailed review is undertaken and, recommendations are made to change or improve practice and services.

Learning from reviewers:

Reviewers have found that some safeguarding investigations can take a long time if the individuals are deceased, this can delay the LeDeR review process. There are also some incidences where safeguarding outcomes are not documented on systems. Some retrospective safeguarding enquiries were also declined on the premise that the individual is no longer at risk due to their death. Looking at the wider impact of safeguarding on care environments, it is important to investigate where poor care for one may impact poor care for others.

Likewise, reviewers have seen multiple instances of missed opportunities to refer to safeguarding, including vulnerable people who have been assaulted multiple times, people living in poor living conditions and people at risk of county lines related crime. Reviewers have also seen a lack of professional curiosity from services when concerns are raised, taking reassurances at face value from people who may lack capacity.

Collaborative working has shown to impact health and wellbeing in a few cases which have required SAR referrals. In some instances, reviews have been submitted together due to very similar themes. An overview of a person's health action plan is important for all professionals to work in an outcome and goal focused way. This is also a good way to monitor quality of care and the degree to which people are being supported to access screening appointments, get their vaccinations, manage their weight, attend chronic conditions appointments etc. When this is consistently missed, safeguarding should be considered.

11. Examples of Lived Experiences

This section is about the stories of people who have died. They have families and friends who cherished their lives and whose deaths will never be forgotten by their loved ones. Therefore, we are sharing some of the stories and experiences from completed reviews. This information has been provided by family members or carers who knew the person well. The details have been anonymised and names changed to further protect their identities.

Hazel

Hazel was a 27-year-old woman who lived with her family. She was a keen Park Runner, and enjoyed reading, doing jigsaws and had a wonderful sense of humour. Before COVID, Hazel had a job working in a charity shop, which she really enjoyed, but found it hard to return after the lockdowns. Hazel found the pandemic very difficult due to the restrictions and her anxieties around her health. Hazel had two of her COVID vaccines but had a third dose declined on her behalf with no consideration of capacity or best interest decision making.

Hazel had great support from her epilepsy nurses and was seizure free for the 6 months before her death. Hazel did have depression but was never seen by wellbeing services despite being referred when she was diagnosed. Her anti-depressant medications were poorly managed and for at least three years, due to an unmanaged weaning process, Hazel was on a suboptimal dose of both an SSRI and an SNRI. NICE guidelines suggest these should be prescribed with caution in patients with epilepsy.

Overall, Hazel's review demonstrated how little her voice was considered by the professionals working with her, and it is not clear Hazel ever had the opportunity to speak to professionals on her own, so that her wishes and aspirations could be fully understood.

Mitch

Mitch was a 72-year-old gentleman who lived in his own home. Mitch used to work as a forklift driver but retired after being made redundant a few years back. Mitch was very proud man, with a great sense of humour and loved to tell funny stories. He liked to watch TV and read the newspaper every day. Mitch had a very close relationship with his mum, who he lived with before she sadly died 10 years previously. Unfortunately, Mitch had struggled to take care of himself in the following years and had no other family looking out for him.

Mitch was referred to the community learning disability team and then social care after a visit to the GP. A home visit found he was living in a neglected environment which was unclean, with no heating, no electricity and he was eating food which had gone off. Within 6 weeks his house had been deep cleaned and all his white goods replaced. He had also been supported with his finances and banking, to make his money safe and helped with future planning.

After being diagnosed with cancer, Mitch had incredible support from his community and hospital learning disability teams, who worked very closely with other specialties to make sure he had the care he needed. His GP practice had a very good approach to

reasonable adjustments and helped Mitch by supporting him to read letters, ensured he was aware of where his appointments were and providing easy read Health Action Plan.

Thomas

Thomas was a 65-year-old man who lived in a supported living environment with high levels of care. Thomas had lived in institutions for much of life. When these closed down he moved into more community-based settings. Thomas was beloved by all the staff at his home. Thomas had had a great sense of humour and he loved dogs, food, and his family. In that order according to his sister. He also enjoyed listening to music, going out on trips and holidays with the staff, and when he was well enough, visiting his family who all lived around the country. Overall, Thomas liked nothing more than sitting with a cup of tea and people watching.

Thomas had deteriorated in the 2 years before his death. The GP had arranged for a ReSPECT form which was discussed with Thomas' family. However, the reason for a DNACPR decision was recorded as being because Thomas was "non-verbal" and had a "learning disability". Thomas had a few hospital admissions in this time which he found very distressing, despite the hard work from the acute learning disability liaison nurses who had worked hard to keep him comfortable.

His ReSPECT form was reviewed, updated and a plan was made in Thomas' best interest to avoid future hospital admissions because they were unlikely to result in any positive outcomes. This significantly improved the quality of Thomas' life. The support of the community teams was invaluable in keeping him out of hospital and managing his symptoms at home. It was testament to everyone involved that Thomas was able to stay in his familiar surroundings and with familiar staff until his death. It was unusual for the care home to provide end-of-life care, but their hard work and the support of the palliative care team made it possible.

Phoebe

Phoebe was a 46-year-old lady who lived at home with her mum, who was her main carer. Phoebe liked sensory stimulating experiences, being out in nature, and being in the swimming pool. Phoebe attended a day centre 5 days per week, which she loved, but following the pandemic her family felt the availability of services and activities that she used to have, had gone.

Phoebe had complex learning and physical disabilities meaning she needed support from multiple services and was completely reliant on her mum as a primary carer. Phoebe was born with a genetic developmental condition, with which she was not expected to live beyond 2 years old. Yet she did, and it was clear from the review just how much her mum's expert and dedicated care and attention contributed to Phoebe reaching the age she did. Phoebe's mum told us she tried to make every day as good as possible

for her, and tried to think how she could experience everything. She spoke to Phoebe all the time and told her she loved her every day.

Overall, the staff involved in Phoebe's life were very caring and dedicated. However, Phoebe's family did find professionals work is largely hampered by bureaucracy and red tape, which had worsened since the pandemic. Ultimately this impacted Phoebe's access to the equipment and services that she needed in a timely manner. For example, the GP practice not providing reasonable adjustments by way of annual health checks at home. Or difficulties and delays in adjusting her wheelchair and provision of a shower chair, which were essential parts of Phoebe's health and wellbeing. Staff turnover increased which was frustrating for the family because there was no consistency for Phoebe and the quality of her care at home was impacted. Post pandemic there was a decrease in face-to-face contact, which Phoebe's family felt resulted in care and understanding being lost.

Phoebe sadly died at home following a short illness. Her family received over 300 condolence cards, showing how many lives Phoebe had touched.

Daniel

Daniel was a 50-year-old gentleman who enjoyed watching TV, listening to music, cooking, drawing, video games and playing or watching others playing pool. He had lived in Manchester before moving to Ipswich with his partner, where they lived for 20 years until his partners death. Following this, Daniel had periods of homelessness and a history of alcohol and substance misuse and mental health difficulties, which required hospital treatment under section. In 2019 he was admitted to hospital under a Ministry of Justice section of the mental health act.

Daniel had regular Care Programme Approach (CPA) meetings to establish where he was on the road of recovery and set future goals with aim for discharge. Daniel had extreme anxiety about discharge because in his mind that meant that he would be left without support and made homeless. For this reason, he declined having Section 17 leave for some time during his admission. With support and reassurance from staff he accepted the leave while looking at a possible discharge and a search for a suitable placement was started. When a home was sourced, discharge planning was done carefully and included a transition period as well as a coordinated support and community follow up from a specialist forensic learning disability team and mental health care coordinator.

Daniel was very well cared for in hospital, where his physical health needs were met as well as his mental health needs. He was eventually discharged to a care home, which was carefully planned and coordinated. His handover to community mental health

teams was well done with a clear change in care coordination and responsible clinician. His new home was at a placement of Daniel's choosing after he had visited several different settings. There was a transition period where Daniel visited the care home three times a week and had an overnight stay to get accustomed with staff and the environment. Unfortunately, he only lived there for 2 weeks before being admitted to an acute hospital after becoming unwell, and sadly passed away.

Pamela

Pamela was a 79-year-old lady who lived independently. She had attended a specialist school and later spent time working in the laundry industry. Pamela had been married but lost her husband some time before her death which had a detrimental effect on her life and mental wellbeing. Pamela liked to knit, draw, and complete crafts. She also took part in cooking lessons at the day centre she attended twice a week, before COVID. During the lockdowns the centre's staff were incredibly supportive with wellbeing calls and visits. Unfortunately, this centre closed in 2021, and this left a gap in Pamela's life as she had formed close bonds with both staff and other service users. Pamela tried to remain in close contact with her friends from the hub, and they used to go shopping together, but this was harder to do.

Pamela had close friends but due to their ill health contact reduced and her family had concerns Pamela was becoming increasingly isolated and lonely. A befriending service was arranged by the local authority but there was no suitable alternative to the centre following its closure. Pamela did not have a face-to-face Care Act Assessment following her changes in circumstances and family concerns being raised. This could have better identified similar services which provide a vital source of friendship and fulfilment. Closure of services needs to be seen as a risk to health and wellbeing, with relevant steps taken to replace what has been lost.

Pamela's GP were very good at helping Pamela with her appointment letters and the staff on reception would often help her by explaining what letters were and what she needed to do. Despite this additional support however Pamela was never diagnosed as having a learning disability and was not added to her GP's learning disability register, as such had never had an annual health check. Pamela became unwell at home as was admitted to hospital. Unfortunately, she didn't respond to treatment and so end-of-life care was commenced with a focus on comfort and symptom management.

Evan

Evan was a 54-year-old gentleman who lived in supported living with 24-hour support. Evan was gentle, content, and happy. He was very social and loved to be around people. He had a mobility car and loved going out for meals, visits to the city centre,

cinema, shopping and museums. He enjoyed being in the company of people and liked to sit in a café watching the world go by. Evan had recently gone on a cruise to Norway for his 50th birthday which he had really loved.

Evan required support from familiar staff for all his health and care needs. Evan has lived in his home for 30 years, and most of the staff had known him a very long time and were familiar with his needs and worked exceptionally to keep him well and able to pursue his interests and passions. When Evan became unwell, carers spotted this early and liaised with the GP who advised admission to hospital. Evan was found to be very unwell with an acute bowel obstruction, likely due to cancer. While in hospital Evan had a lot of support from the acute learning disability liaison nurses and continued to have his familiar care staff with him.

A cross speciality medical discussion was had which agreed invasive intervention was unlikely to be in Evan's best interest and palliative care was started. His staff were kept up to date after the decision but there is little documentation of any wider involvement in this best interest decision outside of clinicians. Neither was there evidence of an Independent Mental Capacity Advocate being used to inform this decision. Evan deteriorated quickly and sadly passed away a few days after his admission, with his key carers by his side.

Claire

Claire was an 84-year-old woman who lived in a care home. Before her stroke Claire was a very active person. She used to go to a day centre several times a week and participated in activities organised there. She loved reading and helped with the mobile library. Claire was involved with a local church which she attended every week, and sometimes did the readings. Claire loved music and dancing and even went to a group to learn flamenco dancing.

Claire had lived in her home for nearly 30 years. Her care staff were very familiar with her needs, and they provided excellent support in managing her multiple comorbidities. Claire had epilepsy and two years after her stroke had a severe epileptic seizure leading to a cardiac arrest. Claire was resuscitated but was left frail and was discharged home on end-of-life care and with an admission avoidance care plan.

Claire remained frail, though her condition stabilised over the next few years until the year of her death when she became more unstable. Claire had regular palliative care reviews from her GP surgery, and anticipatory medication was prescribed. Her care was focused on comfort and symptom management and although she was referred to community palliative care team, she never

required assistance from them as her symptoms were so well managed by her home. Claire passed away in her own home with her carers by her bedside.

Anna

Anna was a 19-year-old young lady who lived at home with her family. Anna attended a special needs school and required support in meeting all her care needs. Anna required an intensive and complex care regime to keep her well, and it is a testament to the care and support of her family as main carers that kept Anna so well for so long. Anna had robust and holistic care from paediatric services which became more complicated as she transitioned into adult services.

Notable changes in provision impacted the whole family. Hospice care between paediatric and adult services is very different meaning reduced developmentally appropriate respite and not enough support for grieving families after losing a loved one. Anna's special needs school allowed a continuity in education until she was 19, but options for adults with complex and profound multiple disabilities are limited in our area and so more independent living for Anna wasn't felt to be an option.

Anna was eligible for children's and adults Continuing Healthcare (CHC) and her home care transition was managed very well with a continuous dedicated package of care including provision for private respite. Anna had contact with the learning disability liaison nurse at her local hospital who provided invaluable support during admissions as Anna transitioned into adult services including hospital passport updates. Anna had holistic, wrap around care from paediatric services and this was relatively well managed into adult care via rehabilitation medicine. However, coordination for this was heavily dependent on mum, and such young people without access to this level of advocacy would surely experience a much more disjointed process.

Anna was admitted to hospital following a severe and enduring seizure and was admitted to ITU. Her family were kept fully up to date on her condition and what her likely journey would be. As Anna deteriorated her family agreed palliative care was in her best interest, so active treatment was stopped the focus was moved to comfort and symptom control. Anna's family stayed by her side for end-of life care and Anna passed away peacefully with her family by her side.

Jake

Jake was a 48-year-old gentleman who lived in the family home with his parents. Jake was fully dependent on carers to meet his daily needs and his home was adapted for this purpose. Jake liked films, music, and computer games. He loved having baths and spending time with his family, going for long walks by the seaside or on the Sandringham Estate.

Jake was diagnosed with cancer the year before he died. A decision was made that the approach to his overall care should be palliative and focused on comfort and symptom control. He was referred to the community palliative care team and had a care plan formulation, anticipatory medication prescribed, as well as DNACPR and a ReSPECT document completed, which stated that he was for hospital admission only for reversible causes. Although the integrated palliative care team was involved, they had more of an advisory role as it was decided that it was best that Jake's community learning disability nurse should continue to coordinate his end-of-life care. Jake was CHC eligible and although his package of care was well staffed and consistent there was limited case management from CHC which impacted the response to package issues.

Jake's palliative care was managed spectacularly with regular reviews, making sure all referrals and necessary interventions were completed, but also with support for Jake's family. Jake's palliative care status and what that involved, was hard for this family to understand. So, his community learning disability nurse arranged a joint visit with his consultant in palliative care medicine. This offered more clarity to his family and gave them a chance to have their questions answered. As the care coordinator, his nurse was able to arrange equipment, consumables, and training to manage Jake's secretions, using a new pathway designed to solve this exact issue. This learning from previous LeDeR reviews meant Jake was able to avoid an unnecessary hospital admission, despite an exacerbation of symptoms.

The multidisciplinary approach to Jake's care and excellent co-ordination through his community nurse was pivotal to the success of his hospital avoidance plan and end of life care at home. After a short deterioration Jake peacefully passed away during night with his family by his side.

James

James was an 81-year-old gentleman who had recently moved into his new care home, after his previous home closed. His new home was chosen as he had attended a day service on the same site, which meant that he was familiar with the environment and staff which eased his transition. James was described as a wonderful person with a very loving nature and a great sense of humour. He liked to have a strict routine and would join in with all the activities arranged at home including arts and crafts and baking. He also loved a disco and would join in with the dancing and liked to go out every day, especially on the bus.

James had regular annual health checks and all his vaccines, including for pneumonia. There was evidence of the GP recognising that due to James' limited communication, he was not always able to reliably express pain and discomfort in a way that was

understood. During the pandemic they made home visits to review him and had a low threshold for referring to acute services. There was also evidence in all the records that professionals had assessed James' mental capacity to make decisions and there was noted good practice in capacity assessments and best interest meetings, including the use of an IMCA for decisions around life changing health interventions, such as investigations and treatment of a potential malignancy and end-of-life care decisions.

James had chronic kidney disease and went into renal failure, and a best interest meeting was arranged which agreed invasive intervention was not in his best interest moving forward. Unfortunately, James became unwell with a chest infection a month later and was admitted to hospital where he sadly passed away. James received excellent end-of-life care in hospital, and although his carers wanted to bring James home for this, he was too poorly.

If James' choices around end-of-life care had been discussed and a plan agreed before his discharge a month earlier, a hospital avoidance plan could have been created. The care home could have identified support to recognise that James was actively dying so that a decision could have been made to make him comfortable at home. He may then, have been able to die at home surrounded by the people who knew him.

Charlotte

Charlotte was a 69-year-old lady who lived independently and at the end of her life was receiving some home care support but was predominately supported by neighbours and friends. Charlotte had been married and widowed twice, she attended a day service two times per week and loved to watch TV, colour, and knit. Charlotte likely had a mild learning disability and the level of support she had from friends and family meant her needs were well met for a long time, and so Charlotte never had a formal diagnosis, which impacted her later care and support.

This was highlighted when she was unable to manage post operative wound care including dressings, ordering consumables, and understanding instructions and appointments. Charlotte could not read or write and had limited understanding of her now complex self-care needs. Yet there were difficulties arranging home visits with the district nurses as Charlotte wasn't "housebound".

Charlotte didn't have any learning disability annual health checks as she wasn't on the register however, she did have regular diabetes reviews, which noted abnormal blood tests and some weight loss. This led to timely further investigations which diagnosed her with pancreatic cancer. Similarly, although not alerted as having a learning disability, the consultant who diagnosed Charlotte with cancer identified the need for more support and referred her to the acute learning disability practitioner. They in turn continued

to work with Charlotte as an outpatient and on her repeat admissions, giving her a known face to support her through a very difficult time.

Charlotte was admitted to hospital following a fall and quickly deteriorated. A decision involving the acute learning disability team was made for ward-based care and a palliative care referral was made. Charlotte sadly passed away in hospital.

12. Learning into Action

Once a review has been completed and learning has been identified, the team works with system partners including people with lived experience to make changes to services locally. Locally this is called Learning into Action and has the aim of preventing people dying from something that could have been treated and/or prevented and reducing health inequalities. Every review will generate areas of learning and most follow similar themes. Actions are agreed at LIAG and assigned a responsible person. They are recorded on an action log which is reviewed and updated every meeting. From last year's annual report, a lot of work has been done to respond to what we found including actions and work undertaken on behalf of the LIAG, and other works completed by the LeDeR team to further the aims of LeDeR within Norfolk and Waveney.

12.1 Learning into Action Group Work

Below is a selection of some of the work which has come out of LIAG in 2023/2024:

- Responding to reviews to make deaths relating to bladder cancer a local priority for focused reviews. We also had a meeting with the ICB cancer team, which was very successful and able to establish clear actions too look at this in more detail. Recurrent UTIs are not a red flag symptom or a referral criterion for the two-week cancer pathway. However, guidance suggests that a health professional might consider a non-urgent referral to urology should the recurrent symptoms occur. There is certainly an association between urinary tract infections and bladder cancer, but this is not unique to learning disabilities. However, this could be reflective of general issues in late diagnosis and diagnostic overshadowing. The meeting was able to agree some actions:
 1. The cancer team are due to update the bladder cancer referral form and will include recurrent urinary tract infections in this.
 2. The cancer team holds a monthly webinar for primary care. They will contact a urologist from the James Paget to discuss bladder cancer in those with a learning disability. Hopefully after July 2024.

3. The cancer team will add social care staff to their Talk Cancer Project, planned for the 2024/2025 financial year. They will include the insights gained from Opening Doors and create cascade training for social care staff working with people with a learning disability on common symptoms of cancer and how to spot them. This will include train the trainer options.
- We have started a new transition working group to look at some of the difficulties faced in transition to adult services and help services to work better together in planning and coordinating care across paediatric and adult services. We agreed to firstly look at improving the health services information on the Local Offer Website. Secondly, to formalise a process for monitoring and managing high risk transitions, modelled on the Dynamic Support Risk Register.
 - We have focused on celebrating good practice over the last year, sending letters when possible, to highlight to teams where their practice has been exemplary and the impact this had. We have had much feedback noting how valuable and grateful teams are in receiving these letters.
 - Work has started to support NCH&C and NSFT in collaborating to develop robust Dementia diagnosis and management pathways for people with a learning disability.
 - NSFT have worked with acute teams to review the use of adapted assessment tools with all NSFT services and look for any training needs in scales such as MossPass. Also, to look at how joint assessments are managed with acute mental health and learning disability teams.
 - We have been working with NSAB to look at improving MCA adherence across the region by collaborating on an education offer and work planning.
 - Feeding back relevant case studies via the primary care newsletter to highlight areas of learning to GP practices.
 - Work to clarify the responsibilities of mainstream and specialist learning disability community SALT teams to ensure people with mild learning disabilities, who could be supported by mainstream services, do not have delayed support due to refused referrals.
 - Identifying areas for specialist training sessions for the Primary Care Learning Disability Leads Network including, the MCA, Care Education Treatment Reviews and the Dynamic Support Register, STOMP, maternity care for people with learning disabilities, social prescribing and cancer screening.
 - Liaison with quality monitoring officers when specific care quality concerns are identified in specific care settings. Our team shares concerns and learning, which is used to guide how improvement plans are structured.

- Work between social care and community learning disability nursing colleagues to agree pathways so all people with a learning disability on a social care pathway that are presenting with end-of-life care needs will be referred to learning disability nursing. In addition, the palliative care team have been in contact with the local authority and been provided the contact details to all specialist residential and supported living units in Norfolk to ensure that providers have access to advice and support around providing end-of-life care to their residents.
- Supporting with the printing of 14+ birthday cards and pre-AHC questionnaires to support uptake and quality of annual health checks.

12.2 Other Work

- Using LeDeR learning to collaborate with the skills plan scoping phase underway for Norfolk and Suffolk.
- Supporting roll out of the Reasonable Adjustment Digital Flag for Learning Disability and Autism Services.
- Collaborating on a long-term care toolkit by the Learning Disability Quality Improvement Team by NCC which we informed using LeDeR learning.
- Contributing to the working group which is implementing the recommendations from the Clive Treacey Independent Review within our region.
- Work with public health commissioning to improve the accessibility of tier 2 weight management services.
- Supporting with Structured Judgement Reviews meetings to share learning from LeDeR where reviews are complete.
- Supporting a nationally chaired working group to co-author new NHS England Health Care Passport Guidance.
- We started a project to explore how our system could use the Health Equalities Framework (HEF) in learning disability services to implement an outcome-based way of working which better highlights vulnerabilities for people across their lives. A workshop was held to look at how this could be implemented in the system. Three achievable priorities were agreed as initial areas of action:
 1. The LeDeR team are introducing HEF to our learning disability LeDeR reviews. This is a novel way of using HEF and we hope HEF reports will help to identify where a person's risks of health inequalities were and highlight gaps between inequality risk and service provision. This will better guide our learning into action work. Currently we cannot use HEF for Autism only reviews, as the tool has not been validated for use with autistic people.
 2. It has also been agreed the community learning disability nursing service will commence the rollout in the summer 2024. of completing HEF assessments upon allocation and discharge for all new episodes of care.

3. With some big commissioning projects on the cards over the next 18 months we hope to continue to show the benefit and value of HEF, with the potential for advocating for HEF to support outcome-based commissioning.

12.2.1 Training

Teaching has been a big part of our new work plan, spreading awareness and learning from LeDeR reviews, and changing practice by improving education. We have delivered training and education sessions to over 30 teams across health, social care and education over the last year. The aim of these sessions has been to share our learning and highlight and advocate for good practice. We have worked with colleagues at UEA to try novel approaches to imbed learning disability and autism education into health and social care courses by including LeDeR review case studies into academic work, including exam questions and assignment titles. In every session we requested feedback from participants to tell us how we did and suggest areas for improvement. We have highlighted some of the feedback below to demonstrate the impact.

	Score (<i>n</i> =112)				
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The session was informative	67%	32%	0%	0%	1%
The presentation was interesting	55%	38%	4%	2%	0%
The session was engaging	49%	38%	10%	2%	1%
The presenter was knowledgeable	88%	12%	0%	0%	0%
The content was relevant to your role	65%	32%	1%	1%	1%

12.3 Health Inequalities Team

The Health Improvement Team have continued with supporting people with learning disabilities and autism and GP practices, to promote health and wellbeing and increase the uptake and quality of annual health checks in 2023/2024.

- The team have worked with 21 surgeries who had a lower percentage of attendance for the annual health checks, this covered practices in Norwich, South Norfolk and the Waveney areas.
- Outreaching to patients (or their carers) who have not had their Annual Health Check for more than 12 months to support with attendance. Over 342 patients were identified from practices as requiring support. The team have made over 350 calls to patients and 120 home visits. The outcomes of these were vast but mainly included supporting a person to have their health check and onward referrals to social services or safeguarding.

- Provided training at 16 surgeries, including training for clinical and admin staff. The team hosted a session which was open to all admin staff across Norfolk and Waveney of which 60 people attended. Feedback following the training indicated that most attendees had an increase in confidence in arranging the annual health checks post attendance.
- Supporting surgeries with a learning disability register review to ensure its accuracy. We advised and supported practices to remove 67 patients from LD registers who did not have a learning disability.
- Supporting practices with implementing the guidance on reasonable adjustments and the digital flag.
- Along with colleagues from delegated commissioning team, we presented at the NCHC LD Community Team meetings to form closer working relationships and to share updates on the annual health checks.
- Engaging care and residential homes and day centres, directly and via quality teams to promote best practice and supporting residents with annual health checks.
- Promoting health and wellbeing at learning disability events, including those targeting ethnic minorities.
- Regularly attending meetings with the POCT (Point of Care Testing) project team to support the development and implementation of this project, of which data is currently being collected.
- Development of a venepuncture pathway is in process following feedback that this was required to support primary care.

12.4 Looking forward to 2024/2025

Some of the workstreams mentioned above will continue into next year and develop in response to any changes. However, from the reviews undertaken in 2023/2024, we know that we need to do more work in the following areas:

- Improving prevention and early recognition of respiratory illness.
- Strengthening practice in use of the MCA and decision making.
- Identifying where improvements are possible in the wider housing market to support vulnerable people.
- Improving the transition experience for young people with complex needs moving into adult services.
- Improving the use and quality of health action plans as part of a robust annual health check.
- Identifying lasting change which could improve cancer screening uptake.
- Continuing to raise awareness and knowledge of LeDeR in services supporting autistic people.
- Improving the early identification of end-of-life and planning of palliative care.
- Increasing the knowledge and understanding of ReSPECT and advocating for it to be used well, in its intended purpose as an emergency care planning tool.
- Improving service access to adapted talking therapies to reduce psychotropic medicines being offered as a front line treatment for mental health issues.

13. Feedback and Further Information

13.1 Working in Partnership

If you have a learning disability and/or autism, we want you to tell us what your own lived experience is like. We want you to tell us whether what we are doing is making any difference to your life. We want you to tell us if we are not doing enough to make change happen. We will find better ways of asking you, and better ways of listening to what you say. We will use the learning from the LeDeR programme and from your experiences to keep improving and make changes. Please contact us via these links:

nwicb.contactus@nhs.net

[Facebook](#)

[Twitter](#)

13.1.1 Knowledge NoW

A QR code has been shared below where providers can access resources to evidence-based health and wellbeing from our NHS website: <https://nwknowledgenow.nhs.uk/>

14. Conclusion

The team have experienced significant challenges over the last year due to an increase in workload. Despite the team having completed more reviews than last year and more detailed focused reviews, we are not completing reviews as quickly as we would like to. Our work continues to be incredibly well supported by health and social care providers across the ICS. We also continue to be indebted to the contribution from experts by experience and people with lived experience. Although our data collection has some limitations regarding generalisation, we do feel there have been some improvements in the quality of care and accessibility and effectiveness of services last year.

There has been an increased uptake in vaccinations and continued working and engagement from the ICB health improvement team in health promotion and preventative health interventions. This can also be seen in the increase in annual health checks and health action plans, something we will continue to promote and ensure all people with a learning disability from the age of 14 find a benefit to their long-term health and wellbeing. Quality remains an important part of this and there will remain continued work in this area. We also have seen improved use of reasonable adjustments to support people to access healthcare and improved evidence of use of the Mental Capacity Act. Yet, there remain areas for improvement in advocacy and listening to the voices of those we support.

Work continues to need improvement in preventing and treating respiratory infections and reducing respiratory related deaths, especially pneumonia. Better collaborative working and care planning is also required for those with chronic conditions and those at end-of-life. Application of Deprivation of Liberty Safeguards needs improvement as does documentation of decision making when this is being done on someone's behalf. Less people are taking psychotropic medications but there remains room for improvement in adhering to STOMP principles. Quality oversight of residential services feels to be improving with a quicker response to concerns and good support resulting in lasting changes. However, service gaps remain for those living more independently, and vulnerabilities are not being identified early enough.

We have seen a continued increase to our notifications, we feel, due to our ongoing engagement and promotion of LeDeR within the system. We aim to better represent the experience of those with a sole diagnosis of Autism by continuing to outreach into services, raise awareness and support more referrals for those who have died. Lastly, it is important we conclude this annual report by again remembering each death which has been reported. Each referral was for a person from our community, with hopes, feelings and loved ones. It is vital therefore that we continue to use their stories and experiences to improve the service provision for all people with learning disabilities and/or autism across health and social care.

**Report title: All Age Carers Strategy for Norfolk and Waveney
2024 – 2029**

Date of meeting: 04 December 2024

Sponsor

**(ICP member): Ian Wake, Executive Director, Adult Social Services, Norfolk
County Council**

Reason for the Report

To bring to the Integrated Care Partnership (ICP) the first coproduced All Age Carers Strategy for Norfolk and Waveney. In addition, to request endorsement and sign off from the Partnership linked to the report's key focus areas and recommended actions.

Report summary

The Health and Wellbeing Board (HWB) and Integrated Care Partnership (ICP) have championed the development of an All Age Carers Strategy for Norfolk and Waveney. This report brings the Strategy to the ICP. The All Age Carers Strategy (see Appendix A) has been produced from detailed findings from user-led research and engagement. It has been coproduced with Carers of all ages, including Young Carers and Parent Carers and builds on research and coproduction with practitioners systemwide across Norfolk and Waveney. The strategy is based on what Carers have told us with identified key focus areas and recommended actions for the first stage of delivery which have been reviewed with partner organisations. Carers will be part of a monitoring group with representatives from the members of the ICP.

The following statements were coproduced with Carers and formed the basis for the key focus areas and recommended actions:

1. **As a Carer**, I have rights that will be upheld.
2. **As a Carer**, I am identified, recognised, valued and respected. I am an equal partner in the care of the person I look after which includes clear communication with me.
3. **As a Carer**, I am made aware of, and have access to, good quality information and services including a single and reliable point of contact.
4. **As a Carer**, I have access to good and appropriate support with my mental health, physical health and wellbeing.
5. **As a Carer**, I am an equal partner in the creation, monitoring and evaluation of services where my experience is recognised and valued. This will enable Carers, and the people we care for, to receive the services we need and want. This is vital to support our health (including mental health) and wellbeing.
6. **As a Carer**, I can access education, employment and training.
7. **As a Carer**, I am able to have time for myself/ away from my caring role including access to peer support and community groups.
8. **As a Carer**, I know the person I care for will be safe and have access to a good quality of life if I am no longer able to care on a temporary or permanent basis.

The Key Focus Areas together with recommended actions in the All Age Carers Strategy concentrate on the importance of:

- Identifying and raising awareness of all ages of Carers, their rights and their value (including hidden Carers).
- Improving access to good quality information and services including a single point of contact.
- Recognising and involving Carers as equal partners in the care of those they care for.

- Undertaking to coproduce services with Carers wherever possible recognising their expertise and ability to influence and shape services that they need and want to support their health and wellbeing.
- Having a framework and knowledge of commissioned services for all age Carers.
- Recognising the importance of peer support and access to services which enable Carers to have a break from their caring role.
- Developing a Carers pathway.

Recommendations

The ICP is asked to:

- a) Endorse and promote the first coproduced All Age Carers Strategy for Norfolk and Waveney 2024 – 2029.
- b) Commit to supporting the All Age Carers Strategy for Norfolk by sending representatives from all partner member organisations to be part of the Monitoring group as appropriate.
- c) Ensure all partners commit to developing Action Plans based on the Focus Areas and Recommended Actions within the Strategy document.

1. Background

- 1.1 A Carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The 2021 Census together with ONS Census data for Scotland and Northern Ireland, suggests that the number of unpaid carers across the UK is 5.8 million with a further 12,000 people becoming Carers every day. According to the 2021 census, there are over 95,000 unpaid carers in the Norfolk and Waveney Integrated Care System with a fifth of these being Young Carers and Young Adult Carers. Many of these Carers are providing over 50 hours of care a week and care for more than one person.
- 1.2 Without the continued support of Carers, the health and social care services within Norfolk and Waveney, which are already overstretched, would face further formidable challenges. Supporting Carers enables hundreds of thousands of patients to be cared for in their own homes with a reduced pressure on the NHS. Providing timely support to patients and their Carers helps prevent crisis and reduces the burden on the existing healthcare system
- 1.3 Following the Health and Care Act of 2022, the Integrated Care Board (ICB) and other health partners for Norfolk and Waveney has a duty:
 - To involve Carers in the planning and commissioning of services.
 - To promote the involvement of Carers in decisions which relate to the prevention or diagnosis of illness or the care or treatment of the person they care for.
 - To involve Carers in plans relating to discharge from hospital as soon as feasible if the person they care for is likely to require care and support.
- 1.4 In September 2022, having co-produced the Carers Engagement Report ([go to www.carersvoice.org](http://www.carersvoice.org) to read this report in detail). Carers Voice continued to develop and co-produce the All Age Carers Strategy for Norfolk and Waveney. Building on the evidence base provided by extensive research with Carers, Carers Voice has worked systemwide with partners within Norfolk and Waveney (see appendix of partners contacted). Throughout this period, the research has been supported by Norfolk County Council and the Norfolk and Waveney Integrated Care Board.

2. All Age Carers Strategy for Norfolk and Waveney 2024 - 2029

- 2.1 The All Age Carers Strategy aligns with the agreed priorities of the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024 of Driving integration; Prioritising Prevention; Addressing Inequalities and Enabling Resilient Communities to enable systemwide support for the people of Norfolk and Waveney to live longer, healthier and happier lives. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024.](https://improvinglivesnw.org.uk)
- 2.2 The work of the All Age Carers Strategy is key to the success of the ninth priority of supporting the needs of families and unpaid Carers in the Ageing Well Strategic Framework of the Norfolk and Waveney Integrated Care System which underpins the nine strategic goals of the framework. [Go to improvinglivesnw.org.uk to read the Ageing Well Strategic Framework in detail.](https://improvinglivesnw.org.uk)
- 2.3 Supporting Carers and the people they care for enables greater understanding of the experiences of living with health inequalities and what factors influence outcomes. This strategy supports the work of the Norfolk and Waveney Health Inequalities Strategic Framework for Action 2024 – 2034, in particular Young Carers who are identified as one of the Core20plus groups. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Health Inequalities Strategic Framework.](https://improvinglivesnw.org.uk)
- 2.4 The All Age Carers Strategy for Norfolk and Waveney has identified key focus areas with specific recommended actions for the first stage of delivery which encompass, for example, access to and maintenance of education, employment and training for Carers of all ages; a lead within organisations, including all educational settings, who champions coproduction with Carers and has the capacity to drive change; positive transitions for Young Carers and Parent Carers, creation of clear pathways to support Carers at the different ages and stages of caring and the need to address the lack of long term care planning for people cared for by those who may no longer be able to care.
- 2.5 The Strategy has ensured a strong foundation which has been led by Carers to support future planning. Key to tangible outcomes for people will be the establishment of a Monitoring Board with agreed actions and outcomes from partners within the ICP which can be tracked and measured and against which individual partners can be held to account.
- 2.6 Put simply, without unpaid Carers, our health and social care system would collapse (Holzhausen, 2015). It is essential that support for Carers of all ages is addressed effectively and prioritised. They are the hidden backbone of society often referring to themselves as ‘propping up’ the health and social care system. By ensuring effective support for Carers across Norfolk and Waveney, we will not only empower Carers to live their best possible lives but also enhance the quality of care for the people they care for. We have the opportunity to work together to create a sustainable future where Carers are respected and supported as invaluable contributors to society.

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If you need this report in large print, audio, Braille, alternative format or in a different language please contact 0344 800 8020 or 0344 800 8011 (textphone) and we will do our best to help.

All Age Carers Strategy for Norfolk and Waveney 2024-2029

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2. Preface:

Sharon Brooks - Chief Officer, Carers Voice Norfolk and Waveney

Carers Voice Norfolk and Waveney are privileged to have been able to work with Carers to coproduce the first All Age Carers Strategy for Norfolk and Waveney. The strategy includes Young Carers, Young Adult Carers, Adult Carers and Parent Carers whilst recognising their different support needs. Carers Voice is a well-established charity with a membership of over 2400, working to empower the voices of Carers in the design and delivery of services across Norfolk and Waveney. Carers and co-production are at the heart of the work of Carers Voice (see appendix 6 for examples of coproduction).

There is an absolute need for an All Age Carers Strategy now. Carers need our support at all times but, with the aftermath of Covid, the increased cost of living and pressures on our health and care services, Carers are desperately in need of support now so that they can stay well and continue to look after the people they care for should they wish to do so.

Carers across Norfolk and Waveney have given much of their time and shared their lived experience to inform this piece of work. Carers have seen that Carers Voice Norfolk & Waveney commit to improving the health and wellbeing of Carers. We understand that support for Carers has to encompass getting the best and most appropriate care at the right time for those they care for as well as supporting the Carer directly. Carers are in the unique position of balancing not only the needs of the person they care for but often their own support needs too, enabling them to see how well or not systems support the person and the Carer.

This strategy has had the continued support of the Norfolk and Waveney Integrated Care Partnership (ICP) and its members who have committed to work with Carers on the focus areas and recommended actions to improve support for Carers so that they and the people they care for live their best possible lives. This Strategy aligns with the agreed priorities of the Norfolk and Waveney Integrated Care System strategies including the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024, the Ageing Well Strategic Framework and Health Inequalities Strategic Framework for Action 2024-2034 (See appendix 1 for further information).

We believe that through this work, change can happen systemwide and we are committed to continue to work and coproduce with Carers to develop and achieve the relevant actions through the Monitoring Group and associated activities.

Special thanks are due to all the Carers who have supported the development of the Strategy and particularly our Carer Ambassadors.

3. Background: State of Caring

Definition:

A Carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. (NHS England)

Types of caring roles: Example caring roles can be viewed at appendix 2 and 3.

- **Adult Carers**
- **Parent Carers**
- **Young Carers**
- **Young Adult Carers**
- **Sandwich Carers** (Those with caring responsibilities for different generations, for example both children and parents)
- **Mutual Carers**
- **Carers of victims of crime and trauma**
- **Kinship Carers** (Kinship care means that children whose parents are unable to look after them on a short or long term basis are cared for by other relatives such as grandparents, uncles, aunts or siblings, or by other adults who have a connection to the child, such as neighbours or a close friend of the family)
- **Past Carers**
- **Distance Carers** (People caring for someone in Norfolk and Waveney who live outside of the area)
- **Hidden Carers** (People who look after someone but do not recognise themselves as being Carers)

National Picture:

There are 5.8 million Carers in the UK according to the most recent Census 2021, with 120,000 being Young Carers under the age of 18. This equates to around 9% of the population who are providing unpaid care. However, Carers UK research estimates that the number of people providing unpaid care could be as high as 10.6 million with a further 12,000 people becoming Carers every day. (Carers UK, 2022).

Carers in England and Wales are estimated to save the government £162 billion per year or £445 million per day, which is equivalent to a second NHS (Petrillo and Bennett, 2023). The cost of living crisis has caused increasing pressure on Carers finances with the latest Carers UK research indicating that 28% of Carers have cut back on essentials such as food or heating, 61% are worried about living costs and managing in the future, with 60% having reduced time spent seeing family and friends. Over half of Carers said that their financial situation is negatively impacting their mental health (Carers UK, 2024).

One in seven people in the workplace are also unpaid Carers. (Carers UK, 2019). Within the NHS, this increases to one in three employees also providing unpaid care. (NHS Staff Survey, 2022).

50,000 children and young people spend at least 50 hours a week providing care. Carers Trust estimate that there are two Young Carers in every classroom in the UK. (Carers Trust, 2024)

Without the continued support of Carers, the health and social care services, which already faces significant demand challenges, would face further formidable challenges. Supporting Carers enables hundreds of thousands of people to be cared for in their own homes with a reduced pressure on the NHS. Providing timely support to people and their Carers helps prevent crisis and reduces the burden on the existing system.

Following the Health and Care Act of 2022, the Integrated Care Board for Norfolk and Waveney has a duty:

- To involve Carers in the planning and commissioning of services.
- To promote the involvement of Carers in decisions which relate to the prevention or diagnosis of illness or the care or treatment of the person they care for.
- To involve Carers in plans relating to discharge from hospital as soon as feasible if the person they care for is likely to require care and support.

Carers in Norfolk and Waveney:

According to the 2021 census, there are approximately 95,000 Carers in the Norfolk and Waveney Integrated Care System with a fifth of these being Young Carers and Young Adult Carers. Many of these Carers are providing over 50 hours of care a week and care for more than one person.

Findings from the Carers Voice Coproduced Engagement with All Age Carers in Norfolk and Waveney Report 2022:

- Almost half of respondents (47.5%) provide more than 50 hours of care per week, and some of this will result from the number of respondents caring for more than 1 person (25.6%).
- Nearly 50% of Carers taking part in this survey had not received a Carer's Assessment. A further 20% were unsure if they had received an assessment, meaning that the number of respondents without an assessment could be as high as 70%.
- Carers who said there had been negative change to the following aspects of their lives where applicable:
 - Time for themselves: 76.28%
 - Mental health: 72.83%
 - Day to day life: 71.69%
 - Physical health: 56.84%
 - Relationships: 57.79%
 - Financial circumstances: 54.62%
 - Employment: 53.44%
 - Education: 32.48% (including separate Young Carers Engagement Survey)

4. Methodology and Coproduction

In September 2022, having co-produced the Carers Engagement Report ([go to www.carersvoice.org to read this report in detail](http://www.carersvoice.org)), Carers Voice continued to develop and co-produce the All Age Carers Strategy on behalf of Norfolk and Waveney Integrated Care Partnership. Building on the evidence base provided by extensive research with Carers, Carers Voice has worked systemwide with partners within Norfolk and Waveney. Throughout this period, the research has been supported by Norfolk County Council and the Norfolk & Waveney Integrated Care Board. Ongoing engagement has been facilitated through various methods to ensure broad participation including:

- Sense check survey
- All Age Carers Strategy Working Group
- Carers Involvement Meetings
Carers Voice Norfolk and Waveney Partnership Meeting
- Carers Groups and public events
- Engagement with health, social care and Voluntary Community Social Enterprise (VCSE) partners (see appendix 5 for list of partners engaged)

5. Aims, Focus Areas and Recommended Actions

Coproduced 'As a Carer' Statements:

The 'As a Carer' statements have been co-produced with Carers and are the overarching aims of the Strategy. They are accompanied with 'what would this look like/feel like' points which can be viewed in Appendix 4. The following statements formed the basis for the key focus areas and recommended actions for the first stage of delivery:

1. **As a Carer**, I have rights that will be upheld.
2. **As a Carer**, I am identified, recognised, valued and respected. I am an equal partner in the care of the person I look after which includes clear communication with me.
3. **As a Carer**, I am made aware of, and have access to, good quality information and services including a single and reliable point of contact.
4. **As a Carer**, I have access to good and appropriate support for my mental health, physical health and wellbeing.
5. **As a Carer**, I am an equal partner in the creation, development, monitoring and evaluation of services where my experience is recognised and valued. This will enable Carers, and the people we care for, to receive the services we need and want. This is vital to support our health (including mental health) and wellbeing.
6. **As a Carer**, I can access education, employment and training.
7. **As a Carer**, I am able to have time for myself/ away from my caring role including access to peer support and community groups.
8. **As a Carer**, I know the person I care for will be safe and have access to a good quality of life if I am no longer able to care on a temporary or permanent basis.

Focus areas and recommended actions across the Norfolk and Waveney Integrated Care System:

We have worked with Carers and practitioners across health and social care to coproduce the focus areas for the first stage of the strategy along with the recommended actions. These are broken down into seven Focus Areas detailed below:

1. To identify and raise awareness of all ages of Carers, their rights and their value (including hidden Carers).

Recommended actions:

- Recognise and promote the Carers Identity Passport.
- Organisations, including all educational settings, to have or be working towards local and national Carers accreditation.
- Carer Awareness Training (including information on Carers Rights) to be embedded in staff induction and regular training in all organisations including educational settings.
- Awareness of Carers Rights within mental health services.
- Participate in annual Carers Conference.
- Recognise national Carers weeks/days including Carers Week, Carers Rights Day and Young Carers Action Day.
- Identify and build support for Carers in community settings.
- Promote Carers Leave legislation and the right to discuss flexible working options.
- Work with Carers UK- [Employers for Carers](#).
- Support the employment of Carers in the recruitment and selection process, recognising Carers transferrable skills and experience.
- Have in place or be working towards a Carers Policy, which details Carers Rights and support available within the organisation.
- Integrated Care System Carers Page to include information on Carers Rights
- Carers Rights to be included in the All Age Carers Handbook.
- Promote a whole family approach to identification and support. Awareness of Supporting Parents with Disabilities procedure and identification of Young Carers not in school.

2. To improve access to good quality information and services including a single point of contact.

Recommended actions:

- Resources in different formats that are accessible to everyone (large print, easy read, screen reader accessible, translated).
- All communication to be in language that is familiar, precise and appropriate i.e. no use of acronyms.
- Identify a single, named and ongoing point of contact for Carers. For example, a Carers Lead identified within each educational setting.
- Emergency planning to be available to Carers of all ages including Young Carers and Parent Carers.
- Promote Norfolk County Council Carer Safeguarding toolkit. Inclusion of safeguarding information in the All Age Carers Handbook.
- Promote the 'Making Every Contact Counts' approach across statutory and Voluntary Community and Social Enterprise (VCSE) services, recognising that caring roles change.
- Promote the NHS 'Think Carer' principle across statutory and Voluntary Community and Social Enterprise (VCSE) services.
- Agree to contribute to the All Age Carers Handbook as appropriate.
- Promote Carers Assessments and the commissioned support services for all ages
- Improved information for Carers of self funders.

3. To recognise and involve Carers as equal partners in the care of those they care for.

Recommended actions:

- Ensure Advocacy Services include support for Carers.
- Guide to involving Carers of all ages recognising the additional complexities of identifying and including Young Carers.
- Ensure record of support Carers provide is captured- *long term support planning record*.
- To give realistic and clear information so Carers can make informed decisions.

4. To co-produce services with Carers wherever possible recognising their expertise and ability to influence and shape services that they need and want to support their health and wellbeing.

Recommended actions:

- Agree to a standardised protocol for co-production ensuring Carers of all ages have an equal voice.
- Carers Lead identified within organisations, including all educational settings, who champions coproduction with Carers and has capacity to drive appropriate change.
- Staff completing coproduction training i.e. 'Making it Real training'.
- Involve Carers in service creation, development, monitoring and evaluation, recognising the impact on Carers when the support for the person they care for does not meet their needs.
- Integrated Care Board to safeguard Executive Sponsor for Carers position within the Integrated Care System (Currently Director of Nursing and Quality, Norfolk Community Health and Care NHS Trust).

5. Recognise the importance of peer support and access to services which enable Carers to have a break from their caring role.

Recommended actions:

- Clarity on eligibility from Social Services and Commissioned Services around breaks and respite offer for Carers for all ages.
- Recognise importance of Carers Groups and maintain an updated record.
- Support available digitally for Carers who cannot access support in the community due to availability of transport, alternative care or shielding.
- Recognise the rurality of Norfolk and Waveney and the need for viable options of transport when commissioning services.
- Support available to groups to help them continue.

6. To have a framework and knowledge of commissioned services for all age Carers.

Recommended actions:

- Identify interventions available and how these are accessed through the commissioned services.
- Commissioning organisations in the Integrated Care System to ensure Carers are involved in the commissioning process and ongoing when services have been commissioned.
- All services being commissioned for Carers to be presented to All Age Carers Strategy Monitoring Group to allow for continuity of service join up and avoiding duplication.
- The local authorities and Integrated Care Board commit to adopting "No Wrong Doors for Young Carers". [Go to carers.org to view the No Wrong Doors for Young Carers Memorandum of Understanding.](#)
- Research bodies to work with Carers at an early stage to design projects that are meaningful to Carers and the people they care for.

7. Develop a Carers pathway.

Recommended actions:

- Develop and increase identification of clear pathways to support Carers of different ages and stages of caring.
- Pathway of service commissioning.
- Promote transition needs for Young Carers moving schools and moving into adulthood.
- Promote positive transitions for Parent Carers between services.
- Promote commissioned services in Norfolk and Suffolk as a one stop shop for Carers of all ages.
- Explore commissioned support for Kinship Carers.
- Encourage Carers to have a Carers Assessment to inform them of the support that they are entitled to.
- Encourage Care Act assessments and reviews to enable a discussion and recording of a person's needs and the provision available when a Carer is no longer able to care.
- Develop and promote a systemwide process to capture the support a Carer provides and the support needed if they are not able to care on a temporary or permanent basis - long term care planning.

6. Monitoring and review

How the All Age Carers Strategy for Norfolk and Waveney will be delivered, monitored and reviewed:

It is important that the strategy will be a living document and is adaptable. Three main indicators will be used to measure the outcomes of the strategy. These will be linked to what extent the strategy has raised awareness, improved services and given rise to new ideas and projects. The indicators will be framed around the difference to Carers, services, funders and commissioners.

A Monitoring Group will be set up with Carers (representation from Adult Carers, Parent Carers and Young Carers) and representatives from services, organisations across health and social care and the VCSE organisations, funders and commissioners. The Monitoring Group will have overall accountability and responsibility for the action plan. The ongoing action plan will also be developed with reference to the NICE supporting adult Carers guidelines. The Monitoring Group will make sure the actions are accountable and will review the outcomes of the Strategy. The Monitoring Group will meet at least twice a year with separate subgroups being set up where necessary. An annual conference will be held to share updates and success.

The Monitoring Group will coproduce a monitoring form and annual survey. The Monitoring Group will collectively agree on data to be collected with a discussion on what success would look like for service providers. Some of the suggested metrics are:

- Number of Carers Identity Passports issued
- Number of Carers who have had a Carers Assessment
- Carers Handbook production
- Data from training providers

There will be ongoing intelligence gained through engagement with all age Carers across Norfolk and Waveney i.e. Carer Involvement and Carer Partnership Meetings, Carers Forums across health and social care, Carers Groups, Carers Ambassadors, Parent Carer Forums, Healthwatch Norfolk, Healthwatch Suffolk, Norfolk Learning Disability Partnership Board, Norfolk Autism Partnership Board and Norfolk Young Carers Forum.

Some examples of what has been achieved so far include the coproduction of the Carers Identity Passport (see appendix 6) for all age Carers in Norfolk and Waveney as well as the systemwide discharge project which has culminated in a coproduced booklet for Carers.

7. Conclusion and ask of the Norfolk and Waveney Integrated Care System

Helen Walker, Chief Executive, Carers UK said, “*Without the high level of care that unpaid Carers provide, our health and care systems would quite simply collapse.*” (Petrillo and Bennett, 2023). It is essential that support for Carers of all ages is addressed effectively and prioritised. They are the hidden backbone of society often referring to themselves as ‘propping up’ the health and social care system. By ensuring effective support for Carers across Norfolk and Waveney, we will not only empower Carers to live their best possible lives but also enhance the quality of care for the people they care for. We have the opportunity to work together to create a sustainable future where Carers are respected and supported as invaluable contributors to society. The All Age Carers Strategy aligns with three key strategies across the Norfolk and Waveney Integrated Care System (See appendix 1).

The Integrated Care Partnership has been asked to:

- Endorse and promote the All Age Carers Strategy for Norfolk and Waveney 2024 - 2029
- Commit to supporting the All Age Carers Strategy for Norfolk and Waveney by sending representatives to be part of the Monitoring Group as appropriate
- Ensure all partners commit to developing action plans for supporting based on the Focus Areas and Recommended Actions within the Strategy document.

The Integrated Care System is asked to agree the following ways of working:

- Promote and include the work of the All Age Carers Strategy systemwide through the Norfolk and Waveney Integrated Care System Strategies and Frameworks
- Review the commitment to Carers through the Strategy at regular intervals
- Commit to coproduction within their organisations wherever possible
- Ensure Carers are treated as equal partners in the design, development and delivery of services that support Carers and those they care for.

8. Appendix

Appendix 1: Norfolk and Waveney Integrated Care System Strategies

The All Age Carers Strategy aligns with the agreed priorities of the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024 of Driving integration; Prioritising Prevention; Addressing Inequalities and Enabling Resilient Communities to enable systemwide support for the people of Norfolk and Waveney to live longer, healthier and happier lives. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024.](https://improvinglivesnw.org.uk)

The work of the All Age Carers Strategy is key to the success of the ninth priority of supporting the needs of families and Carers in the Ageing Well Strategic Framework of the Norfolk and Waveney Integrated Care System which underpins the nine strategic goals of the framework. [Go to improvinglivesnw.org.uk to read the Ageing Well Strategic Framework in detail.](https://improvinglivesnw.org.uk)

Supporting Carers and the people they care for enables greater understanding of the experiences of living with health inequalities and what factors influence outcomes. This strategy supports the work of the Norfolk and Waveney Health Inequalities Strategic Framework for Action 2024 – 2034, in particular Young Carers who are identified as one of the Core20plus groups. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Health Inequalities Strategic Framework](https://improvinglivesnw.org.uk)

Appendix 2: Types of caring roles

Working Carers

I support my Mum who has dementia. I support with all household tasks, shopping, collecting medication, arranging appointments etc. She lives on her own at the moment, but I am worried about the future as she is forgetting more and more. I also work full time so having to juggle everything is really hard. I feel guilty when I have to leave but I don't have any time for myself and I am exhausted. We have talked about getting care staff in but Mum doesn't want 'strangers' in the house. So, for now, it's just me.

Mutual Carers

I have been looking after my wife for over 20 years who has bipolar but only realised I was a Carer when someone said to me I was. When she is in low mood I have to encourage her to get up from bed, make sure she is eating enough and encourage to go outside as I know this helps her feel better. My wife is now supporting me as my physical health has deteriorated. We look after each other, this is part of our marriage vows.

Distance Carer

I live in Coventry which is over 3 hours away from my sister. I provide a lot of emotional support and reassurance over the phone and visit as much as possible. I coordinate all care and support over the phone. She is fortunate to have a good friend who lives by that takes her to appointments.

Parent Carer

I look after my son who is autistic. I provide emotional support, admin support with all bills and documents, help booking and attending appointments, prompting to take medication etc. I am so worried about how they are going to cope when I am not here.

Young Adult Carers

I help my parents look after my younger sister. I have recently learnt how to drive, and I take my sibling on drives around the block to help calm them. I am planning on going to university next year but am worried about how they will cope.

Carers of victims of crime and trauma

I am a Carer for my child who is a victim of online grooming and sexual assault. I provide ongoing emotional support and help with everyday life. It is really difficult for me to talk to people about this. We are a group of Carers that are not always recognised.

Young Carers

I help my mummy and daddy look after my brother who is autistic. He doesn't like loud noises and can get really upset.

Adult Carer

I have found myself in a situation where I am caring for someone I have no emotional attachment to.

Changing caring role

I have been looking after my wife for over 15 years but she has gradually needed more care and moved into a care home at the start of the year.

Past Carers

I was looking after my partner for over 10 years. Once a Carer, always a Carer.

Hidden Carers

(People who do not realise they have a caring role)

I am just a:

- Parent
- Spouse
- Partner
- Child
- Sibling
- Relative
- Friend
- Neighbour

People do not always want the label. Cultural expectations differ.

Sandwich Carers

(Carers with responsibilities for different generations, for example both children and parents)

I am looking after my child who has SEND and my dad who has dementia. My dad has paid carers coming in three times a day to support with personal care and making sure he has a meal. They often only have time to give him a microwave meal so I try and cook him a home cooked meal once a week. Me and my siblings go round when we can to sit and chat with him, so he's not lonely. This year my child is 18 and I am worried about moving from Children to Adult Services.

Kinship Carers

I am an adult looking after my younger sibling who is a child. It is difficult for me to access support as I don't fit in a box.

Parent Carer

I am a Carer of a child with SEND. I also have a disability myself.

Appendix 3: Example roles shared by Carers in the Engagement Report

- **Meals-** preparing, cooking, nutrition, cutting food up, feeding, reminding to eat, buying food
- **Help with incontinence-** washing linen, changing pads, help to go to the toilet, prompt to go to the toilet, supporting/checking during the night
- **Appointments-** liaising with the doctors and hospital, being the point of contact, travelling to appointments, accompanying to appointments, emotional support to go appointments, being contact due to poor hearing
- **Shopping-** food, household supplies, monitoring and topping up supplies within the house
- **Personal care-** washing, bathing, reminders to shower, shaving, changing, choosing appropriate clothes, help with toileting
- **Moving and practical help-** transferring from bed to chair, help with walking, pushing wheelchair, moving and handling, lifting items including drinks, using hoist
- **Healthcare-** catheter maintenance, massaging painful joints, delivering physiotherapy, monitoring and treatment that local services are unable to provide, help with hydration and nutrition, checking blood pressure and blood sugar levels
- **Everyday tasks-** shopping, cleaning, tidying, reminders, dealing with mail, gardening, assistance with daily needs, dog walking, prompts, lifting, sorting heating, making sure house is an appropriate temperature, switching off lights
- **Monitoring-** checking in overnight, checking in daily, medication, health, how treatment is working
- **Safety-** support with danger awareness, supervising, safety in kitchen with kettle and hob, safety around the home including trip hazards, online safety, checking doors are locked, road safety
- **Emotional support-** listening, phone calls, reassurance, check ins, support to take part in activities, support with panic attacks and nightmares, calming, encouraging, distracting, support with decision making, support with time keeping, constantly answering questions
- **Social support-** keeping company, combatting loneliness, arranging visitors and social activities, companionship, connecting with others
- **Medication-** collecting medication, ensuring medication is taken, monitoring supplies of medication
- **Falls-** supervise safety to prevent falls, supporting if regular falls occur
- **Activities-** encourage activities to stimulate brain function, mental stimulation, transport to activities, support to attend activities
- **Communication-** being the primary contact, explaining what is going on due to impaired hearing, advocating, help with finding words, changing hearing aids, help understanding instructions, interpretation including signing, support as very poor eyesight
- **Organisation-** arranging care, coordinating services, oversight of support, diarise appointments
- **Finance-** overseeing utilities, paying bills, budgeting support, all paperwork, poor eyesight so all personal admin
- **Support with sensory needs**
- **Teaching-** home education, how to manage emotions, support to manage bills and money, teaching how to communicate with new technology
- **Providing childcare-** looking after children, school pick ups
- **Support with technology-** using technology including iPad, phone, tv

Appendix 4: Coproduced 'As a Carer' statements with accompanying 'what would this look like/ feel like' points

1. As a Carer, I have rights that will be upheld.

What would this look/feel like:

- All Age Carers are provided with access to information and training about their rights and support with getting these.
- Training on Carers Rights (for all age Carers) and support available is included in staff induction and regular training.

Information about Carers Rights:

Care Act 2014 and Children and Families Act 2014

Adults caring for other adults

Under the Care Act, you are entitled to a Carer's Assessment where you appear to have needs for support. The person you care for is entitled to a 'needs assessment' if they appear to have needs for care and support.

Young Carers and Parent Carers

The Children and Families Act 2014 gives Young Carers and Parent Carers in England a right to an assessment of their own needs.

Young Carers are equally entitled to have a Carers Assessment. There are different types of assessments for Young Carers depending on how old they are.

1. Young Carer's assessment for Carers under 18.
 2. Transition assessment for Young Carers before they are 18 (Care Act 2014).
- Parent Carers are also entitled to have a Parent Carer Needs Assessment.

Equality Act 2010

The Equality Act 2010 was introduced to stop discrimination and promote equality. The Act could help you if you care for someone who is elderly or disabled. It could protect you against direct discrimination or harassment because of your caring responsibilities. This is because you are counted as being 'associated' with someone who is protected by the law because of their age or disability. If you're treated less favourably than someone else because you're caring for an elderly or disabled person, it is called 'Discrimination by Association'.

The Health and Care Act 2022

This legislation reinforces Carers' rights when it comes to hospital discharge. If someone is likely to need ongoing care and support after they leave hospital, NHS trusts and foundation trusts have a duty, where appropriate, to involve patients and Carers (including Young Carers) at the earliest opportunity in decisions and plans around their ongoing care needs.

Flexible Working Act 2023

If you are juggling work with your caring responsibilities, you have the right to request flexible working. The introduction of the new Employment Relations (Flexible Working) Act means that anyone, including unpaid carers, can ask their employer for changes to their working hours, times of work, or place of work, from day one. They will also be able to change their flexible working arrangement more than once a year, which will be a huge help too.

Carers Leave Act 2023

The Carer's Leave Act came into effect on the 6 April 2024.

- The Carer's Leave Act covers employees in England, Wales and Scotland.
- Employees are entitled to one week's unpaid leave per year if providing or arranging care for someone with a long-term care need.
- This leave can be taken flexibly (in half or full days) for planned and foreseen caring commitments.
- It is available from the first day of employment.
- It provides the same employment protections to employees as other forms of family-related leave, including protection from dismissal.

The right to ask your GP practice to identify you as Carer

People providing unpaid care, can ask their GP practice to identify them as a Carer on their patient record. The benefit of this is that they may then fall into a priority group for vaccines or other public health campaigns.

2. As a Carer, I am identified, recognised, valued and respected. I am an equal partner in the care of the person I look after which includes clear communication with me.

What would this look/feel like:

- Carers are identified and recognised (including Young Carers, Parent Carers and Carers of victims of crime and trauma) as a key partner across health and social care.
- Professional practice and processes are developed across the Norfolk & Waveney Integrated Care System for raising awareness of Carers of all ages (and the wider family) and the All Age Carers Strategy for Norfolk and Waveney.
- A whole family approach to identification and support will be promoted across health and social care.
- The knowledge and experience of Carers of all ages is valued and they are supported and included in plans of those they care for at the earliest possible stage.
- Language is used that is recognised (are you looking after someone?). Language needs to be inclusive and understood by Carers of all ages and those who do not recognise themselves as a Carer.
- Increased communication and data between health and care services so Carers only have to tell their story once.
- Awareness and support for Carers of all ages in community settings.
- Carers are an equal part of the team in the **triangle of care** (partnership between practitioners, the person being cared for, and their Carers).

3. As a Carer, I am aware of and have access to good quality services including a single and consistent point of contact.

What would this look/feel like:

- Carers of all ages can easily access information (available in different formats and languages), advice, guidance and good quality support when and how they need it, early in their caring role.
- Improved communication between services and departments with consistent messages.
- Carers of all ages have equal and appropriate access (no wrong door). There is a clear route to access support.
- Positive transitions for Young Carers and Parent Carers between services.
- The need for human contact is recognised.
- Improved navigation of services including identifying and maintaining a **single point of contact**.
- Information about pathways for specific conditions.
- Awareness of the need for more recognition of all age Carers amongst community and wider advice services i.e. employment support.
- GP surgeries, hospitals and educational settings recognised as often the first point of contact.
- Recognise how community infrastructure can support Carers of all ages.
- Self-funders have access to information and support in their caring role.

4. As a Carer, I have access to good and appropriate support with my mental health, physical health and wellbeing.

What would this look/feel like:

- Access to support is available for all age Carers which is flexible and personalised.
- Recognise the impact caring can have on a person's mental health, physical health and wellbeing. If support is not appropriate and timely for the person being cared for, this may contribute to Carer breakdown and/or crisis and negatively affect their finances.
- Staff have a working knowledge about the support available to Carers and are able to signpost and refer. *Making every contact count.*
- Regular contact/ check ins with Carers to touch base and check they are receiving the support they need.
- Mental health is everyone's responsibility.
- Always check that Carers are willing and able to continue in their caring role
- Support for all age Carers to access flexible appointments.
- All age Carers have access to a break from their caring role to have time to focus on their own health and wellbeing.
- Identify the importance of peer support, companionship, listening ear and time for themselves. Support all age Carers to improve connections to reduce social isolation.
- Coordinated support for Carers of all ages and people they care for. Services need to be person centred to enable people to live their best lives possible.
- Packages of care and support are appropriate at the outset and flexible to reflect change. Safeguards in place to avoid delays and inappropriate levels of support.
- Consistent support including when a caring role changes or ends.
- Young Carers have the same opportunity to achieve their aspirations (recognising the flourish ambition in Norfolk).

5. As a Carer, I am an equal partner in the creation, development, monitoring and evaluation of services where my experience is recognised and valued. This will enable Carers and the people we care for to receive the services we need and want. This is vital to support our health (including mental health and wellbeing).

What would this look/feel like:

- Carers of all ages are included in the design and delivery of services from the start and through to ongoing decision making.
- Carers of all ages receive the support they need to be involved in decisions.
- Organisations across the Norfolk and Waveney Integrated Care System work together and pool knowledge to share expertise. Consultations are not repeated.

6. As a Carer, I can access education, employment and training

What would this look/feel like:

- Early identification of Carers of all ages in educational and workplace settings
- Allow for flexible arrangements to be made to support Carers of all ages with education, employment and training. A Carers Lead/ Carers policy is identified within educational and workplace settings.
- Recognising and creating opportunities for employment, training and volunteering.
- Support for all age Carers and organisations to recognise Carers' transferable skills and experience.
- Carers of all ages have access to employment, financial and benefit advice and support.
- Training for Carers on their rights to enable and empower them to carry out their caring role.

7. As a Carer, I am able to have time for myself/ away from my caring role including access to peer support and community

What would this look/feel like:

- Availability and access to services so Carers of all ages can have a break and time to focus on their own health and wellbeing. This is flexible to meet the needs of the Carer and the people they care for.
- Carers of all ages can access peer support within the community.
- Support and encourage Carers to access a Carers Assessment and the people they care for to have a needs assessment.
- Awareness and links with support in the community.

8. As a Carer, I know the person I care for will be safe and have access to a good quality of life if I am no longer able to care on a temporary or permanent basis.

What would this look/feel like:

- A clear process is in place for long term care planning, and this is linked systemwide to allow for multi-agency support.
- Planning is person centred.
- Recognition of complex needs and range/depth of support required in planning for the future.
- Recognising the continued role of all age Carers when the person they care for is in an alternative place of care.
- Early identification of requirement.
- Awareness of emergency planning.
- Emergency planning to be available to Carers of all ages including Young Carers and Parent Carers.
- Carers of all ages and people being cared for have access to an advocate.

Appendix 5: Organisations engaged

- Access Community Trust
- Active Norfolk
- Age UK Norfolk and Norwich
- Ageing well
- Anglia Ruskin University
- ARC East of England Carer Research Network
- ASD Helping Hands
- Bridges Outcomes Partnerships
- Bridges Plus
- Carers Charter
- Carers Matter Norfolk
- Carers UK
- Carers Voice Members (approx. 2400)
- Carers Voice social media
- Caring Together
- Chief Nurses Norfolk and Waveney
- Community Action Norfolk
- Deaf Connexions
- Dial
- EACH
- East Coast Medical Healthcare
- East of England Ambulance Service
- Equal Lives
- Family Voice Norfolk
- Gorleston and Great Yarmouth Carers Forum
- Headway Norfolk and Waveney
- Health and Wellbeing Partnership Chairs (Breckland, Broadland, Great Yarmouth, Kings Lynn and West Norfolk, North Norfolk, South Norfolk, Norwich and Waveney)
- Healthwatch Norfolk
- Healthwatch Suffolk
- Independence Matters
- James Paget University Hospitals NHS Foundation Trust
- Later Life Partnership Network
- Lowestoft Rising
- Making it Real
- MAP
- Mind
- MND Association
- NCAN
- Norfolk & Waveney Dementia Support Service

- Norfolk & Waveney Integrated Care Board (Ageing Well Programme Board, Dementia Working Group, Children and Young People - Quality in Care, Patient Experience, Care Homes and Housing)
- Norfolk and Norwich University Hospitals NHS Foundation Trust
- Norfolk and Suffolk Care Support
- Norfolk and Suffolk Foundation Trust
- Norfolk Autism Partnership Officers
- Norfolk Community Health and Care NHS Trust
- Norfolk Community Law Service
- Norfolk County Council Adult Social Care/Childrens Services
- Norfolk County Council Care Provider Network
- Norfolk County Council Development Workers networks
- Norfolk Hospices
- Norfolk Local Pharmaceutical Committee
- Norfolk Learning Disability Partnership Board Officers
- Norfolk Older People's Strategic Partnership
- Norfolk Primary Care
- Norfolk Safeguarding Adults Board
- Norfolk Young Carers Forum
- Norfolk's All Age Autism Strategy
- North Norfolk Dementia Working Group and Ageing Well Programme Board
- Opening Doors
- Patient Experience Network Norfolk and Waveney
- Patient Experience, NHS England
- Place Board Chairs (Great Yarmouth and Waveney, North Norfolk, Norwich, South and West)
- Police and Crime Commissioner for Norfolk
- Police and Crime Commissioner Suffolk
- Priscilla Bacon Hospice
- Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust
- Restitute
- St Elizabeth Hospice
- Suffolk County Council
- Suffolk Family Carers
- Suffolk Parent Carer Forum
- Suffolk Safeguarding Partnership
- Tapping House
- University of East Anglia
- Voluntary Norfolk
- West Norfolk Deaf Association
- West Norfolk Carers
- Young Carers Matter Norfolk
- Young Carers Norfolk Steering Group

Appendix 6: Examples of achievements since coproduced Engagement Report Carers Identity Passport for Norfolk and Waveney

The Carers Identity Passport has been co-produced with Carers and practitioners across the Norfolk & Waveney Integrated Care System to ensure Carers are identified and recognised within healthcare settings. It is for all age Carers, including Young Carers and Parent Carers, in Norfolk & Waveney. It is available both physically as card and a lanyard and digitally as an image Carers can save onto their phones.

The Carers Identity Passport is aimed to be a conversation starter to ensure Carers are recognised, valued and respected in their caring role and included in the care of the person they are looking after. It helps Carers to be linked into the existing support within the hospitals (flexible visiting, free parking etc) and wider support for Carers available from other organisations. The card has a QR code and link to the Norfolk and Waveney Integrated Care System website which has a page with information about support for Carers of all ages.



Figure 1 Photo of the Carers Identity Passport card and lanyard and digital Carers Identity Passport

The Carers Identity Passport is free for Carers to request. Carers can apply for a Carers Identity Passport by completing a short form available at: <https://www.carersvoice.org/carers-identitypassport/>. There is a number to call for support with completing the form, this is **07932095312**.

Carers tell us that this passport is key to their identification for support. It is a tangible sign that they are recognised, valued and respected. The digital version enables Carers to discreetly refer to them in a sensitive situation or they wear the lanyard and badge to be easily recognised – Young Carers tell us they wear them with pride in school.

I wear the Carers Identity Passport wherever I go with the person I care for, it helps to show I am a Carer... it has been recognised without question, which makes me feel empowered as an unpaid Carer.

As of 15th November 2024, 4240 Carers Identity Passports have been issued. [Go to www.carersvoice.org](https://www.carersvoice.org) to view a visual overview of the co-production of the Carers Identity Passport. [Go to www.carersvoice.org](https://www.carersvoice.org) to view a summary report which sets out what Carers told us during this project and what we did as a result.

Carers Discharge Project:

A multi-agency discharge group was set up following feedback received from Carers about the discharge process. This work is being co-chaired by the Executive Sponsor for Carers within the Norfolk and Waveney Integrated Care System (currently Director of Nursing and Quality, Norfolk Community Health and Care NHS Trust) and a Carers Ambassador. The sessions provided the platform for Carers to articulate their experiences, address concerns, and explore factors that could improve the discharge experience for Carers. Providers shared their existing efforts to support Carers in the discharge process, highlighting both successful practices and areas needing improvement.

The work has culminated in the coproduction of a booklet for Carers to use when the person they care for is admitted to hospital through to when they are discharged and beyond. The goal is to generate tangible improvements for Carers, enhancing their overall experience with discharge. The booklet will contain sections covering the following topics:

- Support for Carers
- Supporting the person you are caring for during their hospital stay
- Preparing for discharge
- Checklist

It will be piloted in the Queen Elizabeth Hospital and Norfolk Community Health Care Services in the West area (Swaffham Community Hospital).

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