Norfolk Health & Wellbeing Board

Date: **Wednesday 08 November 2023**
Time: **09:30 - 12:30**
Venue: **Council Chamber, County Hall, Martineau Lane, Norwich**

Representing	Membership	Substitute
Borough Council of King's Lynn & West Norfolk	Cllr Jo Rust	Cllr Bal Anota
Breckland District Council	Cllr Tristan Ashby	Cllr Sam Chapman-Allen
Broadland District Council	Cllr Natasha Harpley	
Cambridgeshire Community Services NHS Trust	Anna Gill	Steve Bush
East Coast Community Healthcare CIC	Ian Hutchison	John Niland
East of England Ambulance Trust	David Allen	
East Suffolk Council	Cllr David Beavan	
Great Yarmouth Borough Council	Cllr Emma Flaxman-Taylor	Cllr Donna Hammond
Healthwatch Norfolk	Patrick Peal	Alex Stewart
James Paget University Hospital NHS Trust	Joanne Segasby	Mark Friend
Norfolk Care Association	Angela Steggles	
Norfolk Community Health & Care NHS Trust	Lynda Thomas	Stephen Collman
Norfolk Constabulary	ACC Nick Davison	Supt Chris Balmer
Norfolk County Council, Cabinet member for Public Health and Wellbeing, Leader (nominee)	Cllr Bill Borrett	
Norfolk County Council, Cabinet member for Childrens Services and Education	Cllr Penny Carpenter	Cllr Karen Vincent
Norfolk County Council, Director of Public Health	Stuart Lines	
Norfolk County Council, Interim Executive Director Adult Social Services	Debbie Bartlett	
Norfolk County Council, Executive Director Children's Services	Sara Tough	Sarah Jones
Norfolk County Council, Cabinet member for Adult Social Services	Cllr Alison Thomas	Cllr Shelagh Gurney
Norfolk & Norwich University Hospital NHS Trust	Tom Spink	Nicholas Hulme
Norfolk & Suffolk NHS Foundation Trust	Stuart Richardson	Kathryn Ellis
Norfolk and Waveney Health and Care Partnership (Chair) and NHS Norfolk and Waveney Integrated Care Board (Chair)	Rt Hon Patricia Hewitt	
NHS Norfolk and Waveney Integrated Care Board (Chief Executive)	Tracey Bleakley	
North Norfolk District Council	Cllr Wendy Fredericks	Cllr Liz Withington
Norwich City Council	Cllr Cate Oliver	
Place Board Chair Great Yarmouth	Jonathan Barbour	
Place Board Chair Norwich	Tracy Williams	
Place Board Chair North Norfolk	Dr James Gair	
Place Board Chair West	Carley West-Burnham	
Place Board Chair South Norfolk	Dr Ge Yu	
Police and Crime Commissioner	Giles Orpen-Smellie	Dr Gavin Thompson
Primary Care representative NHS	Dr Satish Singh	
Queen Elizabeth Hospital NHS Trust	Chris Lawrence	Alice Webster
South Norfolk District Council	Cllr Kim Carsok	Cllr Andy Evans
Voluntary Sector Representative	Emma Ratzer	Pete Boczko
Voluntary Sector Representative	Dan Mobbs	
Voluntary Sector Representative	Alan Hopley	Daniel Childerhouse

Additional members invited as guests:

Suffolk Health and Wellbeing Board	Cllr Beccy Hopensperger

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

Integrated Care Partnership

Date: **Wednesday 08 November 2023**
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 Care, Public Health and Prevention
Norfolk County Council, Cabinet member for Childrens Services and Education
Norfolk County Council, Director of Public Health
Norfolk County Council, Executive Director Adult Social Services
Norfolk County Council, Executive Director Children's Services
Norfolk County Council, Leader (nominee)
Norfolk & Norwich University Hospital NHS Trust
Norfolk & Suffolk NHS Foundation Trust
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
Place Board Chairs Norwich
Place Board Chairs North Norfolk
Place Board Chairs South Norfolk
Place Board Chairs 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, Executive Director of People Services
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 Integrated Care Partnership

Wednesday 08 November 2023
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 Edwards Room next to the Council Chamber at County Hall, Norfolk County Council.*

1.	Apologies	Committee Officer	
2.	Chair's opening remarks	Chair	
	Norfolk Health and Wellbeing Board		
3.	HWB Minutes	Chair	(Page 4)
4.	Actions arising	Chair	
5.	Declarations of interests	Chair	
6.	Public Questions (How to submit a question: HWB) Deadline for questions: **9am, Friday 03 November 2023**	Chair	
7.	Urgent arising matters	Chair	
8.	Combating Drugs and Alcohol Partnerships Annual Report (HWB)	Stuart Lines/ Diane Steiner	(Page 13)
	Norfolk and Waveney Integrated Care Partnership		
1.	ICP Minutes	Chair	(Page 4)
2.	Actions arising	Chair	
3.	Declarations of Interest	Chair	
4.	Public Questions (How to submit a question: ICP) Deadline for questions: **9am, Friday 03 November 2023**	Chair	
5.	Driving Integration Through Digital, Data and Technology (ICP) [Presentation]	Tracey Bleakley / Ian Riley Debbie Bartlett / Geoff Connell	(Page 20)
6.	Taking action to address health inequalities in Norfolk and Waveney (ICP) [Presentation]	Tracey Bleakley / Mark Burgis	(Page 31)
7.	Mental Health: Public Health outcomes and prevention priorities for the system (ICP) [Presentation]	Stuart Lines / Suzanne Meredith	(Page 42)
8.	LeDeR Annual Report 2022/2023 (ICP)	Tracey Bleakley / Andrew O'Connell	(Page 54)
9.	Public Health Strategic Plan (ICP) [Presentation]	Stuart Lines / Chris Butwright	(Page 123)
10.	Department for Education Families First for Children Pathfinder Update (ICP)	Sara Tough	(Page 162)

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 27 September 2023 at
in the Council Chamber, County Hall.

Present:	**Representing:**
Cllr Jo Rust	Borough Council of King's Lynn & West Norfolk
Cllr Natasha Harpley	Broadland District Council
Lou Notley	East Coast Community Healthcare CIC
David Allen	East of England Ambulance Trust
Cllr Mike Ninnmey	East Suffolk Council
Cllr Emma Flaxman-Taylor	Great Yarmouth Borough Council
Patrick Peal	Healthwatch Norfolk
ACC Nick Davison	Norfolk Constabulary
Cllr Bill Borrett	Norfolk County Council, Cabinet member for Public Health and Wellbeing, Leader (nominee)
Stuart Lines	Norfolk County Council, Director of Public Health
Debbie Bartlett	Norfolk County Council, Interim Executive Director Adult Social Services
Sara Tough	Norfolk County Council, Executive Director Children's Services
Cllr Alison Thomas	Norfolk County Council, Cabinet member for Adult Social Services
Kathryn Ellis	Norfolk & Suffolk NHS Foundation Trust
Tracy Williams	Norfolk and Waveney Integrated Care Board NHS
Rt Hon Patricia Hewitt	Norfolk and Waveney Health and Care Partnership (Chair) and NHS Norfolk and Waveney Integrated Care Board (Chair)
Cllr Kim Carsok	South Norfolk District Council
Emma Ratzer	Voluntary Sector Representative
Dan Mobbs	Voluntary Sector Representative
Alan Hopley	Voluntary Sector Representative
Carly West-Burnham	Place Board Chair (Kings Lynn and West Norfolk)
Jonathan Barber	Place Board Chair (Great Yarmouth)

Officers Present:	
Stephanie Butcher	Policy Manager Health and Wellbeing Board
Rachael Grant	Policy Manager Public Health
Stephanie Guy	Advanced Public Health Officer
Maisie Coldman	Committee Officer

Speakers:	
Chris Robson	Chair of Norfolk Safeguarding Childrens Partnership
Mark Osborn	Fathers Project Lead
Heather Roach	Chair of Norfolk Safeguarding Adults Board
Suzanne Baldwin	Assistant Director Workforce, Markets and Brokerage, Adult Social Services Norfolk County Council
Christine Breeze	Senior Commissioning Manager, Adult Social Services, Norfolk County Council
Shelia Glenn	Director of Planned Care & Cancer, Norfolk and Waveney Integrated Care Board (ICB)
Rachael Peacock	Winter Director, Norfolk and Waveney Integrated Care Board (ICB)
Dr Abhijit Bagade	Public Health Consultant, Norfolk County Council
Mark Payne	Head of Mental Health, Norfolk & Waveney Integrated Care Board

Norfolk Health and Wellbeing Board (HWB)

1. Apologies

1.1 Apologies were received from Ian Hutchinson (substituted by Lou Notley), Joanne Segasby, Stuart Richardson (substituted by Kathryn Ellis), Anna Gill, Cllr Wendy Fredricks, Cllr Cate Oliver and Cllr Penny Carpenter.

2. Chair's Opening Remarks

2.1 The Chair welcomed Cllr Jo Rust, representative for the Borough Council of Kings Lynn and West Norfolk, to their first meeting. The Chair noted that the Norfolk and Norwich University Hospital has a new interim director who would be the substitute for Tom Spink going forward. Tony Osmanski was retiring, the chair thanked him for his contributions.

2.2 Members were encouraged to sign up to the system wide ICS conference that was being held on the 17 October 2023 at the Kings Centre in Norwich. The conference was being hosted by the Chair, Cllr Bill Borrett, and Rt Hon Patricia Hewitt.

3. Minutes

3.1 The minutes of the meeting held on 21June 2023 were agreed as an accurate record and signed by the Chairman.

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 None.

8. Election of Vice Chairs

8.1 The Chair, seconded by Cllr Thomas, proposed Rt. Hon Patricia Hewitt and Cllr Emma Flaxman-Taylor as Vice Chairs. Rt Hon Patricia Hewitt and Cllr Emma Flaxman-Taylor were both duly elected as Vice-Chair of the Health and Wellbeing Board for the ensuing council year.

9. Amendments to the Health and Wellbeing Board Terms of Reference

9.1 Members received a report that noted necessary amendments to the Health and Welling Boards Terms of Reference following changes to Cabinet roles at Norfolk County Council.

9.2 The Health and Wellbeing Board **RESLOVED** to **agree** to the revised version of the Health and Wellbeing Board Terms of Reference.

10. Norfolk Safeguarding Children Partnership Annual Report

10.1 Sara Tough, Executive Director of Childrens Services, introduced the Norfolk Safeguarding Children Partnership Annual Report which summarises the local arrangements for safeguarding children.

10.2 Chris Robson, Chair of Norfolk Safeguarding Children Partnership, presented the annexed presentation (item 10, appendix A) which provided members with an overview of data and performance, scrutiny, the partnership priorities, project and development, and workforce training. They highlighted those positive relationships that existed within the Norfolk partnership, noting that senior leaders and practitioners are transparent and open to scrutiny. A young person version of this report would also be produced and circulated to members.

10.3 Mark Osborn, Father's Project Lead, described the positive responses that the Norfolk Safeguarding Children partnership had following the 2021 national safeguarding review panel report about the Myths

of Invisible Men. It was felt that services had not evolved in line with research that demonstrated the importance of a father who is positively engaging for the outcomes of children. Members heard that work to involve fathers was progressing positively. Good practice guidance has been produced that was complimented by a tool kit, both of these were developed following input from experts, practitioners, and fathers. Norfolk's response was seen as robust in comparison to other counties.

10.4 The following points and comments were discussed:

- A member raised a concern that the Adoption Panel had seen negative impacts for children when the court had ordered contact with birth parents. In response to this, members heard that the partnership did not have the remit to fully comment and that the role of the partnership in this scenario would need to be considered.

- The work that was being completed on absent fathers was welcomed by the Board, especially given that there have been discussions, and research, on the impact of single mother households but the impact on absent fathers had not been considered to the same extent.

- The work being completed on absent fathers was not just a specific targeted approach but also included universal services such as the Family Habit approach which looks at the start of life and encourages the engagement of the whole family network.

- The challenge of getting the workforce to complete the required learning and training was acknowledged. Adaptions, that moved thinking beyond traditional learning methods, had been implemented to be workable for practitioner's workload and the pressures that they faced. These included seven-minute briefings, lunchtime training sessions, and an online course.

- A member questioned at what point trauma and deprivation become a safeguarding concern, they referred to families that may experience mental health challenges and poverty which could lead to unintentional deprivation. The Chair of Norfolk Safeguarding Children's Partnership replied that these were the types of conversations that were being had within the partnership. There was a need for a balanced approach that did not, where possible, automatically label families with safeguarding issues. Instead, early intervention and a multi-disciplinary approach were needed to support families.

- Members heard that nothing had been raised with the partnership with regard to young carers and safeguarding concerns. This would be explored, but they were keen not to label those individuals as having safeguarding issues.

- Sara Tough, Executive Director of Children's Services, noted that the partnership work had fostered a holistic understanding of children and that solutions were a collaboration from partners. It was shared that another Ofsted inspection was expected and that the focus of this would be partnership working.

- Members congratulated the partnership work that had been completed.

David Allen arrived at 10:19

10.5 Having reviewed and commented on the Norfolk Safeguarding Children Partnership Annual Report, the HWB **RESOLVED** to **endorse** the report and its contents.

11. Norfolk Safeguarding Adults Board Annual Report for 2022/23

11.1 The Health and Wellbeing Board received the annual report which is a statutory requirement to be produced under the Care Act 2021. The Health and Wellbeing Board (HWB) considered the contents and how they can improve their contributions to both safeguarding throughout their organisation and the joint work of the board.

11.2 Heather Roach, Chair of Norfolk Safeguarding Adults Board, introduced and presented the Norfolk Safeguarding Adults Board Annual Report for 2022/23 and annexed presentation (item 11, appendix

A). They highlighted the unique way of working between adults and children Safeguarding. Members were provided with an overview of the safeguarding context in Norfolk, the thematic issues, the highlights over the last 12 months, and the aims of the new safeguarding strategy. They also heard that a peer review with Wigan would be happening in the next 12 months and asked for members to sign up for the NSAB newsletter, follow NSAB on twitter, read the Board Managers blog and attend a Local Safeguarding Adults Partnership meeting as well as highlighting resources on their website.

11.2 The following points and comments were discussed:

- A member asked how the Health and Wellbeing board could help the Prevention, Managing, and Learning subgroup (PML) to have more focus. In response, it was noted that PML was a way of working in which an area of focus was identified via data and then explored in a way that covered the elements of PML. This way of working had not been prioritised whilst work was being done to get the business process in place, but PML would be taken forward in the next 12 months

- The data included within the report was drawn from Norfolk County Council and was the same data that was required for the national safeguarding return, the potential to breakdown the 18-64 age bracket would be explored.

- Norfolk County Council councillors had the opportunity to attend a training session on Adult Safeguarding. The Norfolk County Council Cabinet Member for Adult Social Care noted that the members who did not attend would be encouraged to so they can disseminate information within their communities.

- It was felt that communication needed to be more proactive and ongoing. Getting the right people in the same room to share information would ensure a cross over and strengthen communication streams.

- Data sharing and GDPR policies mean that the voluntary sector does not have access to case notes or previous safeguarding concerns which would help the person. The voluntary sector was encouraged to escalate concerns.

- LeDeRr reviews, contact had been made with the ICB around the LeDeR process and it was acknowledged the process needed to be slightly more aligned.

11.3 The HWB **resolved** to:

a) **Endorse** the contents of the NSAB 2022/23 annual report.

b) **Promote** the work of NSAB to partner organisations and stakeholders.

c) **Use** media and communications channels to promote the safeguarding messages.

12. Norfolk Better Care Fund: 2023 - 2025

12.1 Debbie Bartlett, Interim Executive Director for Adult Social Care, introduced the report and noted that this was the first time that a two-year plan had been submitted. Sign off for the second year of the plan would come to the Health and Wellbeing Board in September 2024.

12.2 Suzanne Baldwin, Assistant Director Workforce, Markets and Brokerage, Adult Social Services, Norfolk County Council, and Christine Breeze, Senior Commissioning Manager, Adult Social Services, Norfolk County Council provided an overview of the annexed report (item 12, appendix A). They highlighted that the two-year allocation of funding was welcomed as it allowed for long term planning and increased levels of stability.

12.3 The following points and comments were discussed:

- Following a member's question, the data on avoidable admissions would be followed up on.

- The Better Care Fund supported innovation but also ensured sustainability within the system by securing funding to allow for the function of critical services such as reablement. There was a need to support people coming out of the hospital to reduce the chances of them needing onward services or being readmitted to the hospital. Norfolk tended to do well in this area as the reablement services were well developed.

- The voids identified within the Housing with Care flats were being utilised to support step down and the transition into the community and independent living. The board also heard that a 10-year programme of work existed, with significant financial investment from Norfolk County Council, to implement independent living schemes

- It was clarified that the closure of Benjamin Court referred to the closure of the building and not the service that it provided. The reablement service would continue and was being expanded and there would be no reduction in the services offered. All staff had been offered new roles in the new service.

- Debbie Bartlett highlighted that for the first time, demand and capacity planning had been included within the plan. This was significant as it included work from across the system looking back at the previous year to identify patterns and data that could be used to inform future planning. The majority of the work that needed to take place was outside the hospital setting and within the community.

12.3 The HWB **resolved** to:

a) **Sign off** the BCF submission for 23/24 and 24/25, which includes;

1. A narrative plan, describing our approach to integration, discharge, housing, and health inequalities.
2. An excel template, describing the BCF income and expenditure, our planned performance against the four key metrics and affirmation that we are meeting the national conditions as set out in the current BCF Planning Guidance, and a Capacity and Demand plan for supporting discharge and intermediate care services.
3. ICB Discharge Planning Template.

b) To **note** the BCF review to ensure improved understanding of the schemes and alignment to BCF priorities, improved alignment of system and place priorities and improved data collection to better understand the impact of the BCF.

The Health and Wellbeing board closed at 11:10

The meeting moved on to Integrated Care Partnership (ICP) matters after a 10-minute comfort break.

Integrated Care Partnership

1. Election of Chair and Vice Chair

1.1 The committee Officer invited nominations for the election of Chair of the Integrated Care Partnership (ICP). Cllr Bill Borrett was nominated by Rt. Hon Patricia Hewitt and seconded by Stuart Lines. There were no further nominations. All in agreement. Cllr Bill Borrett was elected as Chair for the ICP for the ensuing year.

The election of two Vice Chair positions took place.

The Chair, seconded by Cllr Thomas, proposed Rt. Hon Patricia Hewitt. Rt and Cllr Emma Flaxman-Taylor as Vice Chairs. Hon Patricia Hewitt and Cllr Emma Flaxman-Taylor were both duly elected as Vice-Chair of the Health and Wellbeing Board for the ensuing council year.

2. ICP Minutes

2.1 The minutes of the Integrated Care Partnership (ICP) meeting held on 21 June 2023 were agreed as an accurate record and signed by the Chair.

3. Actions arising

3.1 None.

4. Declarations of Interest

4.1 None.

5. Public Questions

5.1 None.

6. Amendments to the Integrated Care Partnership Terms of Reference

6.1 Members received a report that noted necessary amendments to the Integrated Care Partnership Terms of Reference following changes to Cabinet roles at Norfolk County Council.

6.2 The Integrated Care Partnership **RESLOVED** to **agree** to the revised version of the Integrated Care Partnership Terms of Reference.

7. Ageing Well Priorities

7.1 Patricia Hewitt, Chair of Norfolk and Waveney Health and Care Partnership and NHS Norfolk and Waveney Integrated Care Board, introduced the annexed report (item 7). She highlighted the importance of supporting people to age as well as possible to give them a healthy life expectancy.

Shelia Glenn, Director of Planned Care & Cancer, Norfolk, and Waveney Integrated Care Board presented members with an overview of the report. They shared the goal to develop a shared vision and strategy with older people that will help transform services to be proactive, easy to access, and wrapped around the needs of older people. This would be even more important in years to come as Norfolk's aging population would increase. The strategy would be co-produced and a road map would be developed in March 2024. A large workshop had already been undertaken to understand the needs of elderly people. Additionally, best practices nationally and internationally have been drawn on to ensure that best practice was where it needed to be and to ensure that the contents of the strategy would be supported by evidence. Work was also being done to identify the services that were already available to older people and the strategies that were in place at District Councils and NCC to identify gaps and areas of best practice.

7.2 The following points and comments were discussed:

- The Chair highlighted that all parts of the system had a place in the work to transform the service for elderly people.
- A member shared anecdotal evidence that illustrated the difficulties in accessing a blue badge to highlight the challenges, and barriers, that existed with joined up working.
- It was felt that the roadmap and delivery plan needed to make use of existing strategies and ensure that the system was working towards the same aims that were supported by robust measures.
- The importance of looking at the role of the whole community and issues such as recruitment and the relocation of young people was mentioned.
- Members asked how we connect people to be more social, especially those people that experience rural isolation, and engage with the provisions being provided and promoted by

District Councils and NCC.

- The categorisation of the stages of ageing was noted as being helpful and would be beneficial in determining the strategy and clinician direction.

7.3 The ICB **agreed** to:

a) **Endorse** and support the Ageing Well aspiration, 7 priority areas and 3 classifications of ageing.

b) **Note** the proposal to co-create the Older People's strategy by end of December 2023.

c) **Receive** further reports on the development of the Older People's strategy and progress against delivering the ageing well priorities.

8. Right Care, Right Person – Norfolk & Waveney Implementation

8.1 Assistant Chief Constable (ACC) Nick Davison, Norfolk Constabulary, introduced the annexed report (item 8) that was co-produced with Mark Payne, Head of Mental Health, Norfolk & Waveney Integrated Care Board. A project group had been established in Norfolk. They highlighted that the Right Care, Right Person had been divided into four areas; concern for welfare, walk out of health care facilities, absent without leave from mental Health establishments, transportation of patients and Section 136 of the Mental Health Act, as well as voluntary mental health patients. Each area of the project had a scheduled implementation date and learnings were being used from Humberside Police to ensure that the correct training and systems are in place ahead of implementation. They assured members that this was not the police walking away, they still had their statutory responsibilities and would still be attending calls when they were the most appropriate agency to do so. There would also monitoring and overview of the implantation of the Right Care, Right Person policy. ACC Nick Davison offered to present the changes to organisations, senior leadership, and practitioners.

8.2 The following points and comments were discussed:

- A member raised concerns that the Integrated Care Partnership covered Waveney, but that Suffolk were making their changes at a different time to Norfolk. In response, the partnership heard that they were not aware of any issues that would come from differences in timing of implementation. Suffolk Constabulary had representation in the project meetings and plans and Suffolk Constabulary can manage the difference between the Right Care, Right Person policy implementation dates.

- Work would be done with clinicians, leaders and management structures to ensure that polices and resources are being used correctly. It was felt that understanding the policies that already existed in this area would ensure that the police were only involved when it was appropriate.

- Members were reassured to hear that the work being completed was a joined up, multi-agency approach and not just the police and mental health trust.

- Members asked questions about how this information would be shared with the public, and were assured that there was a joint communication plan for the community and public.

- Having executive sign off would give assurance that the responsibilities are known, and changes can be understood and implemented. The impact of the changes would be monitored, and feedback would be fed back into the system.

8.3 The ICB **agreed** to:

a) **Note** the progress made with planning for the implementation of RCRP, and partner organisations are asked to continue to engage with and provide the resources required to support this work.

b) **Note** that RCRP will impact on partner organisations differently and that each organisation will need to understand its own legal framework, responsibilities, and discharge of these to support RCRP.

9. Integrated Winter Plan for 2023/24

9.1 Debbie Bartlett, Norfolk County Council, Interim Executive Director Adult Social Services, introduced the Integrated Winter Plan for 2023/24.

9.2 Suzane Baldwin, Assistant Director Workforce, Markets and Brokerage, Adult Social Services, Norfolk County Council, and Rachel Peacock, Winter Director, Norfolk and Waveney Integrated Care Board presented the annexed report (item 9). The importance of partnership working to alleviate and address the seasonal challenges to help support communities to remain resilient, address inequalities, and prioritise prevention was highlighted. The themes and priorities of the Winter Plan and the mechanism for identifying and dealing with pressures across the system were discussed.

9.3 The following points and comments were discussed:

- The winter plan aimed to join up the work that was happening at county and local level to ensure that people are aware of the support available. Members heard that there was no additional funding to explore extending services such as District Direct. The Chair asked that extending District Direct to a 24-hour service be fedback as an aspiration.

9.4 The ICB **agreed** to:

a) **Endorse** the plan and work being carried out to support the system and residents of Norfolk and Waveney during the coming winter months, and for partners to commit to working collaboratively to promote and support the plan.

b) **Support** the development of a set of system winter metrics that identify areas of whole-system collective action outlined in this document's winter framework, to support partners in collectively identifying and addressing challenges as they arise over winter.

10. Respiratory Disease: Public Health outcomes and prevention priorities for the system

10.1 Stuart Lines, Director of Public Health Norfolk County Council, introduced the report that highlighted the inequalities and disparities across Norfolk about respiratory disease.

10.2 Dr Abhijit Bagade, Consultant in Public Health Medicine, presented the annexed presentation (item 10, appendix A). They highlighted the impact of location on health indicators, the importance of life expectancy indicators in capturing life experiences, the impact of respiratory related deaths, and the need to focus on target areas such as smoking and housing. The link in the presentation was incorrect, members would receive an updated link

10.3 The following points and comments were discussed:

- People living with Asbestosis are likely to be in touch with health and social care teams. The amount of people living with asbestosis was not known but could be explored.

- Education around improving air quality in the home to prevent dampness and mould was mentioned as a piece of work that could be beneficial. Members heard that Environmental Health Officers and Housing Officers would be best placed to be involved and share that type of information.

- The member for the Borough Council of King's Lynn & West Norfolk shared that Kings Lynn & West Norfolk had been promoting energy efficiency schemes that were available to private and social housing tenants. The Director of Public Health noted that signposting to available grants and schemes was important and would inform part of the winter planning preparations.

- The Norwich Place Board had been considering respiratory health and felt that a collaborative approach was needed to tackle the issues.

- Regulations have been successful in reducing the number of people smoking but new issues have emerged with the increase in vaping.

Patrick Peal left the meeting at 12:47

10.4 The ICB **agreed** to:

Endorse that ICP partners to work together to improve respiratory health, reduce inequalities and reduce emergency admissions and deaths due to respiratory diseases in Norfolk and Waveney.

Meeting concluded at 12:52.

Bill Borrett, Chairman,
Health and Wellbeing Board

Report title: Combating Drugs and Alcohol Partnerships Annual Report

Date of meeting: 08 November 2023

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

Reason for the Report

In November 2022, the Health and Wellbeing Board (HWB) agreed to provide oversight of the new Norfolk Drugs and Alcohol Partnership (NDAP). This partnership includes the following members:

- 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 and
- District Councils.

This annual report seeks to update the Board on priorities, progress and work underway by NDAP and to give a brief overview of the equivalent Suffolk Combating Drugs Partnership (SCDP). It is requested that the Board provides its endorsement of the current work and agreement to continue work to reduce the risks presented by new synthetic opioids.

Report summary

Norfolk Drugs and Alcohol Partnership (NDAP): Since it was set up last year, NDAP has considered initial data, agreed four key priorities and progressed on a number of workstreams in a context of high ministerial interest in the progress of local combating drugs partnerships in delivering the national drugs strategy. Progress and work underway on workstreams is reported. The risk of new synthetic opioids is also highlighted, and recommendations are made to the Health and Wellbeing Board to help reduce the risk posed by their availability and impact.

Suffolk Combating Drugs Partnership (SCDP): The SCDP is working to improve collaboration between agencies to ensure the delivery of the national drug strategy ambitions. The partnership is reshaping the local Delivery Plan and the action plan for drug and alcohol related deaths.

Recommendations

The HWB is asked to:

a) Endorse the workplan of NDAP and acknowledge the work of the Suffolk Combating Drugs Partnership in relation to the Waveney part of our ICS.
b) Encourage partner organisations to ensure relevant staff take part in the NDAP joint training programme once this has been agreed. This will be staff that may be working with individuals or families that are experiencing substance misuse issues in the course of their day-to-day work.

c) Ensure partner organisations participate in the Local Drug Information System (LDIS) by sharing intelligence relating to drugs in circulation with CGL and disseminating patient safety alerts relating to drugs within their organisations.
   For those organisations not already signed up, take advantage of distribution and training on the administration of Naloxone by CGL. **Naloxone is a medicine which can reverse opiate overdose.*
d) Support their organisations to identify drug and alcohol users in their care and support them to engage with drug and alcohol treatment to reduce risk.
e) Endorse their organisations and contracted providers finding ways to collect and share appropriate pseudonymised data on non-fatal overdoses and administrations of Naloxone in order to track the impact of opioids, alert the system to emerging trends and target potential supply lines.

1. Background

1.1 The Health and Wellbeing Board agreed on 9 November 2022 to the formation of a new Norfolk Drugs and Alcohol Partnership 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. The Board also had an update from the Suffolk Combating Drugs Partnership, which is part of the Norfolk and Waveney ICS. The Board delegated the sign off of the Norfolk Terms of Reference to the Chair of the HWB, which he has since done. This included the addition of a joint Serious Violence Duty and NDAP Programme Group to enable closer joint working between the two workstreams.

2. Progress updates

2.1 Norfolk Drugs and Alcohol Partnership

2.1.1 Ministerial interest in progress against the national drugs strategy is understood to be high. Due to its size, Norfolk has the 6th largest adult treatment population of all the Upper Tier Local Authorities in England and has the 8th largest 18+ resident population. This makes it more visible in terms of national scrutiny and a programme of work, supported by the Office of Health Improvement and Disparities (OHID), is underway to increase numbers in treatment and improve prison continuity of care (one of NDAP's agreed priorities – see below).

2.1.2 After considering the data and results from several engagement exercises, **four key priorities** were agreed for the first year of the partnership. These have run alongside several other supporting workstreams. The NDAP Strategy Group acknowledged that there is other important work being carried out within the partnership but wanted to focus on a smaller number of key priorities in the first year. The four agreed priorities and progress on other workstreams are shown in **Appendix 1**. It should be noted that there are no additional financial implications from the agreed priorities and workplan.

2.2 Synthetic Opioids

2.2.1 HWB Board members may be aware that there is growing concern about synthetic opioids* being introduced to the UK drugs market, including more recently nitazenes, which can be significantly stronger than heroin and when taken at the same dosage have the potential to result in fatal overdose. Synthetic opioids are often found mixed with other drugs.
** Synthetic opioids are man-made drugs which mimic the effects of natural opioids such as heroin and morphine.*

2.2.2 Drug treatment is a key tool to support people to avoid harm and death, along with the provision of Naloxone to reverse opioid overdoses that occur. Naloxone can be carried by

people at risk of overdoses or those who are likely to witness an overdose e.g., police, family and friends. Naloxone can be obtained by organisations, community groups and individuals from any of the Change Grow Live (CGL) hubs in Norwich, Thetford, Great Yarmouth, and King's Lynn. Many Norfolk police officers carry naloxone and have deployed it to reverse overdoses.

2.2.3 A National Patient Safety Alert for potent synthetic opioids was issued in July 2023 by OHID. CGL and other national organisations have issued drugs alerts. Information has been shared at relevant forums across Norfolk. Agencies in Norfolk including the Police, drug and alcohol services, Norfolk County Council's Public Health team and local NHS partners are working together to identify trends and themes in drug usage and drug related incidents in order to reduce the risks to drug users. Sharing data and intelligence across the system is key to reducing harm – for example, data on non-fatal overdoses and the administration of Naloxone, whether in A&Es or on scene by ambulance.

2.2.4 **Case study:** Over a two-day period in August, four overdoses were reported in Norwich, fortunately non-fatal, thanks to the deployment of Naloxone by Police Officers from Norfolk Constabulary. The local response was informed by national reports on the rise in drug deaths due to potent synthetic opioids, including nitazenes. Following the fourth overdose, the Constabulary's County Lines team recovered remnants of the drug involved, and intelligence indicated this was supplied by a particular county line operating from London. A London drugs runner was found in Norwich with around 100 wraps of the drug which was later confirmed by a specialised lab as containing nitazenes. The London-based County line holder was found with a supply of drugs, arrested by the Metropolitan Police and brought to the Wymondham Police Investigation Centre where both the runner and line holder were charged and remanded, ending this particular supply of nitazenes. In the week leading up to the overdoses, CGL had sent out a warning message to their clients about a possible strong synthetic batch of drugs circulating in the area, and the police had also sent a message to users known to be in contact with this county line to help reduce the potential harm from these drugs. Intelligence proved critical in informing the local response, highlighting the need for sharing amongst partners locally and nationally.

* Synthetic opioids are man-made drugs which mimic the effects of natural opioids such as heroin and morphine.

2.2.5 Information on the Suffolk Combating Drugs Partnership is shown in Appendix 2.

Officer Contact

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

Name: Diane Steiner Tel: 01603 638417 Email: diane.steiner@norfolk.gov.uk

Priority: Dual Diagnosis (DD)
Overview: Develop pathways that support engagement, treatment and recovery for people experiencing both mental health and substance misuse issues.
Update:

- DD now included in ICBP Joint Forward Plan.
  Workplan has been agreed and 7 task and finish groups are now being established with representatives including the Integrated Care Board, Primary Care Networks, Norfolk and Suffolk Foundation Trust, Change Grow Live, the Voice of lived experience and other community providers.
  On target to deliver joint CGL/NSFT pathway in year one.

Priority: Continuity of Care (CoC): Prison to Community Treatment
Overview: Ensure that those moving between prison and community treatment do not fall through the gaps at a particularly vulnerable time.
Update:

- Multiagency group established
- Review and quality improvement activity - process, tools, and pathways.
- Data quality improvement plan underway.
- System Criminal Justice workforce capacity increased.
- CoC transfers are currently above national average at 48%.
- 2 x additional probation funded Dependency and recovery workers recruited to work across the Criminal Justice System (CJS).

Priority: Workforce development
Overview: Identify if staff have access to appropriate training and if gaps are found, to develop appropriate packages of training.
Update:

- Initial focus Mental Health and Substance misuse workforce.
- Training audit has been launched and cascaded across the mental health workforce.
- Synthetic Opioids training being explored.

Priority: Project ADDER expansion
Implement best practice on enforcement, treatment and recovery from the Greater Norwich Adder pilot (which focused on heroin and crack users in contact with the criminal justice system) to the rest of the county and including alcohol and recreational drugs.
Update:

- County wide CJ team now in place.
- Training audit complete.
- Single Point of Contact (SPOC) in place
- Buvidal* now available for all Criminal Justice clients.
- Prison in-reach workers currently undergoing vetting.
- 2 ADDER Youth workers based in Wymondham Police Investigation Centre (PIC) seeing 90% of CYP detained.

* Buvidal is a long-acting medicine used to treat dependence on opioid drugs such as heroin or morphine. This means it can be used in a controlled way to help prevent withdrawal symptoms and reduce the urge to misuse other opioids.

NDAP Stakeholders:

- Norfolk County Council,
- Norfolk Public Health,
- Norfolk Fire and Rescue Service,
- Norfolk Constabulary,
- District and Borough Councils,
- National Probation Service,
- HM Prison Service,
- Department of Work and Pensions,
- Voluntary Norfolk,
- NHS England,
- Norfolk and Waveney Integrated Care Board,
- Change, Grow, Live,
- The Matthew Project,
- Norfolk and Suffolk Foundation Trust.

Current work and progress of key workstreams

Workstream: Drug and Alcohol Related Deaths
Overview: Reduce the number of drug and alcohol related deaths in Norfolk.
Update:

- Local Drug Information System (LDIS) managed by CGL is in place and is working well.
- First Drug and Alcohol Death Review Panel held September 2023.
- Roll out of QES (automated case management system) estimated November 2023.
- Work is underway with Norfolk's three acute Trusts and EEAST to agree information sharing pathways related to non-fatal overdoses (NFOs)
- Nitazenes/synthetic opioids - emerging national issue.
- Police trained and carrying Naloxone overdose reversal drug – used successfully on nine occasions to date.

Workstream: Joint NDAP and Serious Violence Duty (SVD) Programme Group
Overview: Combined Serious Violence Duty and NDAP Programme groups to better facilitate joint working across these areas.
Update:

- Regular meeting schedule in place.
- NDAP, serious violence duty, safeguarding partnership and safeguarding boards are joined by their membership of the Norfolk County Community Safety Partnership.

Workstream: Service user voice
Overview: Ensuring User Voice is intrinsic to all aspects of the NDAP work.
Update:

- Capacity to engage with User Voice being commissioned by Public Health - provider expected to be in place Jan 2024.

Workstream: NDAP Joint Needs assessment
Overview: Conduct a joint assessment of evidence and data to understand better the local issues and patterns of drug and alcohol related harm.
Update:

- JNA is underway - will be used by the Strategy Group to develop a five-year vision, ambitions, key actions, and outcome metrics.
- Outcomes dashboard, aligned to the national drugs strategy outcomes framework is under development.

Workstream: County lines
Overview: Reduce the number of County Lines operating in Norfolk.
Update:

- County Lines Group has shifted its work into the joint SVD/NDAP Programme Group.
- Number of active county lines operating in Norfolk decreased by two-thirds from 2019 to 2022.
- 132 County Lines investigated, 94 closed and total sentencing of 400+ years.

Workstream: NDAP coordination
Overview: Coordination of the NDAP work to ensure successful delivery of the national strategy and outcomes.
Update: Recruitment to post underway.

Item 8, Appendix 2: Suffolk Combating Drugs Partnership - for information only.

The Suffolk Combatting Drug Partnership continues to deliver on the key priorities in line with the National Drug Strategy published in December 2022:

Breaking the drug supply chain by working with the criminal justice system to support victims into recovery services, safeguarding and reducing drug-related deaths. Mainly being delivered through the countywide criminal exploitation work programme. Enforcement remains a key focus, but recent activity also centres around the importance of multi-agency intelligence to better understand demand and the ability to target resources to areas of greatest need.

Collaborate with the treatment and recovery services to strengthen local authority commissioned substance misuse services for both adults and young people, improving quality, capacity, and outcomes.

Suffolk is meeting targets for adults in structured treatment and access to rehabilitation services, but further work is required to meet continuity of care targets. Work is underway to increase the number of young people in treatment.

Monitoring drug-related deaths and working with relevant services to avoid reoccurrence of drug misuse and achieve a generational shift in the use of recreational drugs.

There is an increase in drug related deaths and overdose incidents involving synthetic substances being mixed with opioids that are appearing nationally. Suffolk drug and alcohol teams are collaborating closely with OHID and key partners locally to ensure harm reduction and interventions are being deployed. The Suffolk Drug Alert system is being well utilised to cascade information quickly and efficiently.

Workforce Development
The NHS Benchmarking Network (NHSBN) second annual census has been completed which analyses the workforce currently employed in alcohol and drug treatment and recovery services; lived experience recovery organisations (LEROs) and in local authority (LA) alcohol and drug commissioning teams in England. This will support NHS England Workforce Training and Education Directorate (WT&E) and Office of Health Improvement and Disparities (OHID) to build a comprehensive national workforce profile to inform the next spending review and then monitor changes.

Co-Occurring Conditions (Dual Diagnosis)
Work is underway to develop a dedicated workstream that will bring together key stakeholders, identifying priorities informed by service user experience and partner organisations. Suffolk are attending equivalent dual diagnosis workstreams operating in Norfolk and Waveney.

Report title: Driving Integration Through Digital, Data and Technology

Date of meeting: 08 November 2023

Sponsor (ICP member): Tracey Bleakley, Chief Executive, Norfolk and Waveney Integrated Care Board (ICB)
Debbie Bartlett, Interim Executive Director, Adult Social Services, Norfolk County Council

Reason for the Report
This paper is provided to describe 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 information regarding the current ICS digital maturity and capabilities, reflects on the digital roadmap for further integration and sharing and considers capacity and barriers for doing more.

Report summary
The Digital, Data, Technology and Information Governance professional communities across the Integrated Care System (ICS) have been working closely for some years now and as a result many of the conditions required to enable successful systems integration, data sharing and joined up working are in place, though some barriers still exist. There is effective governance and collaboration established to deliver against the digital roadmap which is described below and illustrated in the presentation.

The two main areas of Integrated Care System (ICS) level digital delivery which are now partially live and progressing positively towards full adoption are Shared Care Records and the Data Hub (previously known as the HCDA). These two projects are good examples of how we are building on solid foundations across many of the ICS organisations and sharing data to enable greater operational efficiency and effectiveness and improved operational and strategic decision making. It should be noted however that the absence of an Electronic Patient Record in the 3 acute hospitals and current use of non-integrated systems and even paper-based systems is a significant current barrier to data sharing.

It is important to also consider the digital skills of the staff and residents who can benefit from the introduction of online, joined up data and systems. This is why we are sharing capacity between Norfolk County Council (NCC), the NHS parts of the ICS plus voluntary communities to digitally upskill our staff and identify and help Norfolk residents who are digitally excluded.

It should also be noted that great technology and enabling data sharing agreements alone do not improve services or efficiency, they need to be accompanied by new ways of working within and across organisations. This is why it is very important that the digital and data committees work closely with the transformation community and that our digital programmes enjoy full engagement and support from the relevant business and practitioner communities.

Barriers to realising the full benefits of systems integration and data sharing are primarily capacity (both financial and DDaT people). The absence of an Electronic Patient Record (EPR) system in the three acute hospitals is a major challenge, where systems are not joined up within an organisation (and data is sometimes paper based) then they cannot easily be shared across the ICS.

The final barrier to highlight is an ICS wide capacity, skills and culture challenge. To overcomes these blockers, ICP system leadership, change enablers (such as Digital) and practitioners al need to be willing to prioritise this work and take risk aware decisions to open up and share data assets for the benefit of the wider system.

Recommendations

The ICP is asked to:

a) System Leaders will commit to the idea of data sharing.
b) Support the use of new joined up systems such as the Shared Care Record System and the Data Hub, as they become available in partnership organisations, to deliver the maximum value from these enabling technologies.
c) Direct the ICS Digital leadership to report back to the board in 2024/25 with a progress update on the ICS Digital Roadmap delivery.
d) Direct the ICS Digital leadership to return to the ICP board with more detailed analysis of the benefits expected and / or achieved from individual projects on the roadmap as required.

1. Background

1.1 The Shared Care Records Project has been introduced to the board in the past, but this is the first time that the wider ICS Digital Roadmap has been presented.

2. Digital Overview

2.1 Digital systems and associated data sharing can enable ICS organisations to improve their efficiency and effectiveness but also work in a more joined up, coordinated, collaborative manner. They can also help our residents and patients to self-serve, look after themselves better and live at home independently for longer.

2.2 There is an established, solid foundation of joined up systems and professional communities which enables considerable joined up working at present, in particular staff working jointly under section 75 agreements. Though more can be done to make this more seamless. Capacity challenges and the absence of some integrated systems do however represent barriers to full scale rollout.

2.3 There are a number of jointly resourced major projects underway and planned which can be seen on the digital roadmap in the presentation. These projects are the things we are doing together as an ICS and they have the potential to dramatically improve our productivity and effectiveness as an ICS.

2.4 The ICS digital roadmap work is only a fraction of the overall digital and data related workload for the ICS as each individual organisation has a significant programme of change to deliver. It should also be noted that this digital change workload is over and above the capacity required to maintain both the modern and legacy infrastructure needed to support existing ICS operations.

2.5 Skills and capacity in ICS organisations are already operating at around full capacity and the ICS digital strategy and roadmap is not currently fully funded. Funding when it does come is often capital only and arrives late in the year with little time left to use it effectively. This must be factored in when considering adjustments to the published digital roadmap.

2.6 The introduction of Electronic Patient Record (EPR) systems in the three acute hospitals will enable much greater systems and data integration. However, this is a huge digital and

organisational change programme which will take considerable time and capacity to deliver. In the meantime many systems are not integrated and in some cases are paper based.

2.7 The information governance community which works alongside digital and technology staff to enable lawful and ethical data sharing is well established and takes a “can-do” enabling approach. Barriers to data sharing have tended to be less to do with the Information Governance (IG) profession and more often be cultural or capacity challenges. IG and technical (IT) complexity does of course slow down the pace of change but not as much as the lack of willingness and capacity to commit resources to design and implement new ways of working enabled by data sharing.

2.8 The absence of an EPR system in the three acute hospitals is a challenge, because where systems are not joined up within an organisation (and data is sometimes paper based) then they cannot easily be shared across the ICS. Over £150m investment has recently been secured to implement three instances of an EPR but the effort required to support this change cannot be overstated and so we need to be realistic regarding how much capacity the hospitals will have to support other concurrent digital change initiatives.

2.9 ICS wide capacity, skills and culture also present a challenge, preventing wider benefits from data sharing. First, there needs to be a business understanding of how data-sharing can enable new ways of working which leads to better outcomes, then commitment to implement the necessary changes. This means ICP system leadership, change enablers (such as Digital) and practitioners need to be willing to prioritise this work, take risk aware decisions to open up and pool data assets for the benefit of the wider system.

2.10 Digital Skills of staff will need significant investment (of time and money) to enable the full benefits of the technology & data sharing investments to be realised.

2.11 The digital systems, technology and joined up data sets will only achieve their full potential benefits when they are used effectively within organisations and across the ICS. Our staff must therefore be made aware of the opportunities and given the encouragement, time and support to learn how to use the systems and adapt their processes to take full advantage.

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

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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.

Improving lives **together**

Norfolk and Waveney Integrated Care System

Driving Integration through Digital, Data and Technology

Geoff Connell, Director of Digital Services, Norfolk County Council

Ian Riley, Director of Digital and Data, Norfolk and Waveney Integrated Care Board

For discussion at Norfolk & Waveney Integrated Care Partnership, 8th November 2023

Norfolk & Waveney ICS DDaT Maturity

Improving lives **together**
Norfolk and Waveney Integrated Care System

Foundations:

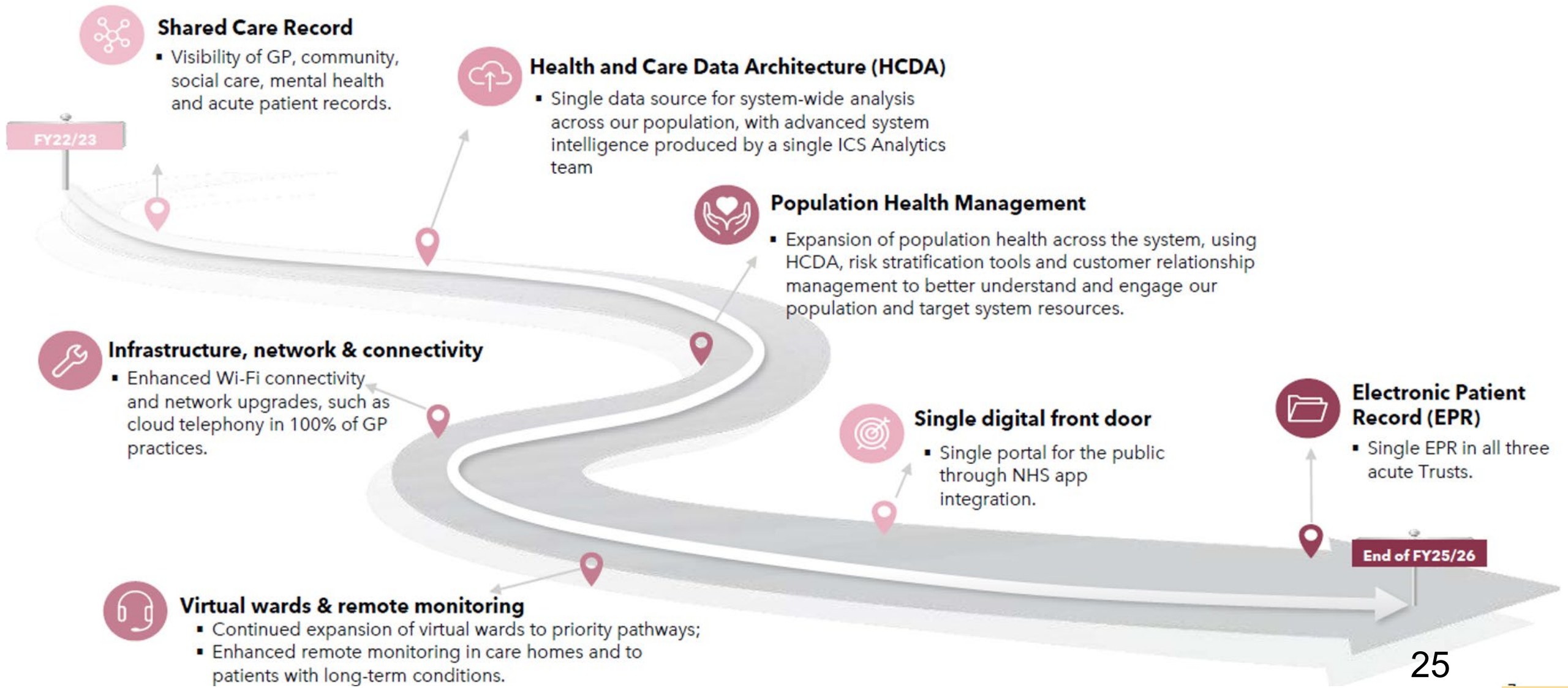
- All large ICS org's use some common components like Microsoft Office 365 with Teams and Azure cloud, enabling a level of joined up day to day working, most use the Govroam Wi-Fi standard so we can connect securely in each-others buildings.
- All except Acutes have EPR/integrated case management systems which provide the platforms for case level data integration (ShCR). The ICS now has a Data Hub intelligence and analytics platform enabling sharing of data for joined up reporting and analytical purposes, this is backed by a capable and effective information governance community.
- Capacity across DDaT professional is limited and delivery of the current ICS Digital roadmap as well as individual organisations programmes does not allow much scope for additional projects.

Digital Maturity Benchmarking

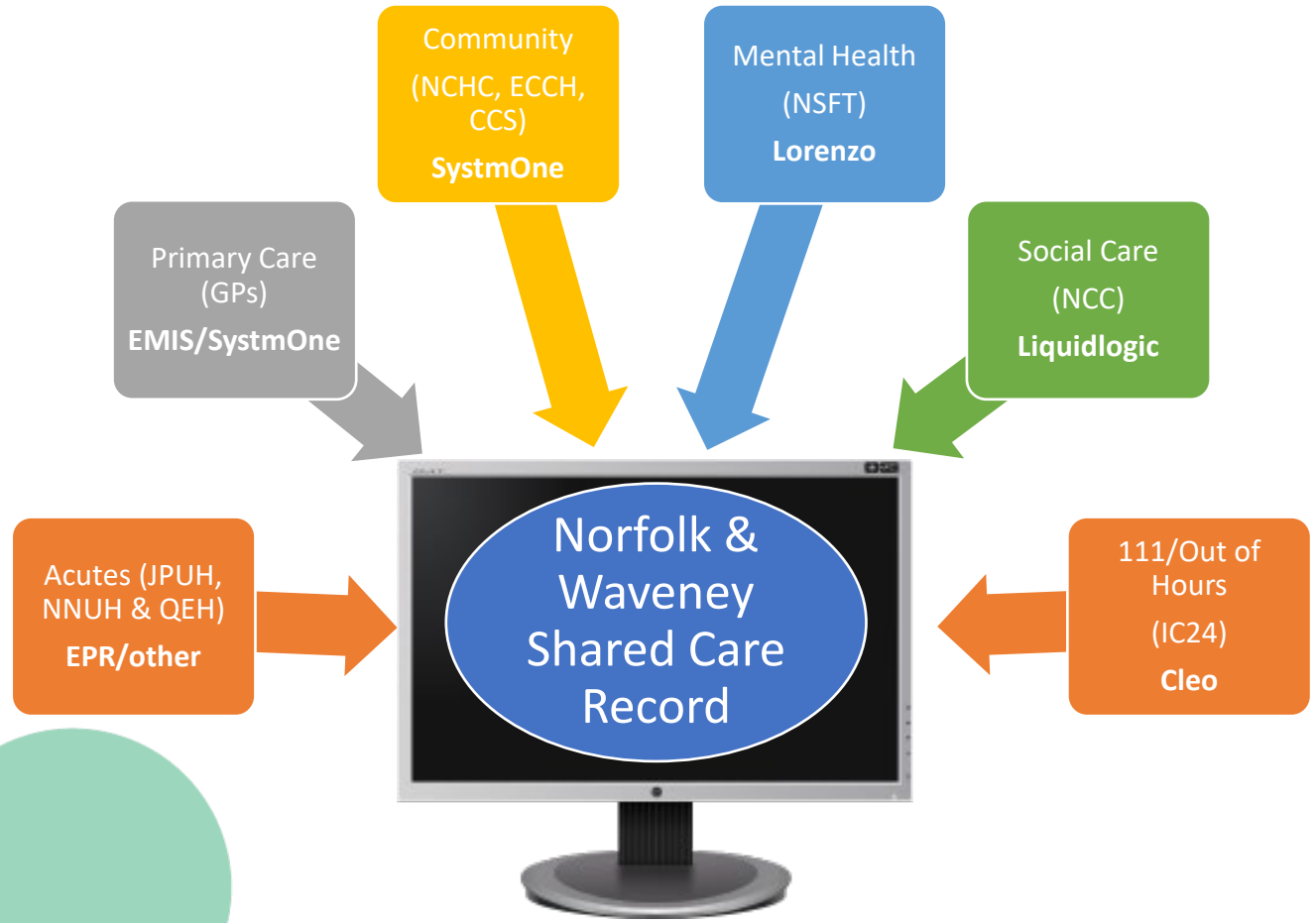
- The recent NHSE Digital maturity Assessment (DMA) survey (July 2023) highlights known issues in our Acutes, which the EPR systems will begin to address, but our other providers benchmark well.
- Our digital maturity will further level up as we continue to roll out elements of the Norfolk & Waveney digital strategy (EPR, ShCR, Data Hub/HCDA) over the next few years.

Strategic Roadmap of ICS Level Digital Initiatives

Digital will enable transformation across all care settings, including outpatients.



Shared Care Record (ShCR) – Tell your story Once



- The shared care record project is now in live use across much of the ICS with more on the way.
- Over 1000 health & care staff can now see real time information from across the partnership, integrated into their usual systems, resulting in better informed decisions, faster responses and greater efficiency leading to better outcomes.
- It also means our patients and citizen do not have to keep repeating their story.

Already Live:

Viewing: NCC (Adults & Children), ECCH, NCHC, CCS, IC24, NSFT, NNUH, QEKL, JPUH (pilots in Acute Hospitals).

Providing Data: GP Connect, NCC (Adults & Children with an active case).

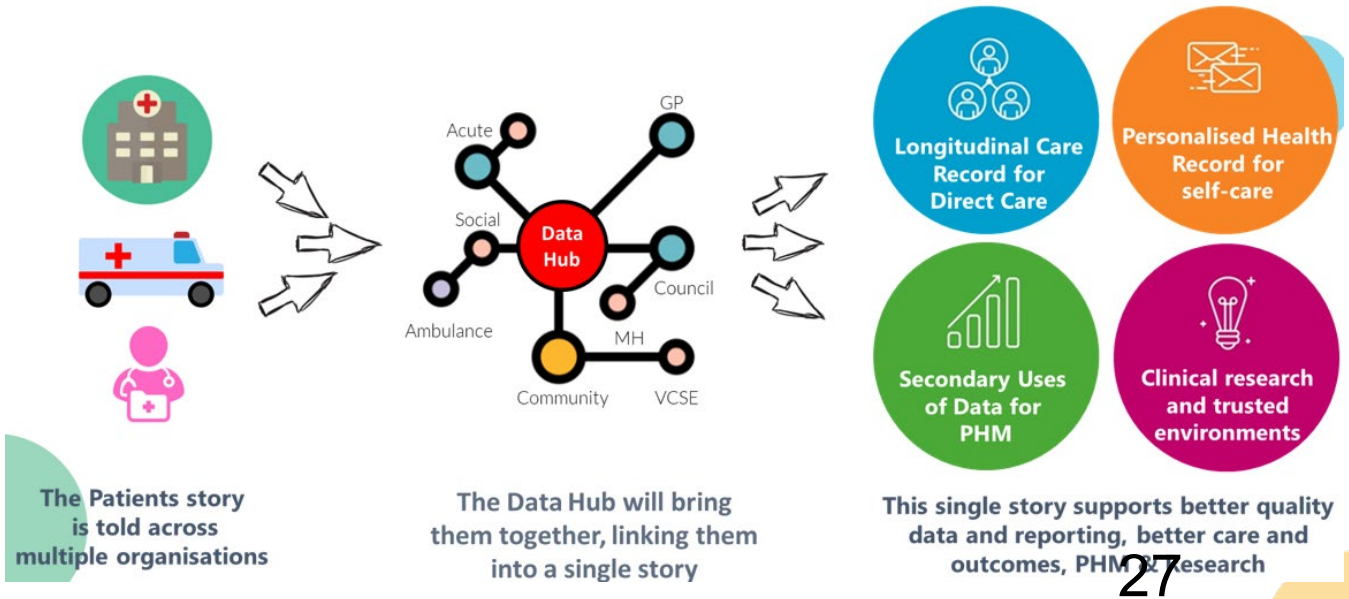
https://improvinglivesnw.org.uk/our-work/healthier-communities/digital/shared-care-record/

Data Hub (HCDA) work and Population Health Management (PHM)

The health and care needs of Norfolk and Waveney residents are changing: our lifestyles are increasing our risk of preventable disease and are affecting our wellbeing, we are living longer with more multiple long-term conditions like asthma, diabetes and heart disease – and the health inequality gap is increasing.

Population Health Management is a way of working to help frontline teams understand current health and care needs and predict what local people will need in the future. This means we can deliver better care and support for individuals, design more joined-up and sustainable health and care services and make better use of public resources.

The PHM programme in N&W is supported by the DATA HUB (formerly HCDA) programme which links historical and current data sets from health and care providers to support the understanding what factors are driving poor outcomes in different population groups. Local health and care services can then design new proactive models of care which will improve health and wellbeing today as well as in future years' time.



Digital Inclusion – Leaving no one behind

We are building on the excellent ‘tech skills for life’ & place based pilot work by NCC to ensure every Norfolk resident is provided with the appropriate digital access opportunities to meet their needs and enable them to be digitally included in all aspects of their lives. If we don’t get this right we will increase inequalities and reduce outcomes as services digitise

Working in partnership to target activity and make best use of resources

Enabling universal access to connectivity in the county

Supporting access to devices and equipment

Increasing digital skills and confidence in key cohorts

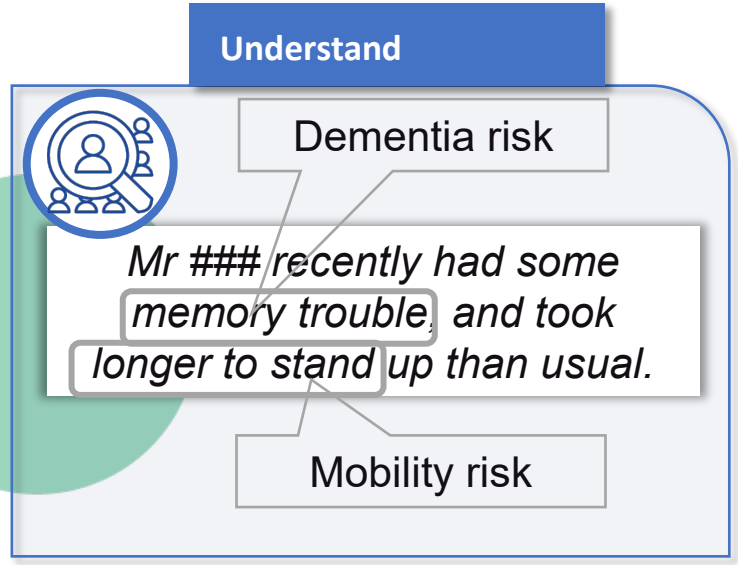
Developing the skills of our staff to understand how to support residents to access and use technology to improve their lives

Proactive Intervention – using AI / machine learning

Transform the way in which Norfolk offers support to its residents.
Move from reactive, formal support towards more proactive, targeted, and preventative support.
We're starting by testing our new capability with people at risk of a fall.

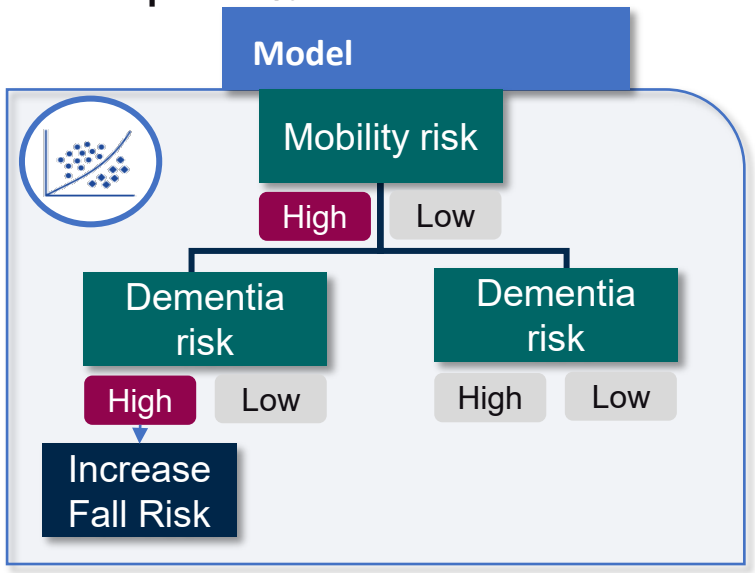
Understand

Extract information from written case notes (social care in phase 1, incorporating South Norfolk district in phase 2). **Use natural language processing** to automatically understand key health, care and lifestyle risks from case notes.



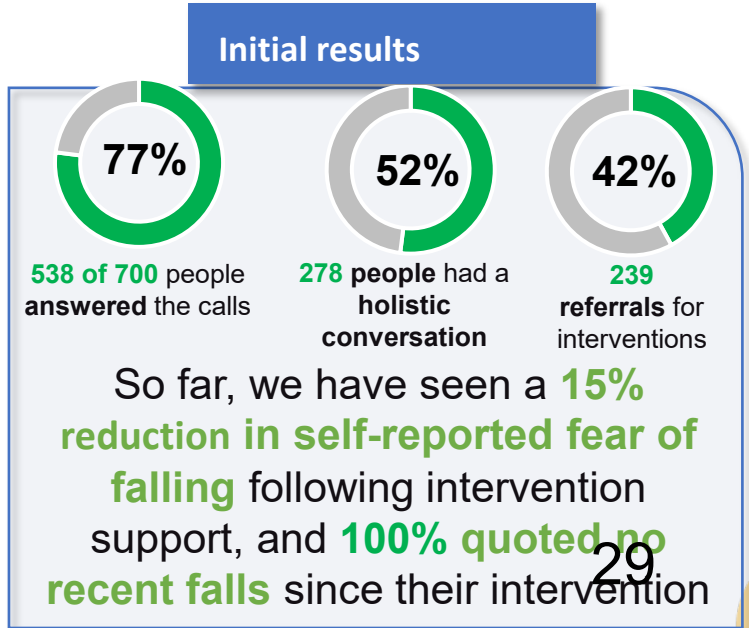
Model

Using historical data, our AI model assesses thousands of relationships between risks and the likelihood of falling to identify which combinations of risks are the best predictors of a fall. It then makes a prediction for every individual. **Tests show the model is correct up to 70% of the time.**



Contact and intervene

Intervening to mitigate the risk – Contacting identified people (via NHS Protect Now and District Help Hub) and offering interventions including environmental adjustments, mobility, isolation support and health interventions.
We are Identifying opportunities to expand and embed the approach.



Next Steps & Recommendations

Next Steps

- The ICS Digital Community will continue to deliver against the published roadmap plus local workloads and will also seek additional funding for projects which would provide additional capacity where the projects take forward the strategy.

Recommendations

1. System Leaders will commit to the idea of data sharing.
2. To support the use of new joined up systems such as the Shared Care Record System and the Data Hub, as they become available in partnership organisations, to deliver the maximum value from these enabling technologies.
3. To direct the ICS Digital leadership to report back to the board in 2024/25 with a progress update on the ICS Digital Roadmap delivery.
4. To direct the ICS Digital leadership to return to the ICP board with more detailed analysis of the benefits associated with individual projects on the roadmap as required.

Report title: Taking action to address health inequalities in Norfolk and Waveney

Date of meeting: 08 November 2023

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

Reason for the Report

Addressing health inequalities is a priority for our system, and much work has been and continues to be done by many partners on the issue. This paper asks the ICP to endorse the approach we are proposing to take to develop a new Strategic Framework for Action for addressing health inequalities.

Report summary

The Norfolk and Waveney Joint Forward Plan includes an objective to develop a Health Inequalities Strategy by the end of March 2024. We want to focus on action, so rather than a high-level strategy, we are proposing to develop Strategic Framework for Action that clearly sets-out what we are going to do to address health inequalities and enables a shared approach allowing all partners to understand how their contributions matter to achieve the shared outcomes. The proposed framework will align with the Transitional Integrated Care Strategy for Norfolk and Waveney, as well as the Joint Health and Wellbeing Strategy Suffolk, build on what we have done to date, and be developed through a programme of 'Health Inequalities Conversations'.

Recommendations

The ICP is asked to:

a) Endorse the proposed design principles for developing the Strategic Framework for Action.
b) Support the programme of 'Health Inequalities Conversations' with stakeholders.
c) Agree to receive and consider a draft of the Strategic Framework for Action in March 2024, with a view to endorsing the framework and agreeing to support its implementation.

1. Background

1.1 The Norfolk and Waveney Joint Forward Plan includes an objective to develop a Health Inequalities Strategy by the end of March 2024. The strategy is to cover how we implement the Core20plus5 national health inequality improvement frameworks, as well as work to address the wider determinants of health.

1.2 We are committed to aligning with the priorities of the Transitional Integrated Care Strategy, as well as other local and national strategic drivers, such as the Norfolk and Waveney Clinical Strategy, which also make a commitment to reducing inequalities.

1.3 Go to improvinglivesnw.org.uk to read the full Joint Forward Plan

2. Developing our strategy

2.1 Design principles

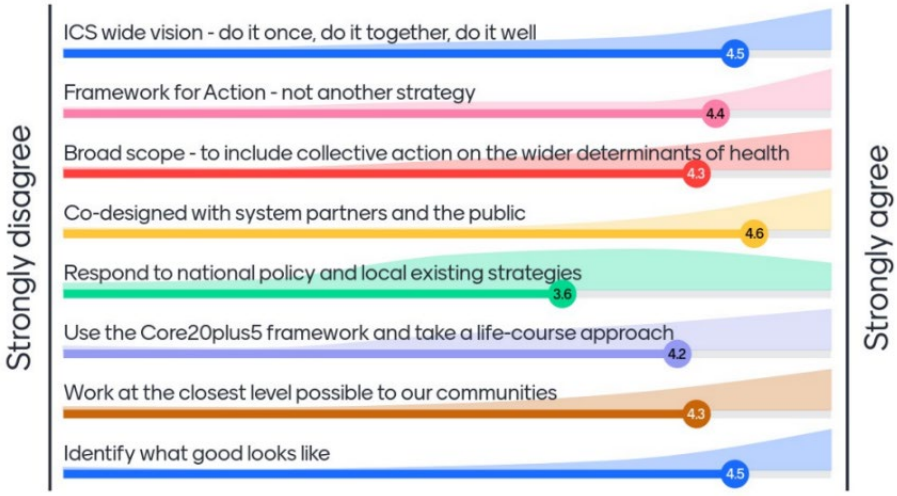
2.1.1 Through the engagement undertaken so far, there is a strong sense of needing to move beyond high-level strategic planning, and to focus on system-wide action. In response to that feedback we are going to produce a **Strategic Framework for Action for Health Inequalities**, that builds on what we have done to date and what partners have already committed to doing.

2.1.2 The development and implementation of this framework will be overseen by the system's Health Inequalities Oversight Group and the Population Health and Inequalities Board. A small taskforce, which includes Public Health representation, has been developed to facilitate a collaborative approach to the framework's design.

2.1.3 The taskforce has developed 10 design principles to underpin the development of our framework, which have been tested in a number of wider stakeholder forums including the Health Inequalities Oversight Group, Population Health and Inequalities Board, ICS Transformation Board, VCSE Assembly Operations Group and District Strategic Leads meeting. These principles were presented to the ICS Conference on Tuesday, 17 October 2024:

1. ICS Vision – do it once, do it together, do it well.
2. Framework for action – not another strategy.
3. Broad scope – to include action on the wider determinants of health.
4. Co-designed with system partners and the public.
5. Build up using existing assets that already exist.
6. Respond to national policy and existing local strategies.
7. Use the Core20plus5 framework and take a life-course approach. Go to England.nhs.uk to read the Core20plus5 framework
8. Work at the closest level possible to our communities.
9. What good looks like will be identified – a baseline and trajectory for improvement.
10. Resourcing will be identified to support implementation.

2.1.4 Delegates at the ICS conference were asked to rate how strongly they agreed with the design principles for the framework listed above. The image below provides an illustrative summary of the agreement levels, which were generally high.

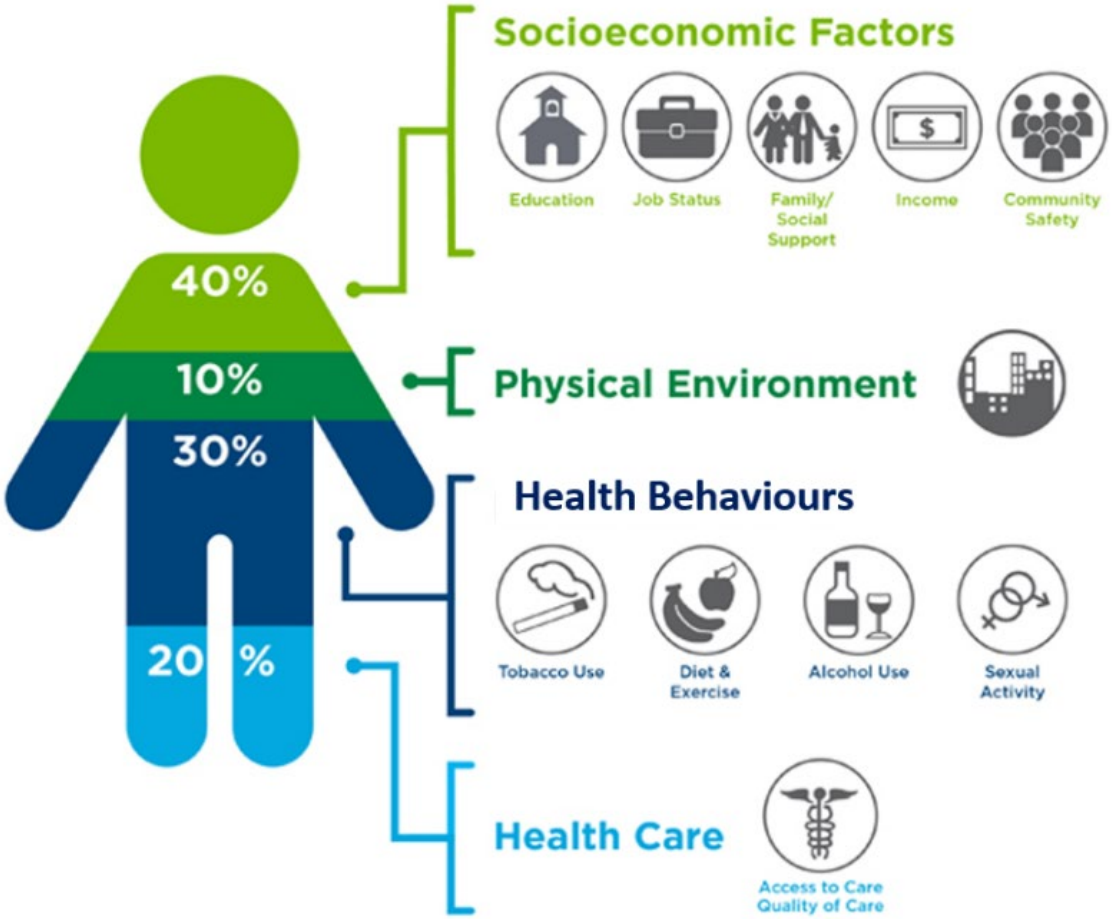


2.2 Implementation of the design principles

2.2.1 The feedback received demonstrates that there is clearly appetite from across the system to work together to reduce inequalities through a shared Strategic Framework for Action, and through the proposed engagement we will work to develop a shared vision or mission statement that we can all adopt.

2.2.2 The approach will include shared action on the wider determinants and lifestyle factors that have a contribution to health. This is vital as access to health and care and the quality of clinical care makes up only 20% what influences a person's longer term health outcomes.

2.2.3 The factors that influence a person's health outcomes are shown in this image below: Socioeconomic Factors account for 40%, Physical Environment accounts for 10%, health behaviours account for 30% and Healthcare Accounts for 20%.



2.2.4 We will work with Public Health colleagues in Norfolk and Suffolk to ensure we have a clear view of our data, existing insights and the evidence base for the impact we can have collectively. We will also seek to highlight where we have 'intelligence gaps' that the framework may need to address.

2.2.5 A programme of 'Health Inequalities Conversations' will be initiated over the next three months with our system partners to inform the development of the framework. We will attend existing fora, such as the Health and Wellbeing Partnerships, Place Boards and VCSE forums, as well as hosting a series of engagement events and workshops and will be developing a toolkit for colleagues that can support us in having these conversations.

2.2.6 The Norfolk and Waveney Community Voices engagement approach, which works with trusted communicators in the VCSE sector and local government, will be utilised to ensure that we include insights from our seldom heard communities, and those experiencing the

greatest inequalities. We will engage people with lived experience throughout the development process and into implementation.

2.2.7 Our engagement will focus on four key themes:

1. Living and working conditions
2. Lifestyle factors
3. Health and care services
4. Creating the conditions for success

2.2.8 We will focus on understanding how we can better utilise our existing assets and resources, scaling what works where possible and establishing principles for the way that we work together.

2.2.9 Further feedback from the ICP conference highlights the need to build a shared understanding of what the system is already doing to tackle health inequalities and to better understand the impact of current approaches. Mapping what we are already doing together will form part of the engagement process to enable us to articulate our start position and baseline.

2.2.10 Resourcing the implementation of a Strategic Framework for Action will require an ongoing conversation with leaders across the Norfolk and Waveney Integrated Care System to further understand the baseline investment position and enable the identification of the required resources to achieve an ambitious shared framework. The ICB is committed to reviewing the position relating to the health inequalities allocation it receives from NHS England through the development of a case for change and would look to systems partners to enable an equally holistic analysis of resources, essential to achieve the framework ambitions.

2.2.11 In summary, there is a commitment to a broad engagement programme to develop the Framework for Action, to enable the necessary collaboration and sense of shared ownership that will be critical for its successful implementation, which we are asking the ICP to support. We would like to bring the draft framework to the March meeting of the ICP to seek endorsement and adoption.

Officer Contact

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

Name: Shelley Ames Email: shelley.ames@nhs.net

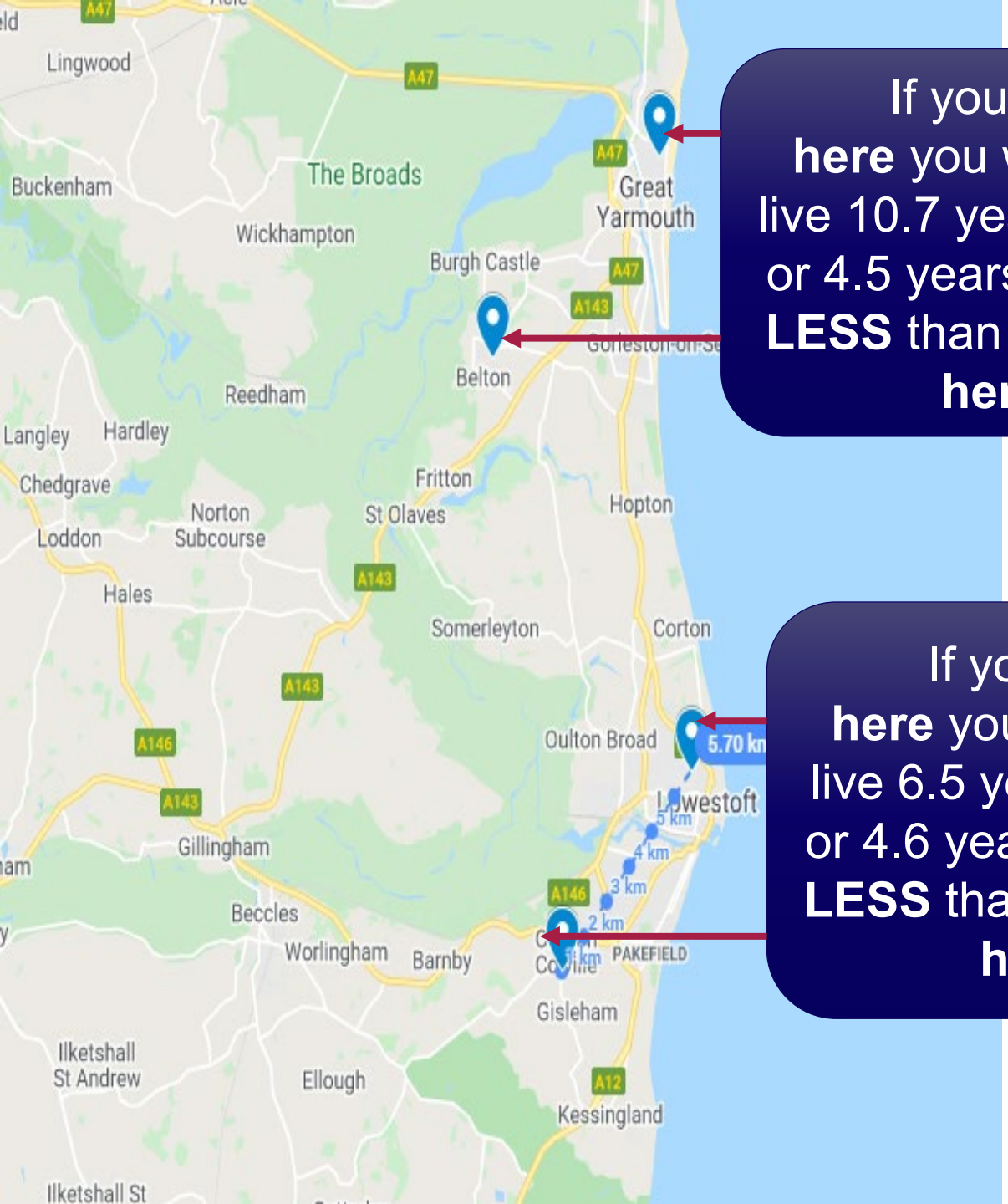
Health Inequalities Conversation

Improving lives together
Norfolk and Waveney Integrated Care System

Developing our health inequalities framework for action

Presented by:

Mark Burgis, Executive Director Patient and Communities, and Senior Responsible Officer for Health Inequalities



If you live **here** you will likely live 10.7 years (male) or 4.5 years (female) **LESS** than if you live **here**

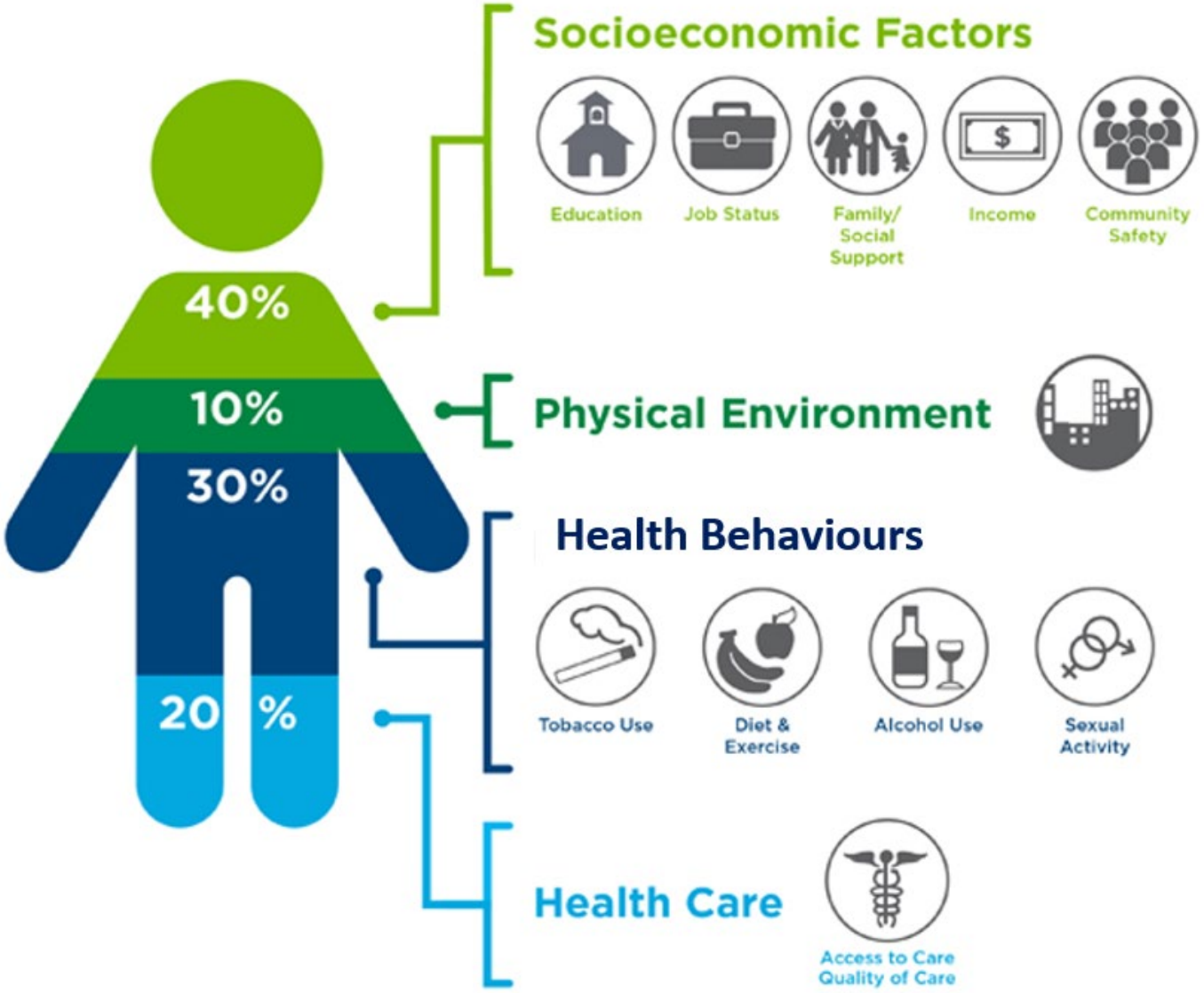
If you live **here** you will likely live 6.5 years (male) or 4.6 years (female) **LESS** than if you live **here**

The Norfolk and Waveney Joint Forward Plan contains an objective to develop a **Health Inequalities Strategy by the end of March 2024.**

Commitment to a whole-system approach that seeks to address the causes of inequalities, moves our focus 'upstream' and supports our most vulnerable communities to access health and care.

Opportunity to develop a **Strategic Framework for Action** that responds to our existing local commitments as well as what our communities tell us they need.

Scope



Partners have agreed a broad scope that seeks to address some of the wider determinants of health

We can't address everything all at once, so we need to work with the system to prioritise. We will also build on previous work.

We will focus our engagement around four key themes:

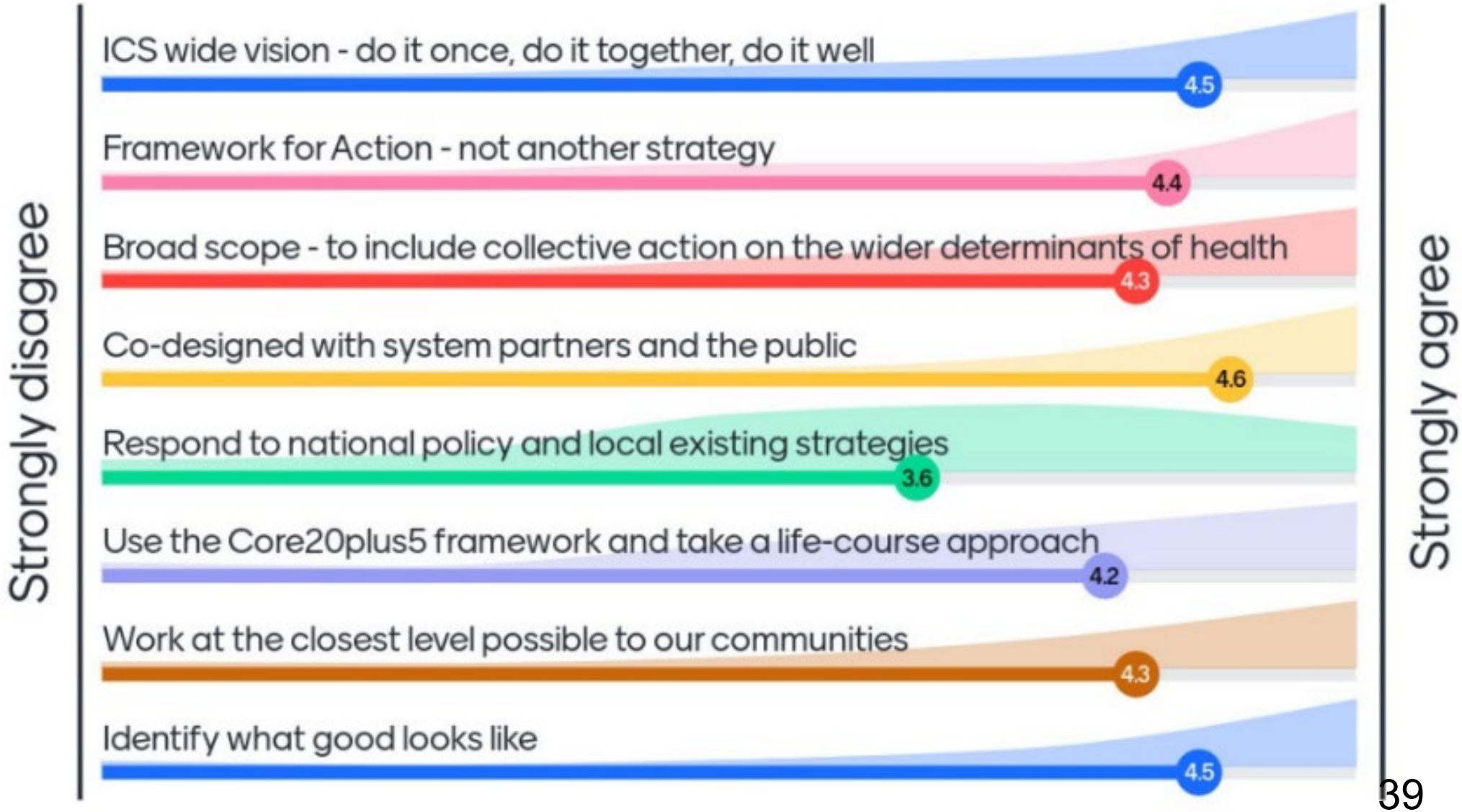
- Living and working conditions
- Lifestyle factors
- Health and care services
- Creating the conditions for success

Strategy design principles

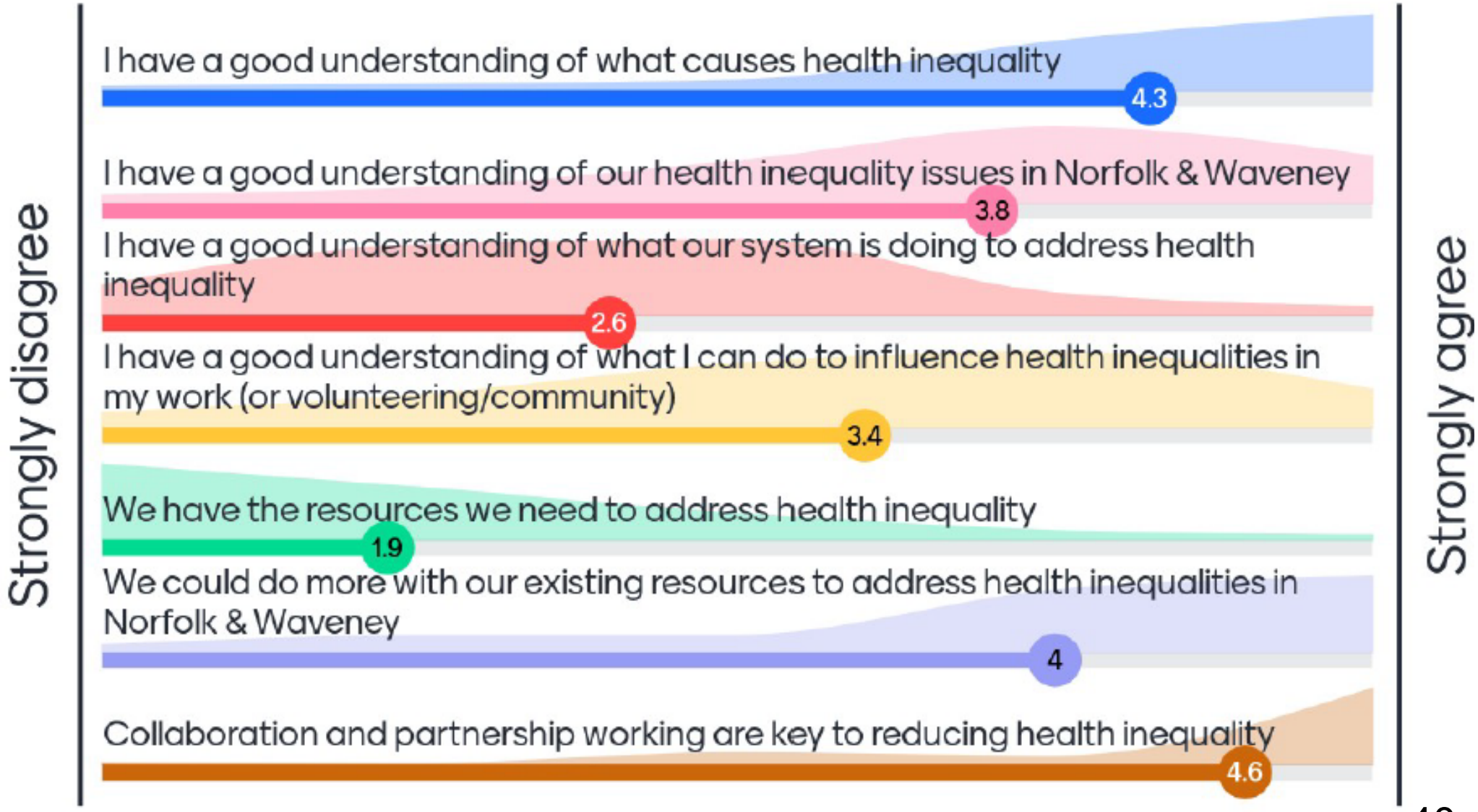
These design principles set out **how** we want to go about developing our strategy and have been tested and agreed through various forums:

1. ICS wide vision – do it once, do it together, do it well.
2. Framework for action – not another strategy.
3. Broad scope – to include action on the wider determinants of health.
4. Co-designed with system partners and the public.
5. Build up using assets that already exist.
6. Respond to national policy and existing local strategies.
7. Use the Core20plus5 framework and take a life-course approach.
8. Work at the closest level possible to our communities.
9. What good looks like will be identified – a baseline and trajectory for improvement.
10. Resourcing will be identified to support implementation.

Feedback from ICS conference



Feedback from ICS conference: Temperature check



Next steps

- We are starting our ‘health inequalities conversation’ with system partners.
- We will be asking our system partners to support us with wider engagement and participate where possible to help shape our framework.
- We will be utilising the Community Voices programme to hear from our communities and seeking input from people with lived experience.
- Recognise the need for an ongoing conversation to ensure we make tackling health inequalities everyone’s business.

Report title: Mental Health: Public Health outcomes and prevention priorities for the system

Date of meeting: 08 November 2023

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

Reason for the Report

The Integrated Care Partnership (ICP) Chair has asked Public Health to provide reports on a number of health conditions, with a particular focus on prevention, so that the Integrated Care Partnership (ICP) can work together to improve the health of the population. It has been agreed that these reports will cover four major heath conditions: Cardiovascular Disease (June 2023), Respiratory conditions (September 2023), Mental Health (November 2023) and Cancer (March 2024). This is third in the series, focusing on Mental Health.

Report summary

Mental Health conditions affect all age groups of our population, but some groups experience much worse outcomes than others. Life expectancy is a key indicator of the health of the population. People living with severe and long-term mental illness (SMI) experience some of the worst inequalities, with a life expectancy of up to 20 years less than the general population.

There are some geographical areas where outcomes for Norfolk and Waveney are significantly worse than the national average. The “core 20” most deprived population experience around 6,000 more emergency admissions to hospital for patients with SMI conditions compared to the Integrated Care Board (ICB) average. There are prevention opportunities across the life course relating to mental health.

Recommendations

The ICP is asked to:

a) Note the data and information relating to Mental Health for people living in Norfolk and Waveney for use in their strategic and operational planning and note there is additional information contained within the Norfolk Joint Strategic Needs Assessment (JSNA).

1. Background

1.1 Previous analysis has shown that Mental Illness in Norfolk and Waveney is a key driver of health inequalities and places a significant demand on the health and care system. There is also unwarranted variation in the care and support provided for people with mental health conditions.

2. Public Health outcomes and prevention priorities for the system

2.1 Children and Young People

2.1.1 Over 18,000 Children and Young people (CYP) aged 5-19 are diagnosed with one or more mental health conditions.

2.1.2 Self-harm - although people across all age groups may self-harm, females and young people are recorded to self-harm in greater numbers than the rest of population.

2.1.3 Hospital admission rates for self-harm for 10-to-14-year-olds in Norfolk are significantly worse than England.

2.1.4 Children in care who self-harm and LGBTQ+ cohorts have also been identified as groups who should be considered for interventions locally.

2.1.5 Mental health issues generally start at a young age. Across Norfolk and Waveney areas such as Great Yarmouth, Gorleston, Kings Lynn, and Norwich are likely to see the greatest need for mental health services for CYP.

2.2 Adult population

2.2.1 Depression and Anxiety are commonly diagnosed conditions.

2.2.2 There is variation in the care provided across the Primary Care Networks (PCNs) - which gives opportunities for improvement.

2.2.3 Depression is a major and treatable risk factor for suicide, there are also opportunities for prevention in this area. The Norfolk Suicide Audit identified higher rates of people dying by suicide in Norwich and areas of higher deprivation, as well as higher risk cohorts such as middle-aged and very old men.

2.3 Older Population

2.3.1 The proportion of the population diagnosed Alzheimer's disease or dementia is higher than the England average and is likely to almost double in the next 20 years.

2.3.2 More than 1 in 3 females over the age of 90 are estimated to have dementia in Norfolk and Waveney.

2.4 Health Inequalities

2.4.1 People living with severe and long-term mental illness (SMI) experience some of the worst health inequalities, with a life expectancy of up to 20 years less than the general population. Adults with SMI have a 383.3% higher risk of premature mortality compared to those without SMI in Norfolk.

2.4.2 The “core 20” most deprived population experience around 6,000 more emergency admissions for patients with SMI compared to the ICB average.

2.4.3 There is a strong correlation between emergency admissions and PCN income deprivation. In seven Primary Care Networks (PCNs) there were greater numbers of emergency admissions than expected for their population size and age distribution- those in Kings Lynn, Norwich, Great Yarmouth, Lowestoft, Swaffham & Downham Market.

2.4.4 Self-harm and excess alcohol and drug use account for about half of emergency admissions for Mental Health conditions, and are significantly higher in Great Yarmouth and Waveney, West Norfolk and Norwich.

2.4.5 The Norfolk & Waveney mental health & wellbeing JSNA briefing has also identified the following groups as highest priority:

- People with low incomes living in areas of deprivation or Parents with young children
- Looked after children
- Children involved with youth justice system
- Men’s wellbeing
- Unemployed
- Homeless
- Adult social care users
- People who access drug and alcohol services

2.4.6 Alongside these high priority groups, there are areas within Norfolk and Waveney which have higher levels of need in terms of self-reported mental illness and use of emergency mental health services. These areas are Lowestoft, South Waveney, Gorleston and Norwich.

2.4.7 People with long term mental health conditions, especially from more deprived areas, are at substantially higher risk of physical illness such as obesity, asthma, diabetes, COPD and cardiovascular disease. This disparity is largely due to modifiable risk factors such as smoking, obesity, substance misuse and inadequate medical care.

2.5 Prevention opportunities

2.5.1 The Life Course approach recognises different points in life where there are opportunities to promote mental wellbeing and intervene in at risk populations.

2.5.2 Risk factors for mental illness relating to the wider determinants of health include; Looked after children, poverty, social isolation, substance and alcohol misuse, unemployment, violence and abuse, homelessness and crime.

2.5.3 Supporting changes in health behaviour and improving clinical care can also reduce inequalities in outcomes. There are opportunities for improved care of people with diagnosed mental health conditions, e.g., increasing the proportion with a comprehensive care plan or with a blood pressure / Body Mass Index (BMI) check where this is lower than the England average. For example, Gorleston has a relatively high proportion of people diagnosed with mental health conditions, and there is an opportunity for around 200 extra patients with SMI to have a comprehensive care plan to increase performance to equal the England average.

2.5.4 The data included in this report focus on recorded information about people with mental health conditions that are in contact with health services. We are identifying gaps in our knowledge locally, especially relating to variation in mental wellbeing and opportunities to improve. There could be a focus on closing the quality and prevention gap and moving away from ‘medicalising’ managing wellbeing.

3. Further Information on Mental Health in Norfolk and Waveney

3.1 Norfolk Insight is a locality-focused information system providing data and analysis for neighbourhoods in Norfolk and Waveney. There are a range of documents gathered on the Norfolk Insights website that provide further detail regarding mental health:

- Go to Norfolkinsight.org.uk to read the Mental health and wellbeing in Norfolk and Waveney: briefing paper from March 2022
- Go to Norfolkinsight.org.uk to view a presentation outlining the Mental Health journey for Norfolk and Waveney Residents using Public Health Intelligence.
- Go to Norfolkinsight.org.uk to read the Public Health Audit on Suicide in Norfolk 2022.

Officer Contact

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

Name: Dr Abhijit Bagade Tel: 07825851227 Email: abhijit.bagade@norfolk.gov.uk

Mental Health: Public Health outcomes and prevention priorities for the system

Integrated Care Partnership (ICP) meeting 8th November 2023

Suzanne Meredith, Deputy Director of Public Health

Acknowledgements:
Dr Abhijit Bagade, Dr Tim Winters, Joshua Robotham, Public Health

Norfolk County Council

Summary of Mental Health & Wellbeing in Norfolk and Waveney - outcomes

What is the situation?

Mental illness contributes to **21%** of the total **disease burden** in the UK

6% of **children and adolescents** have **emotional, social and mental health needs**

Prevalence **is increasing** and **is higher** than national average

16% of **adults** have **diagnosed mental health conditions**[2]

Self-reported mental illness is **higher** than national average, at 12%, identifying potential unmet needs

Who is most likely to be affected?

76% of deaths due to suicide were among **men**

1/3 of adults **with mental health problems** are **parents**

Emotional wellbeing is a cause for concern for **46%** of **looked after children**[3]

64 per 10,000 of **children are in care**

People living in **poverty, 15%** of the population are **fuel deprived**[3]

59% in **drug and alcohol treatment** reported a **mental health need** (England)

26% of people with **SMI*** are **smokers**[3] (compared to 15% of the general population)

People who are **unemployed,** which is **5%** of the population

People with **long-term conditions, 20%** of people have a **limiting long-term illness or disability**[3]

What are the impacts and risks?

Rates per 100,000 population...

395 Hospital admissions due to self-harm (10-24 years)[1]

12 suicides

Self-harm, excess alcohol and drug use **account for more than half of emergency** admissions for mental health

32 per 1000 claim **employment support** allowance for mental & behavioural disorders[3]

The highest excess mental health admissions are in **Lowestoft, Gorleston and Norwich**

Prevention

Exposure to **green, outdoor spaces** and **physical activity** can **improve mental health**

Research suggests **25-50%** of adult mental illness may be **avoided** through prevention and intervention **in childhood**

*Serious Mental Illness
1- Lower than national average
2- Similar to national average
3- Higher than national average

Infographic produced by Insight & Analytics - April 2022. Data taken from 'Mental Health Needs Assessment'. Data shown is for Norfolk and Waveney where possible, else is shown for Norfolk, unless stated otherwise e.g. national data.

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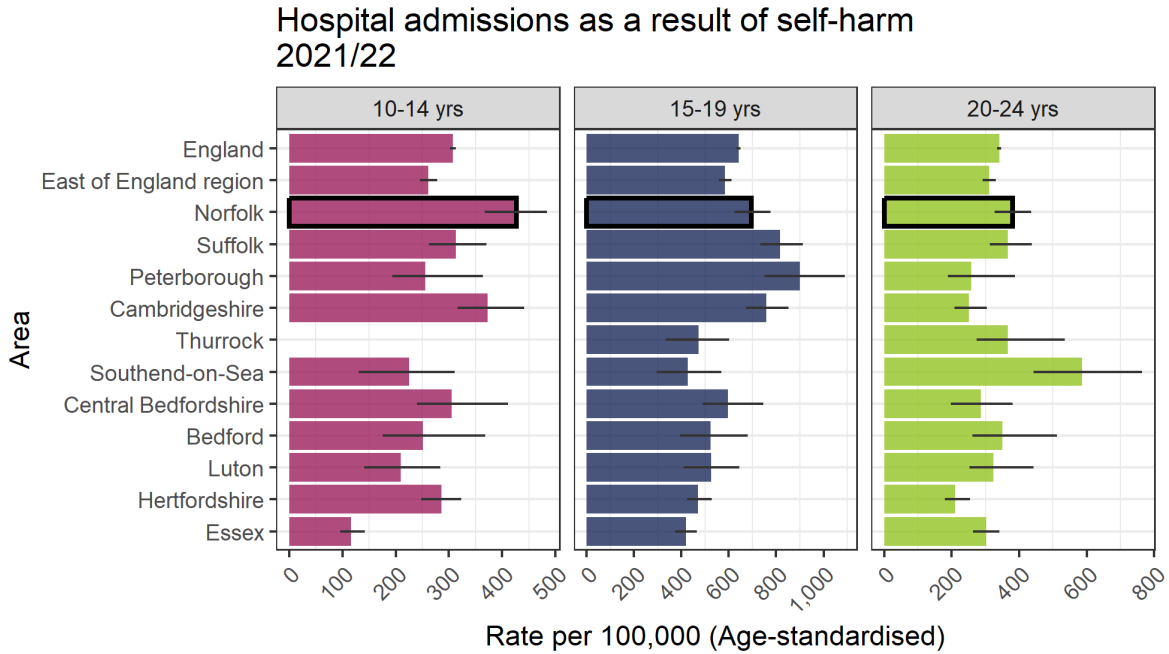
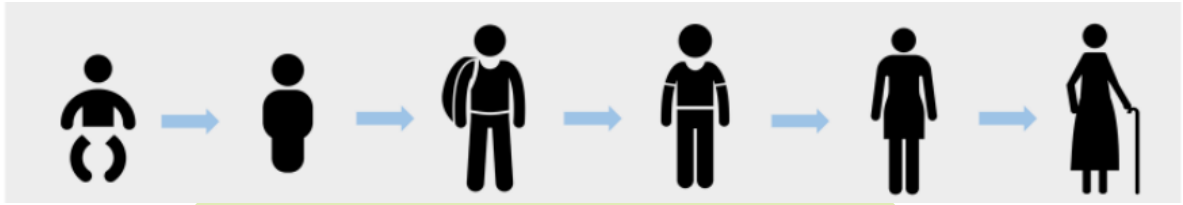
Children and Young People

- Over 18,000 Children and Young people aged 5-19 are diagnosed with one or more mental health conditions.
- Self-harm - although people across all age groups may self-harm, females and young people are recorded to self-harm in greater numbers than the rest of population.
- Hospital admission rates as a result of self-harm for 10-to-14-year-olds in Norfolk are significantly worse than England.





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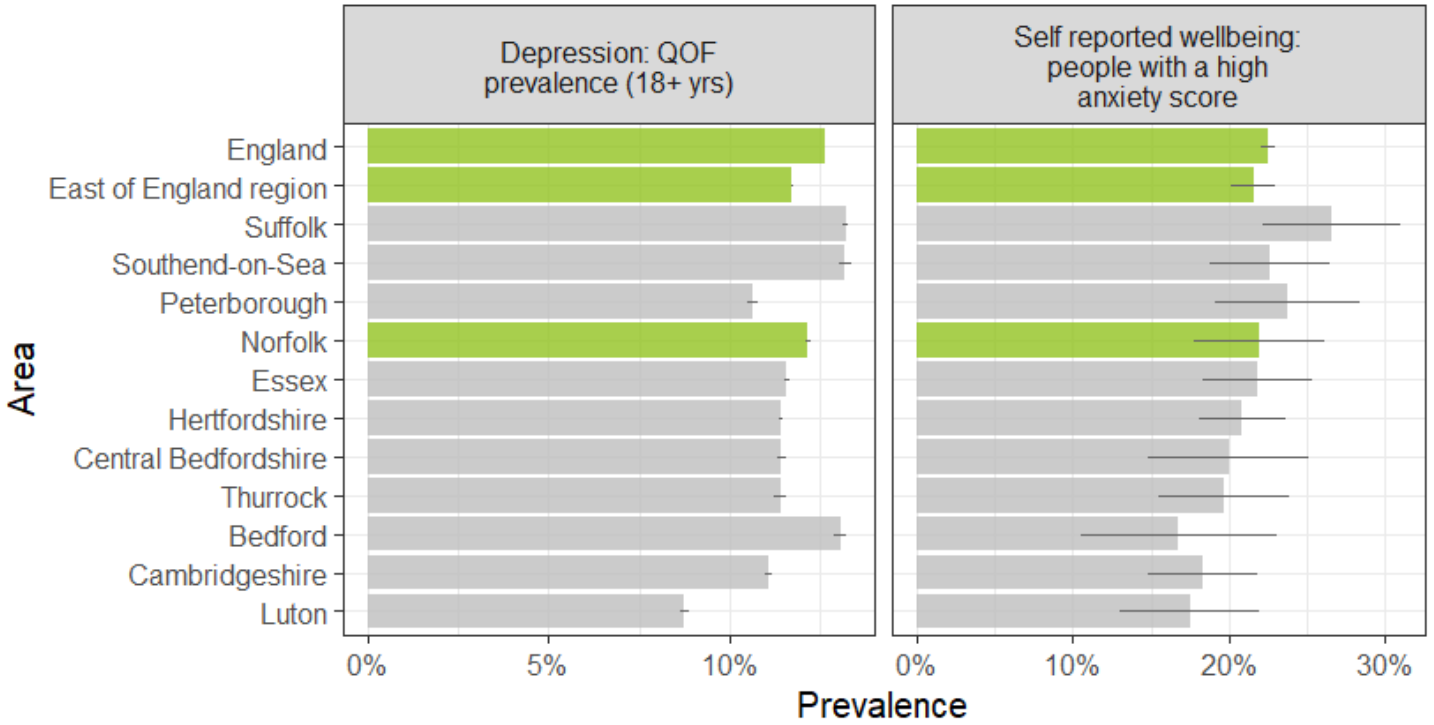
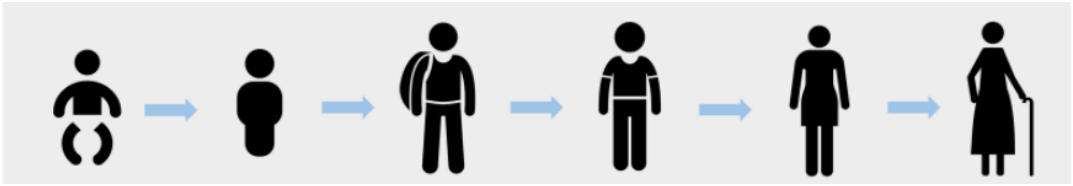
Adult Population

- Depression and Anxiety are commonly diagnosed Mental Health conditions.
- The proportion of the population diagnosed with depression is similar to the England average.
- There is variation across the PCNs in terms of prescribing practices and patient management.
- Depression is a major and treatable risk factor for suicide.



OHID fingertips - 2021/22



The Norfolk Suicide Audit identified higher rates of people dying by suicide in Norwich and areas of higher deprivation, as well as higher risk cohorts such as middle-aged and very old men.

What is the situation?

Around **90** people die by suicide in Norfolk every year

Suicide rates in Norfolk are **higher** than **regional** and **national** rates, but **not significantly** so.

Highest rates are in **Norwich**

No increase during Covid-19 **pandemic**

3 in 4 suicides are **men**

Rates highest in **middle-aged** men and women, and **older men**

Who is more likely to be affected?

People **living alone**

People who are **unemployed**

People born in an **EU country**

People living in more **deprived** areas

People working in **trades, construction, agriculture, driving, health & social care**

Contacts and Engagement with Services

47% attempted suicide before, half of whom more than once

In the **year** before their death…

- **52%** had seen **primary care** for their **mental health**, and 58% of those were also known to mental health services
- **1 in 3** had **no contact** with primary care or mental health services

In the **week** before their death…

- **7%** had been in contact with primary care **and** mental health services

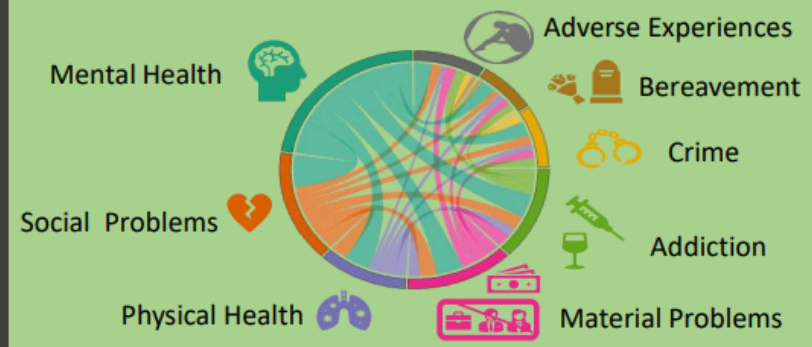
Of those with recorded mental health data…

- **69%** had been in contact with mental health services
- **Fewer men** had been in contact than **women**

Of those who were referred to the services or signposted for self-referral…

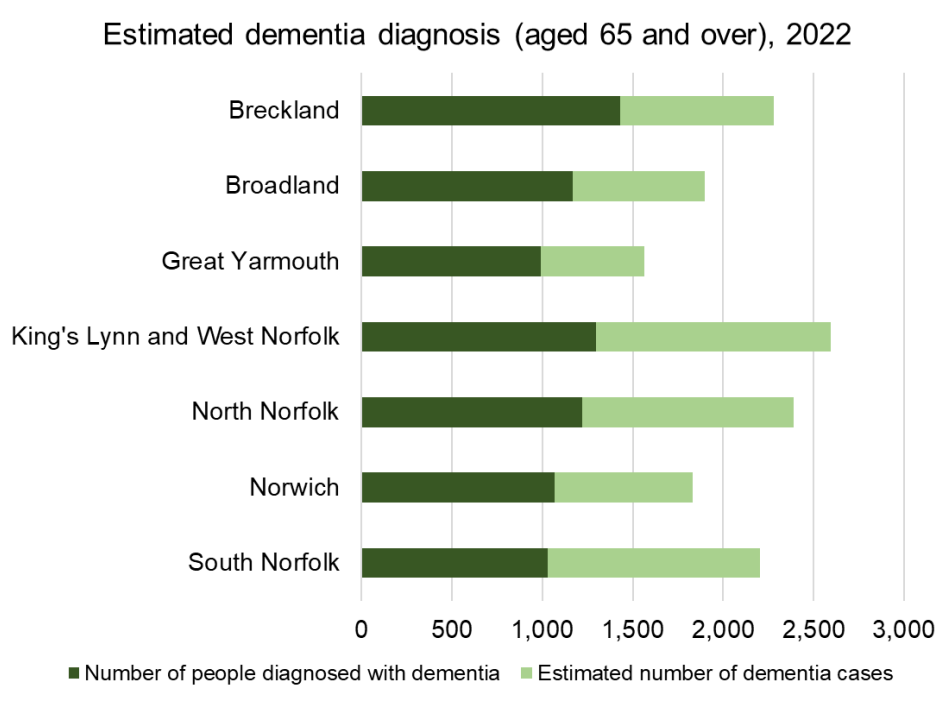
- **30%** refused or failed to engage with services

Suicide is **complex**, and individuals often faced multiple **interrelated risk factors**…



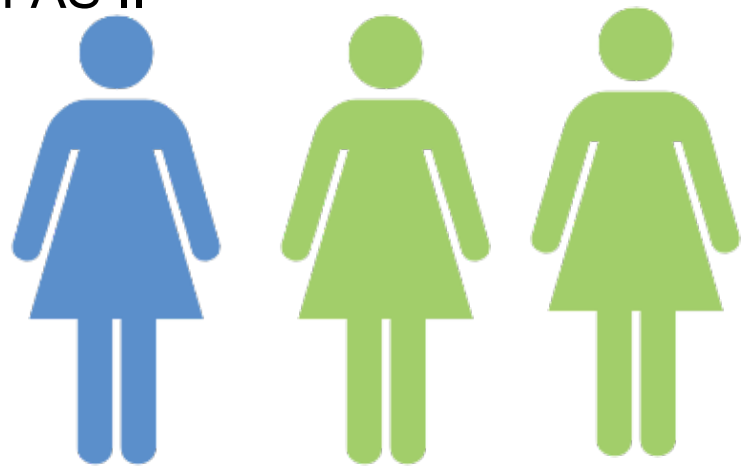
If you are struggling, call Samaritans for free on 116 123, email them at jo@samaritans.org, or visit www.samaritans.org
Or visit this page for more support www.norfolk.gov.uk/care-support-and-health/health-and-wellbeing/adults-health/suicide

The proportion of the population diagnosed Alzheimer's disease or dementia is higher than the England average and is likely to almost double in the next 20 years.



More than 1 in 3 females over the age of 90 are estimated to have dementia in Norfolk

- CFAS II



There are approximately 14,800 people living with dementia in Norfolk now; this is forecast to double to by 2040. Almost 3 out of 4 of these additional diagnoses will be in those aged over 85.

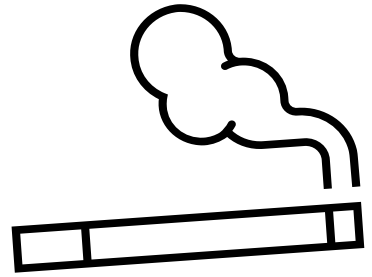
Source: Pansi, fingertips.phe.org.uk

Currently around 50% of patients with dementia have had their care plan reviewed in the previous 12 months, and this is as low as 30% in Primary Care Network areas such as West Norfolk Coastal or Ketts Oak.

Norfolk County Council

Health Inequalities

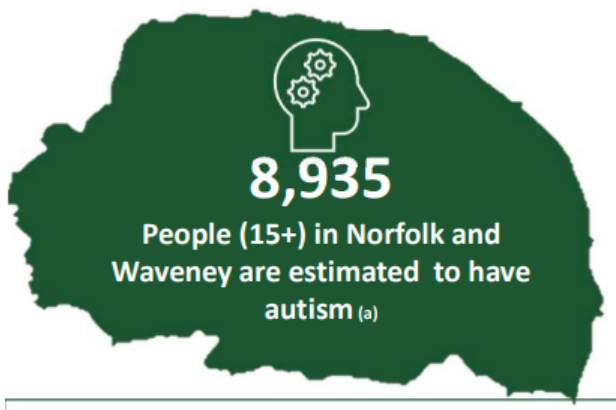
- Adults with Severe Mental Illness (SMI) have a **383.3% higher risk** of **premature mortality (before aged 75)** compared to those without SMI in Norfolk.
- People living with **SMI** experience some of the worst inequalities, with a **life expectancy of up to 20 years less** than the general population.
- **People with long term mental health conditions, especially from more deprived areas, are at substantially higher risk of physical illness such as obesity, asthma, diabetes, COPD and cardiovascular disease.**
- **This disparity is largely due to modifiable risk factors such as smoking, obesity, substance misuse and medical care.**
- There are opportunities for improved care of people with diagnosed mental health conditions, such as increasing the proportion with a comprehensive care plan or with a blood pressure / BMI check where this is lower than the England average. e.g. In Gorleston, 200 extra patients with SMI would need a care plan put in place to meet the England average.



26% of people with **SMI*** are **smokers** (compared to 15% of the general population)

Neurodiversity - Autism

Situation in Norfolk & East Suffolk



In addition,

1,950

children in Norfolk have autism as a primary special educational need. This means the figure is likely to be higher than this as others will have autism as a secondary need (2021/22).

Autism is a set of lifelong, neurodevelopmental conditions characterized by difficulties with social and communication, narrow areas of interest, and repetitive behaviours.

Health Care Barriers and Considerations

Autistic individuals have higher healthcare utilization, higher likelihood of hospitalization, prescription drugs claims, a greater number of emergency room, primary care, outpatient, inpatient, mental health, neurological, and speech therapy visits. Community and voluntary organisations play an important role in providing support for people with autism.

Autistic people have self-reported **poorer quality healthcare** than their peers. Healthcare adjustments are needed but infrequently available, such as:

- **Sensory environment adjustments**
- **Knowledge and communication of healthcare professional**
- **Flexibility of clinical service context** (e.g., offering online appointments, changing appointment length according to patient preference, etc.) *(c)*

Health Need

Males are **4 times more likely** than **females** to be **diagnosed** autistic

Autism affects all **ethnic** and **socioeconomic groups** but **minority groups tend to be diagnosed later** and less often. **Early intervention** affords the best opportunity to support healthy development across the lifespan.

It is likely that many of the adults in Norfolk with autism have **not been formally diagnosed**. In particular, it is thought females are less likely to receive a diagnosis, as autism may present differently.

Psychiatric conditions

Those with autism and a mental health problem may not **access services** as often as the general population with mental health problems, leading to **health inequalities**.

Research has also shown that **54% of people with autism are diagnosed with a psychiatric condition.**

Research has shown people with autism are *(b)*:

- **14 x** more likely to have **OCD**
- **4 x** more likely to have **dementia**
- **6 x** more likely to have **bipolar**
- **5 x** more likely to have **attention deficit disorders**
- **3 x** more likely to have **depression**
- **5 x** more likely to attempt **suicide**

Chronic conditions

Many areas in Norfolk have identified **gaps in provision of preventative services**, to avoid the need for escalation to **specialist services*.**

Nearly all chronic medical conditions are significantly more common in adults with autism.

Research has shown people with autism are *(b)*:

- **2 x** more likely to have **dyslipidaemia**
- **16 x** more likely to have **epilepsy**
- **2 x** more likely to have **hypertension**
- **3 x** more likely to have **nutrition conditions**

*For more detail please see our needs assessments on Norfolk Insight: Adults and children with autism in Norfolk (Mar-19)

Infographic produced by Insight & Analytics - May 2023. (a) estimates calculated using 2018 SNPP CCG pops (for 2023) based on the assumption that 1% of population have ASD. (b) Croen LA et al. (2015) doi: 10.1177/1362361315577517. *(c)* Weir, E et al. (2022) doi: 10.1186/s13229-022-00501-w

Norfolk County Council Public Health

Officer Contact:

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Further detailed information is available on the Norfolk Insight website:
https://www.norfolkinsight.org.uk/jsna/healthcare-evaluation/

Norfolk County Council

Report title: LeDeR Annual Report 2022/2023

Date of meeting: 08 November 2023

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

Reason for the Report

LeDeR is a service improvement programme for people with a learning disability and autistic people. It was established in 2017 funded by NHS England and NHS Improvement. A review is undertaken for every autistic person with a learning disability who die.

This is the sixth annual report in Norfolk and Waveney (N&W) on the reviews of the lives and deaths of people with a learning disability and/or autism since the inception of the LeDeR programme (Learning from deaths review 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 N&W LeDeR programme demonstrates the work covered in the reporting period from 1st April 2022 to 31st March 2023.

Report summary

Sadly, people living with learning disabilities and/or autism people continue to have a much shorter life expectancy with the average being over 20 years younger than the general population for women and for men. Mortality data shows that the leading single cause of death for the learning disability and autism population relates to aspiration pneumonia and pneumonia, followed by cancer and sepsis.

We continue to see improvements in the uptake of annual health checks, 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. We also have seen really good examples of widespread use of reasonable adjustment to support people to access healthcare.

We will endeavour to explore improving respiratory care and reducing respiratory related deaths, especially pneumonia. We will look to better listen to the voices of those we support through improved use of the Mental Capacity Act and advocacy. We hope to look at care coordination and develop collaborative working in care planning for those with chronic conditions and at end-of-life. We aim to better represent the experience of those with a sole diagnosis of Autism by outreaching into services, raising awareness and supporting more referrals for those who have died.

Recommendations

The ICP is asked to:

a) Agree and approve the reccommendations from the LeDeR annual report and system learning.

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. 6683 are registered with GP practices in Norfolk and Waveney out of a total population estimate of 916,120. This gives our area one of the highest percentage representations in England. 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.

1.2 The median age of death for people with a learning disability in Norfolk and Waveney for the 2022/2023 year was 60. In comparison the median age of death for the general population in 2018-2020 was 83. On average people with a learning disability and/or autistic people are known to have 4 or more complex physical health complications.

1.3 In Norfolk and Waveney 21% died over the age of 65. Nearly 70% of the people we reviewed lived in an area with an Indices of Multiple Deprivation score of 5 or less. People with a learning disability were 6 times more likely to die prematurely. The leading cause of death is pneumonia by a significant margin and 49% of deaths were classified as "avoidable" for people with a learning disability.

2. Key highlights from the LeDeR Annual report 2022 – 2023

2.1 Below presents some of the key findings from this year's annual report (see appendix A):

2.2 The quality of residential services in our region, with a focus on performance and quality monitoring.

2.3 Oversight of care quality in specialist inpatient services had increased, thanks to health and wellbeing reviews and Care, (education) and treatment reviews (C(E)TRs).

2.4 Notifications for those with autism have been low and we hope to improve this through engagement, to support our learning.

2.5 System partners could benefit from auditing their compliance, and staff knowledge, of the Mental Capacity Act; and address gaps in practice.

2.6 Primary Care and residential services need to be more proactive in supporting weight management.

2.7 As a region we achieved over 70% completion of annual health checks for those eligible, and we hope to continue improving quality.

2.8 Uptake for screening programmes is poor, and could be increased with better preparation and follow up for non-attendance.

2.9 Our hospital really value the importance of familiar carers, but could improve the use of hospital passport.

2.10 System use of the Gold Standards Framework could help with earlier identification of deterioration and referral to palliative support.

2.11 Our region had a brilliant uptake in COVID-19 and flu vaccinations. However pneumonia vaccinations remain scare for those eligible.

2.12 Nearly 80% of focused reviews indicate the person experienced care and service availability which fell short of expected good practice.

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

2.14 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) documents and end of life care planning needs to happen earlier and in a more collaborative manner.

2.15 As young people move into adult services there is still a notable decline in care co-ordination, despite excellent moves to improve transitional care.

2.16 Best practice in the use of the Mental Capacity Act was mostly seen when the acute learning disability teams were involved.

2.17 Health action plans are an important part of an annual health check and they need to be robust and collaborative.

2.18 Primary care are good at offering face to face appointments but we could improve preparation for interventions such as blood tests.

2.19 Paediatric end of life care in Norfolk and Waveney is excellent, providing a holistic approach for the whole family.

2.20 Earlier referrals are needed for advocacy and care co-ordination, for those with complex health profiles and limited social support.

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

2.22 The LeDeR Annual Report for 2022-2023 can be seen in detail in Appendix A. Go to improvinglivesnw.org.uk to find an animated video guide that talks you through this years LeDeR annual report alongside an easy read report.

Officer Contact
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Learning from Lives and Deaths – People with a Learning Disability and People with Autism (LeDeR)

Norfolk and Waveney

Annual Report 2022-2023

Title	Norfolk and Waveney LeDeR Annual Report 2022-2023
Authors	Andrew O'Connell - Senior Nurse Manager for LeDeR Nikki Goble - LeDeR Co-ordinator Andy Hudson - Associate Director for Quality in Care Rachel Garwood - Senior Nurse for Quality Improvement Learning Disability and Autism
Responsible Executive Lead	Patricia D'Orsi - Executive Director of Nursing NWICB

Forewords

Patricia D'Orsi: 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

NHS Norfolk and Waveney Integrated Care Board (ICB) is grateful to the families, carers, and friends affected by the passing of a loved one, friend or colleague, for their input into the review process and for helping to tell the stories of the lives and deaths of people living with learning disabilities and/or autism in Norfolk and Waveney. The value of the knowledge and insight held by families and friends is particularly evident in the report's section on lived experiences, which can be found on pages 54-57. We would also like to recognise and thank all staff from across the health and social care system for their involvement, sharing invaluable insights from their professional practice and for their time spent working with and supporting the people and families whose lived experiences are central to this report.

Sadly, people living with learning disabilities and/or autism people continue to have a much shorter life expectancy with the average being over 20 years younger than the general population for women and for men. Mortality data shows that the leading single cause of death for the learning disability and autism population relates to aspiration pneumonia and pneumonia, followed by cancer and sepsis. We have observed a heightened number of excess deaths in younger ages, through our reviews, as well as an increase in deaths of people aged over 65, due to the impact of the global COVID-19 pandemic in 2020/2021. This year's report found several themes for improvement, including:

- Prevention of respiratory illness, particularly pneumonia, needs to be to be a focus for learning and action following this report and Annual Health Checks should be routinely used to offer cancer and other screenings, and to identify people eligible for a pneumonia and other preventative vaccines.
- A consistent primary care Health Action Plan template for use across the Norfolk and Waveney Integrated Care System (ICS) could help to standardise practice for quality purposes and support its use across other services involved in a person's health and wellbeing

- Transitional care between child and adult services remains a difficult experience for young people and their family. Greater collaboration between paediatric and adult services is needed and better preparation for families as to what to expect could be beneficial.
- A Norfolk and Waveney strategy for stopping over medication of people (STOMP) would be a welcome step to embed its principles for people with a learning disability, autism or both with psychotropic medicines, into all prescribing practice.

It is also important to acknowledge the excellent work of the Learning Disability Mortality Review (LeDeR) system working groups this year, around end of life and palliative care support, improving uptake and quality of Annual Health Checks (AHC), dietetic weight management support, a pilot pathway for non-invasive long-term ventilation care and a project improving communication between care organisations at the point of hospital admission and discharge, to improve service user and carer experiences and coordinate community-based care more seamlessly.

We welcome the publication of this, our sixth LeDeR Annual Report in Norfolk and Waveney. The ICB continues to be committed to ensuring that Norfolk and Waveney people living with learning disabilities and/or autism live well, and we recognise that this work must be informed by the learning identified within the report, using lived experiences to help identify opportunities to improve services and support. Our focus for the year ahead must be on using these insights to improve the quality of care offered, working collaboratively with partners to deliver care with better oversight and monitoring of placements and training for staff.

Paul Benton: Director for Quality in Care for the Norfolk and Waveney Integrated Care Board (NWICB) - Chair of the LeDeR Steering Group
I would like to start by expressing how immensely proud and grateful I am of all the staff who are working tirelessly keeping our people and communities safe across the whole of Norfolk and Waveney.

The LeDeR steering group only functions as effectively as it does due to the commitment of our dedicated team. Despite being new in my role, it's very clear the people who work in our directorate and partners across the system are very committed to providing outstanding quality and care. Norfolk and Waveney had some significant challenges during the winter which all the partners witnessed. The system faced unprecedented challenges in delays and finding appropriate and safe care settings for the most vulnerable.

It would be fair to describe the experience as one of the most challenging winters we have ever had. Whilst the pandemic is now becoming a more distant memory, the impact will continue for some time as the system continues its recovery phase. The LeDeR steering group has, despite the challenges, kept its principles and direction focused on the things that matter the most, quality and

safety of the residents within our care and whilst we know that we are still on this journey, we as partners are committed to improving the lives of those around us.

There have been significant changes in 2022/2023 with the new Integrated Care System was formed on July 1st 2022 and all system partners working in a new and exciting way together. This has been a long and awaited journey to reach this point and should therefore allow us to make significant improvements in the lives of the most vulnerable. Now that the new financial year is upon us it's important for us to evaluate the direction the steering group takes ensuring that for 2023/2024, we are meeting the needs of the population, reaffirm the importance of making change happen across all aspects of care, and more importantly despite the financial challenges that lay ahead, we see an improvement in all domains of care. We cannot do this alone, but we are confident that the partners that we work with will make the changes required that have a positive impact for all our people and communities.

Rachel Clarke: Co-ordinator for Family Voice Norfolk
My name is Rachel Clarke, and I am the co-ordinator of Family Voice Norfolk (FVN). Family Voice Norfolk is the Norfolk parent carer forum for families who have children 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 the past 18 months. We currently have two parent carer representatives attending these meeting, namely Laura Godfrey and myself. Both Laura and I are parents of children and young people who have autism, learning disability and other conditions.

We believe that having parent carers present at the 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 with autism 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. We are struck by how dedicated everyone is within the meetings to make improvements, prevent recurrences of failings and to truly take learning from each case we review. Laura and I are grateful for the support and 'open ears' that are offered to us by colleagues should we find a case to be upsetting.

We have been part of, and brought our own lived experiences, to the Learning Disability Health Check Working Group and we actively take part in the respiratory, nutrition and end of life groups. There are plans for colleagues from the meetings to bring some of the

important topics we have discussed, such as mental capacity and the Learning Disability health checks to a Family Voice Norfolk parent carer engagement sessions called Let's Talk About… We look forward to getting these in place in the next academic year and to continuing to learn from the LeDeR meetings we attend.

Contents

1. Acknowledgments

Firstly, the team would like to remember, and thank, all the people who have contributed to LeDeR by sharing their stories with us, following their death. It is 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 go to families, friends, and the 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 made the achievements and progress it has 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 real 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 people with autism over the last year.

2. Executive Summary

Welcome to the Norfolk and Waveney Integrated Care Board (NWICB) LeDeR report. This is the sixth 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 2022 to 31st March 2023. The deaths reviewed can cover a longer period dating back to 2018. This is due to death reporting delays but also delays in the review completion which is addressed in section 5.

There is little comparison available between this and last years' annual report. Local data collection has been significantly more robust this year, allowing for analysis of all 72 reviews. Last year's available reviews were restricted to 18, due to the significant change in the

review format and therefore it would not give a reliable or accurate comparison. As such, figures have been presented to describe the current situation in Norfolk and Waveney and future reviews 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 Reports[1]. Summary findings from the Norfolk and Waveney reviews in 2022/2023 can be seen on the next page:

[1] https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf

The quality of residential services needs to be improved in our region, with a focus on performance and quality monitoring.	As a region we achieved over 70% completion of annual health checks for those eligible, and we hope to continue improving quality.	Nearly 80% of focused reviews indicate the person experienced care and service availability which fell short of expected good practice.	Health action plans are an important part of an annual health check and they need to be robust and collaborative.
Oversight of care quality in specialist inpatient services has increased, thanks to health and wellbeing reviews and C(E)TRs.	Uptake for screening programmes is poor, and could be increased with better preparation and follow up for non-attendance.	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 but we could improve preparation for interventions such as blood tests.
Notifications for those with autism have been low and we hope to improve this through engagement, to support our learning.	Our hospitals really value the importance of familiar carers, but could improve the use of hospital passports.	ReSPECT documents and end of life care planning needs to happen earlier and in a more collaborative manner.	Paediatric end of life care in Norfolk and Waveney is excellent, providing a hollistic approach for the whole family.
System partners could benefit from auditing their compliance, and staff knowledge, of the Mental Capacity Act; and address gaps in practice.	System use of the Gold Standards Framework could help with earlier identification of deterioration and referral to palliative support.	As young people move into adult services there is still a notable decline in care co-ordination, despite excellent moves to improve transitional care.	Earlier referrals are needed for advocacy and care co-ordination, for those with complex health profiles and limited social support.
Primary care and residential services need to be more proactive in supporting weight management.	Our region had a brilliant uptake in COVID-19 and flu vaccinations. However pneumonia vaccinations remain scarce for those eligible.	Best practice in the use of the Mental Capacity Act was mostly seen when the acute learning disability teams were involved.	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 aged four years and over. We report on deaths of people with a diagnosis of autism, with no learning disability, for those 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 disability[2]. 6683 are registered with GP practices in Norfolk and Waveney out of a total population estimate of 916,120.[3] This gives our area one of the highest percentage representations in England[4].

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 2021 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 22 years younger and females die 26 years younger[5]. 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 programme[6] uses the national policies definition of a learning disability. For people with autism to be included within the LeDeR programme they must have a diagnosis of autism recorded within their health records prior to their death and be over the age of 18. 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 policy[7].

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, especially in some sub-categories (such as children) and as such must be interpreted with caution. Data interpretation and analysis is an important part of finding trends in poor practice and identifying gaps where improvement is needed.

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[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
[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

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 people with autism and use the framework set out in the LeDeR policy by NHS England. Data collection significantly changed for 2022/2023 and this has allowed us to provide a more detailed report than previous years, with more information to analyse and draw themes from. This does mean, however, that we are limited in our ability to draw reliable comparisons between previous reports and this one. With consistency in data collection however, future annual reports will start to show trends.

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 ICS partners and colleagues. Significant changes have been implemented over the last year to fully realise the LeDeR policy published in 2021[8]. This includes:

- Establishing local governance groups responsible for signing off initial and focused reviews, agreeing care grading and setting appropriate actions.
- Establishing robust escalation routes where learning requires a systemic approach or support.
- Expanding the LeDeR programme to accommodate referrals for adults with a diagnosis of autism without a learning disability.
- Delivering focused reviews for national and local priorities. For example: people from ethnic minorities, adults with autism, or on request by family.
- Creating appropriate reporting and education routes to update the wider health and social care community on learning from LeDeR.

[8] https://www.england.nhs.uk/learning-disabilities/care/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/

As a result of the incredible hard work of all involved, the longstanding backlog of reviews was completed by June 2022. The team is also exceeding its target of 95% of reviews completed within 6 months and it has reduced the number of reviews carried over by more than 50%. A more detailed breakdown can be found in section 5.

We have experienced many challenges in delivering LeDeR over the past year, due to both national changes and local barriers. Firstly, the online platform which the team uses to complete reviews has been through multiple formatting changes. This has presented challenges with consistency of reviews but has benefitted the completeness.

In the case of someone with a learning disability who has died in hospital, the trust will complete a Structured Judgement Review (SJR). Ideally these should be completed in a timely manner and made available to the LeDeR review team as part of the hospital notes, complementing the available information for the review. There have been significant delays in completion of SJRs which has meant the LeDeR review has often been competed first. However, mortality leads from all trusts have worked well with LeDeR over the last year to share findings and learning for all shared reviews, with a reviewer attending all SJRs for a person with a learning disability. Moving forward all trusts in Norfolk and Waveney have made significant improvements over the past year and this is resolving.

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.

Since completion of the review backlog, families are being contacted and invited to particate 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. We will explore this moving forward to try and see if there is anything the team can do differently to support families in contributing to the review.

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 at the LeDeR steering group.

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 LeDeR Steering Group

The LeDeR steering group is chaired by the NWICB Director for Quality in Care and is a subgroup of the Learning Disability and Autism Partnership Board. It is attended by a wide range of senior stakeholders to review identified learning, the strategic actions and quality improvement work streams. Work undertaken in this group is presented at the Learning Disability and Autism Programme Board which is chaired by the Senior Responsible Officer for Learning Disability and Autism for Norfolk and Waveney.

5.4 Reporting Structures

The Learning Disability and Autism Partnership Board and the NWICB Quality and Performance Committee receive monthly reports on the performance of reviews undertaken and the learning into action. The team also report to the ICS Learning from Deaths Forum. The team follow a specifically written safeguarding policy for the reporting of safeguarding concerns which is detailed in Section 11.

6. Performance

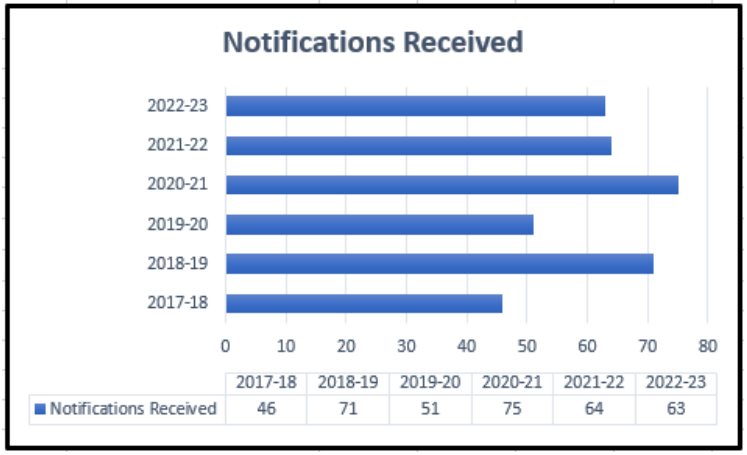
The team works to achieve 95% of reviews completed within 6 months of notification. Due to the backlog of reviews accumulated over past years additional reviewers were commissioned to address this. The last of these reviews were completed and signed off in June 2022, however, it still impacts our performance figures for the year. At the end of Quarter 4 (Q4) the team has completed 66% (44 out of 66 adult reviews) within 6 months of notification in the 2022/2023 year. However, looking at performance just in Q3 and Q4, once the backlog had been resolved, the LeDeR team has a combined completion target of 96% reviews completed in under 6 months of notification.

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 counted to have exceeded the 6-month timescale have 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.

We carried forward 41 reviews from the 2021/2022 review period and this year we are carrying over 32 reviews into 2023/24, so 20% fewer than previous years. This is on top of receiving 25% more referrals in 2022/2023 than before Covid. The team is also tasked by NHS England to convert a minimum of 35% of adult reviews from initial too focused. This year the team has exceeded this target and achieved 37% of reviews being focused.

7. Overview of Notifications

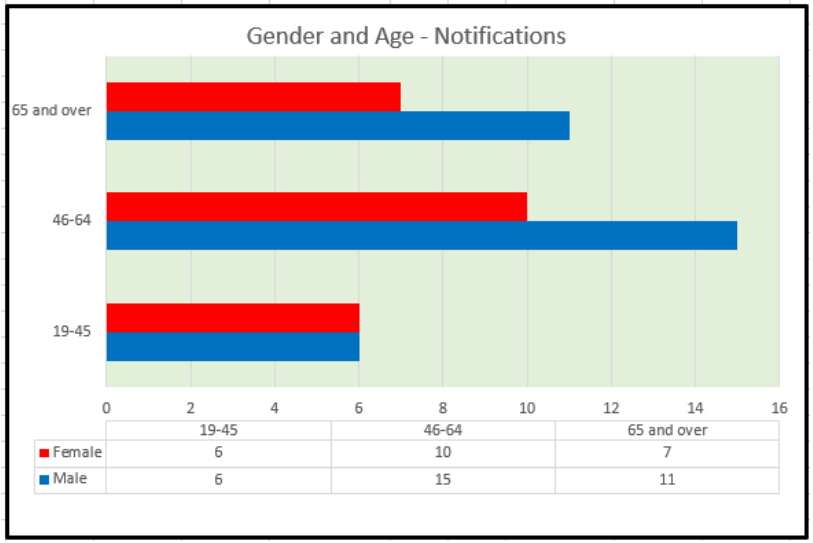
Since the start of the LeDeR programme in 2017, England has recorded 15690 deaths, 1768 of which were within the East of England region and of those 369 were Norfolk and Waveney deaths. These numbers are only based on the numbers of referrals received and as reporting to LeDeR is not mandatory, the true number of deaths is likely to be higher. The graph below shows how the number of notifications has changed over the years. To compare the number of notifications, 2019/2020 is used due to the number of excess deaths from COVID which is also exampled in the graph below. Overall, our notifications have increased by 24%.



	2017-18	2018-19	2019-20	2020-21	2021-22	2022-23
Notifications Received	46	71	51	75	64	63

7.1 Gender and Age

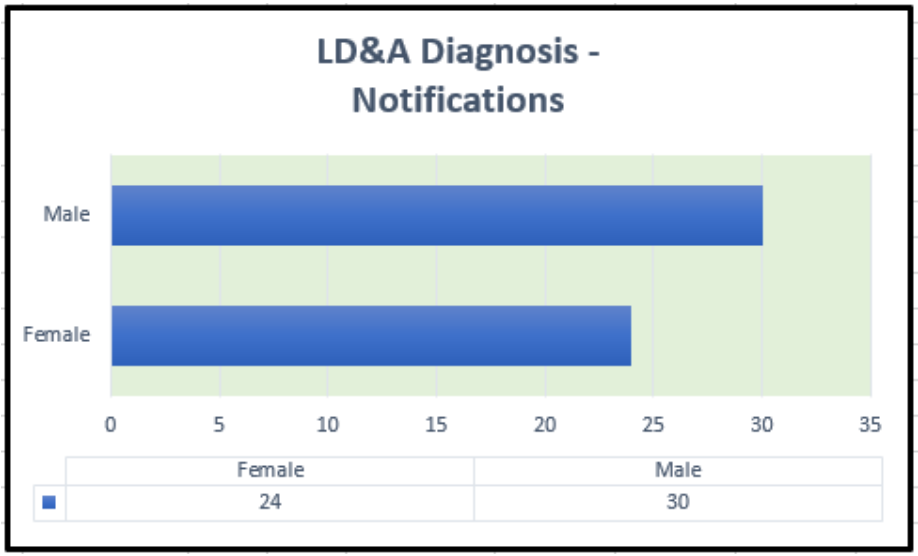
Overall, we had more referrals for men than women, a difference of 20%, and this was represented in all the age groups except one, where the numbers for men and women were the same. Due to the low number in the under 18 category these have been omitted from the graph, however 75% of these notifications were for boys. The youngest reported death during 2022/2023 was 8 years of age and the oldest was 84 years. Most of our referrals were for people between the ages of 46 and 64, which fits with the median age of death of 57.5 years of age for those referred to us. This year's data shows a fall in the median age at death from 60 years of age for notifications in the 2021/2022 year. Data collection is difficult for previous years, but we know that more reviews in previous years have been for people 65 and over. Potentially due to the increased COVID-19 mortality in older people, which may account for the drop in age this year. For the general population in Norfolk and Waveney the average age of death between 2018 and 2020 for men is 79 years old and for women is 84 years old. [9]



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

7.2 Diagnosis

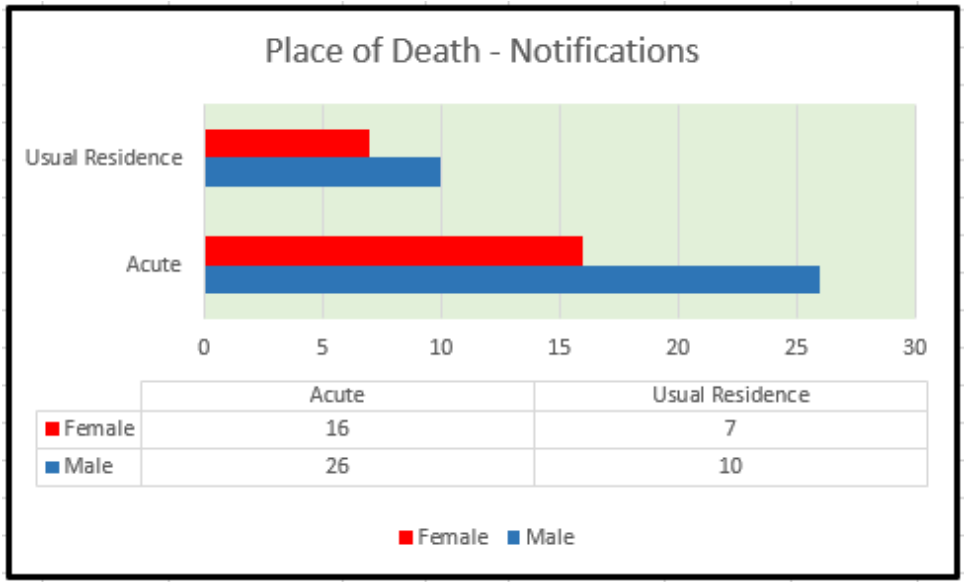
The majority of our referrals were for those with a diagnosis of a learning disability with a smaller number referred with a diagnosis of both a learning disability and autism. As would be expected with the gender difference in our overall referrals there were more men in both categories. However, the difference between men and women for each diagnosis is notable, with it being much higher when the person has an autism diagnosis. This has been omitted from the graph below due to the low numbers, however only 11% were female in the Learning Disability and Autism category. This could be due to substantially lower diagnosis rates in women for autism. The team has not received any referrals in 2022/2023 for anyone with a sole autism diagnosis. 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 people with autism is 17 deaths per 10,000. This shows the LeDeR team what is being missed and the need for communicating the importance of autism referrals will be a priority for 2022/2023. The team also hopes with the establishment of the medical examiner role for acute and community will aid these referrals as well work done to secure referral pathways with the coroner's court.



7.3 Place of Death

Most deaths referred to us in 2022/2023 happened in hospital, 67% (*n*=42) overall. 27% (*n*=17) occurred in the person's usual residence. Less than 10% happened in other areas including hospice care. This has been omitted from the graph due to the low

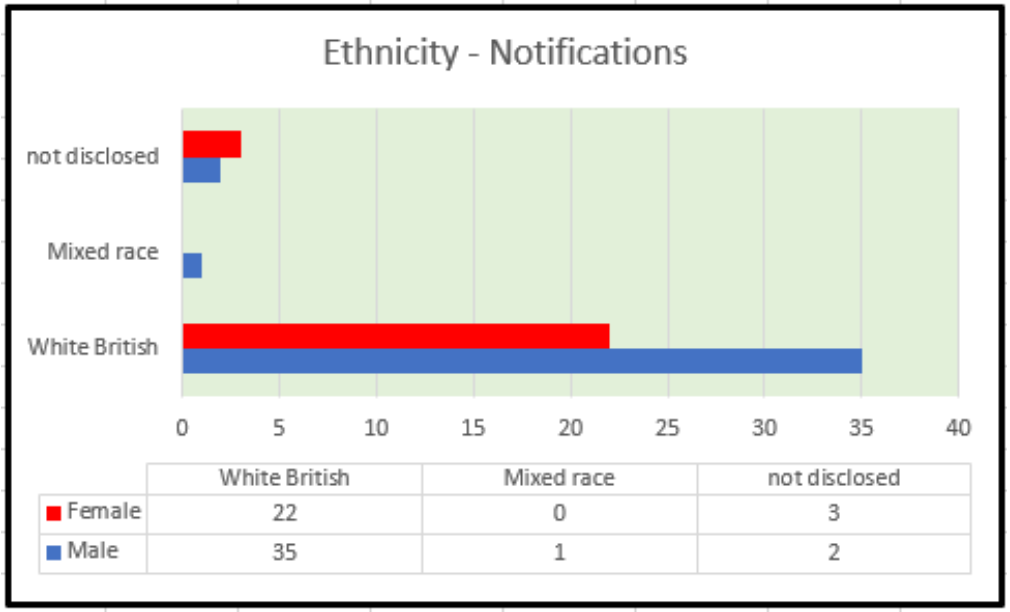
numbers. In contrast, the general population has a higher combined percentage of people dying in their usual residence, whether this be home or residential services.[10]



7.4 Ethnicity

Of the notifications from 2022/2023 where the ethnicity was disclosed, 98% (*n*=58) were for white British people. Only one referral was for someone from an ethnic minority. Usually, we would not report such low numbers to protect anonymity. However, it has been reported here to demonstrate the disparity in notifications. Ethnicity is not a mandatory question for a referral, so we do have a few notifications where the reviews have not yet been completed, and we are unaware of the person ethnicity. Therefore, there may be more representation than we are aware of.

[10] https://fingertips.phe.org.uk/profile/end-of-life/data#page/1/gid/1938132883/pat/15/par/E92000001/ati/167/are/E38000239/yrr/1/cid/4/tbm/1/page-options/car-do-0



7.5 Leading Cause of Death

From notifications the leading single cause of death (COD) in Norfolk and Waveney was aspiration pneumonia, with all pneumonias combined being the leading cause of death. This is also seen in the completed reviews. This profile is different to the general population where the top three COD in 2021 were diseases of the circulatory system, then COVID-19 and then cancers. Again, a COD is not a mandatory question for referral completion. As such, at the time of writing, only 54 of the notifications had an identifiable COD in the referral or in the available notes. This means some of the figures below may change if all COD were available. There were other causes of death with under 5 incidences which have not been listed to protect anonymity.

Cause of Death	Number of Notifications	Percentage
Aspiration pneumonia	17	27%
Pneumonia	9	14%
Cancers	7	11%
Sepsis	5	8%

7.6 Area of Deprivation

The Indices of Multiple Deprivation (IMD) show a mode score of 6 which is slightly higher than the completed reviews. However, the overall breakdown in representation into the higher and lower IMD areas are very reflective of the completed reviews for 2022/2023, with more people with a learning disability and autism living in areas with an IMD score of 5 or less. This is higher than the general population where 2019 data shows 52% in Norfolk live in an area with an IMD score of 5 or less.[11]

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	13%	42	67%
2	10	16%		
3	6	10%		
4	8	13%		
5	10	16%		
6	11	17%	21	33%
7	4	6%		
8	2	3%		
9	4	6%		
10	0	0%		

8. Overview of Completed Reviews

The LeDeR review performance report as at the end of March 2023 shows that 91% (*n*=337) of 370 reviews received since 2017 have been completed by year end 2023. 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

[11] https://www.norfolkinsight.org.uk/deprivation/reports/#/view-report/8b97d75c317745b3a6016fc0788469d1/E10000020/G3

2021-22	63	85	41
2022-23	63	72	32
Total	**369**	**337**	

In 2022/2023 72 initial and focused reviews have been signed off as complete. At year end (March 2023), the team have 10 reviews in progress and 18 unallocated. This includes 4 which are on hold, awaiting statutory processes to be concluded. For some demographics, our 2022/2023 data collection allows us to break these down into initial and focused reviews. This will allow us to see if improvements can be made in how we select which reviews convert to a focused review. CDOP cases are not included in the initial review section, as this is covered in section 8.

For certain variables such as cause of death, avoidable deaths, areas of deprivation and chronic conditions all reviews, including CDOP 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 64 adult reviews completed in 2022/2023, 40 were initial reviews.

8.1.1 Gender and Age

As with our notification data, we had a higher percentage of men (60%) than women who had an initial review. The median age of death for initial reviews was relatively similar, with 62 years old for women and 59 years old for men. This matches the table below showing most had an age of death between 46 and 64. It is of note however in this age range there were many more men dying than in the 65 and over range, which was mostly women at 73%. The total median age of death was 58.5 years old.

Age at Death – Initial Reviews	Men	Women
19 - 45	<5	<5
46 - 64	19	7
65 and over	<5	8

8.1.2 Ethnic Groups

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.

8.1.3 Diagnosis

In 2022/2023 all 40 initial reviews had a learning disability diagnosis. None had a diagnosis of a learning disability and autism as they were all converted to focused.

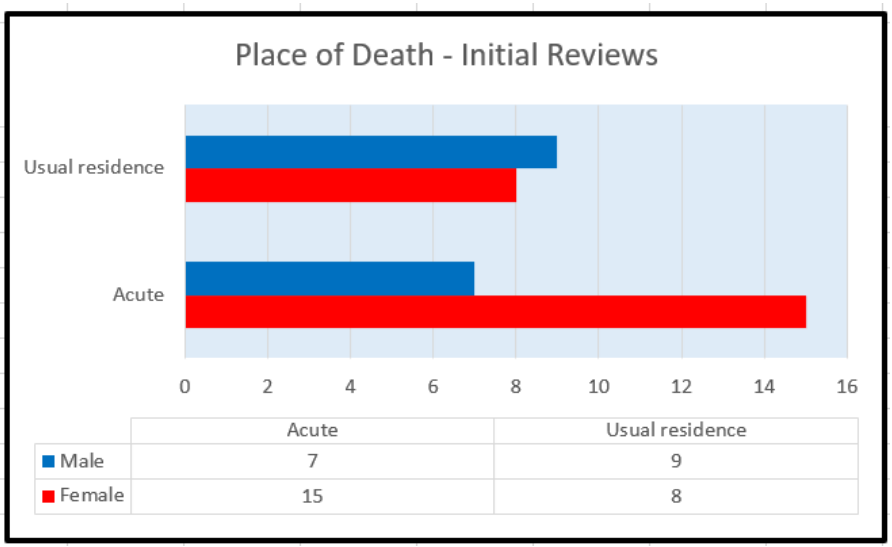
8.1.4 Level of Learning Disability Severity

Most initial reviews (43%) were for people with a moderate learning disability. Followed by severe (35%) and then mild (22%). More men had a moderate and severe learning disability whereas more women had a diagnosis of a mild learning disability.

Level of Learning Disability – Initial Reviews	Men	Women
Mild	<5	6
Moderate	11	6
Severe	10	<5

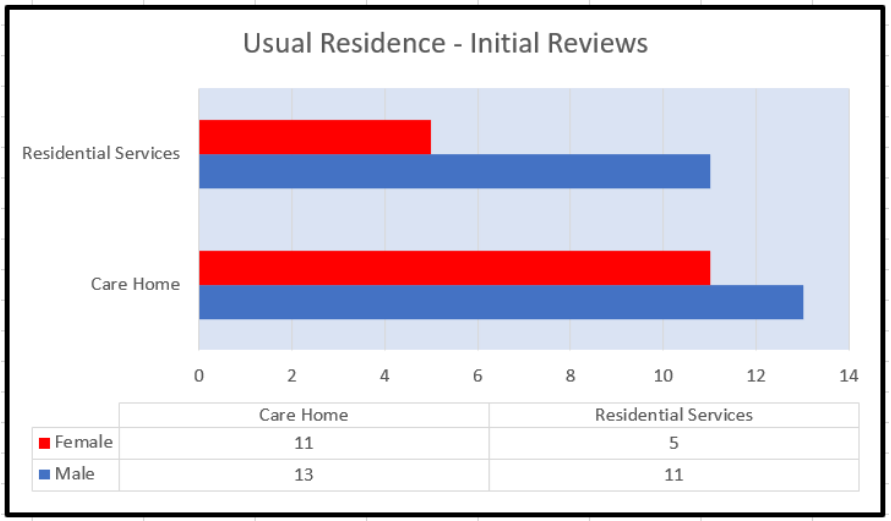
8.1.5 Place of Death

From our initial reviews, most people died in hospital (55%), followed by a care home as a usual residence (35%). The least represented place of death was in hospice, with only slightly more dying in their home when they were living independently.



8.1.6 Types of Accommodation

The overwhelming majority of people who had an initial review lived in a care home (60%), increasing to 75% living in residential services when combined with supported living.



8.2 Focused Reviews

Of the 64 adult reviews completed in 2022/2023, 24 were focused. Only focused reviews are graded on the delivery of quality of care and accessibility and effectiveness of services. The table below show the breakdown of reasons why a review was moved to focused.

Reason for Focused Review	Number	Percentage
Care Quality Concerns	9	38%
Reviewer Professional Judgement	5	21%
Under Section of the Mental Health Act	4	17%
Case Complexity	2	8%
Family Request	2	8%
Ethnic Minority	1	4%
Autism	1	4%

8.2.1 Age and Gender

Of the 24 focused reviews there were slightly more women (54%) represented. Most reviews were conducted within the 18-45 age group, which suggests the team are prioritising focused reviews for those who have died significantly more prematurely. The least number of focused reviews happened in the 65+ age group. This is especially telling as Norfolk and Waveney typically has a higher-than-average population over the age of 65. The median age of death for focused reviews was 57 years for the 2023 annual report.

Age at Death – Focused Reviews	Men	Women
18 - 45	5	6
46 - 64	<5	5
65 and over	<5	<5

8.2.2 Ethnic Groups

Norfolk and Waveney general population data from 2021 shows 94.7% people reported themselves to be white, with the broad minority groups representing 5.3%[12] of the population. However, this year LeDeR only completed one adult review from an ethnic minority (2%).

8.2.3 Diagnosis

In total there were 6 reviews for people with a diagnosis of autism and a learning disability.

Diagnosis – Focused Reviews	Men	Women
Learning Disability	8	10
Learning Disability and Autism	<5	<5

8.2.4 Level of Learning Disability Severity

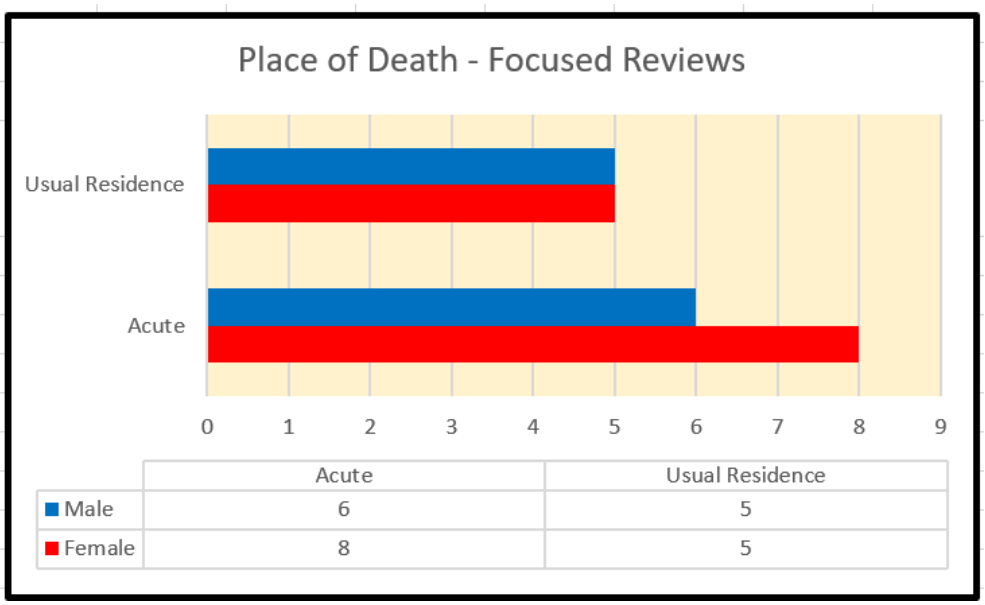
Most focused reviews were completed for those with a moderate learning disability (50%), followed by severe (25%) and then mild (21%). The only review completed in 2022/2023 for a person with a profound learning disability was a focused review, likely due to the complexity of the case. This distribution is similar to our initial reviews, and likely explained by the prevalence of moderate level learning disabilities in all our adult reviews for 2022/2023 (45% *n*=29).

[12] Norfolk - Population - STP | Norfolk and Waveney | InstantAtlas Reports (norfolkinsight.org.uk)

Level of Learning Disability – Focused Reviews	Men	Women
Mild	<5	<5
Moderate	5	7
Severe	<5	<5
Profound	<5	0

8.2.5 Place of Death

Again, our focused reviews reflect that most people died in the acute setting (58%), with similar number dying in their own home, whether that from living in the family home (21%) or in a care home or supported living (21%). The improvement on this year's review quality means we have no places of death recorded as unknown, this year.



8.2.6 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. Grading is based on the information the reviewer has gathered and presented at panel. Of the 24 completed focused reviews

from 2022/2023, 5 of the reviews graded the quality of care as being satisfactory or above; 79% fell short of expected good practice with 14 cases (58%) where this was judged to have impacted the person's wellbeing. The below table shows the grading of Care for completed reviews for 2022/2023.

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	0	0
5	This was good care (it met current good practice in all areas).	0	0
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).	5	21%
3	Care fell short of expected good practice but did not contribute to the cause of death.	5	21%
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.	9	37%
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.	5	21%

Of the 24 completed focused reviews from 2022/2023, 5 of the reviews graded the Effectiveness and Availability of Services as being satisfactory or above; 79% fell short of expected good practice with 12 cases (50%) where this was judged to have impacted the person's wellbeing. The below table shows the grading of Availability and Effectiveness of Services for completed reviews for 2022/2023.

Rating	Standard	Number	Percentage
6	This was excellent Service Effectiveness and Availability (it exceeded current good practice).	0	0
5	This was good Service Effectiveness and Availability (it met current good practice in all areas).	1	4%
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).	4	17%
3	Service Effectiveness and Availability fell short of expected good practice but did not contribute to the cause of death.	7	29%
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.	7	29%
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.	5	21%

Learning identified from the reviewers:
Reviewers recommended that before any change in care setting is made, the person should be involved in this decision and a thorough health and social care assessment completed to ensure the new placement is suitable and, in the person's, best interest. Better quality oversight and monitoring of placements is also required with an expectation as to staff training and competence.

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 currently has the highest number of reviews. However, looking at the last two years you can see the 46 – 64 age group has surpassed it in numbers. The 65+ age category also saw a heightened number of excess deaths due to COVID-19 in 2020/2021 potentially due to the added mortality risk of age. We suspect in the next couple of years the overall majority will reflect our current findings.

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
2021-22	<5	10	27	23
2022-23	7	12	25	19
Total	**19**	**73**	**131**	**146**

The overall median age of death for all adult reviews was 57.5 years old. As the number of reviews continue to increase and our review method governance strengthens, we believe this represents a more accurate representation of the current picture, compared to previous years. Local historical comparison is difficult and currently we cannot accurately measure any trends. We can, however, compare this to the median age of death of 61 years old from the 2021 annual LeDeR report.

8.3.2 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 5. Areas with a rating of 10 were the least represented in the completed reviews. Overall, as with our notifications for 2022/2023, 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 predominantly live in areas of higher deprivation and more so than the general population.

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	11%	46	64%
2	8	11%		
3	9	13%		
4	8	11%		
5	13	18%		
6	8	11%	26	36%
7	5	7%		
8	6	8%		
9	6	8%		
10	1	2%		

8.3.3 Chronic Conditions

Most people with a learning disability and/or people with autism are known to have other complex physical health complications. Analysis of the 64 completed adult reviews demonstrate all but one of the people we reviewed had one or more chronic physical health conditions. 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 adult reviews (most people had more than one condition recorded). There were multiple other chronic conditions seen in less than 5 reviews which have not been listed here to protect anonymity:

Health Condition	Frequency	Percentage
Epilepsy	23	34%
Hypertension	11	17%

Depression/Anxiety	10	16%
Congenital Syndrome	10	16%
Dysphagia	10	16%
Cerebral Palsy	9	14%
T2 Diabetes	8	13%
Hypothyroidism	8	13%
Asthma	6	9%

8.3.4 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. An 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 and 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).

8.3.5 Leading Causes of Death

In comparison to last year, <5 completed reviews were a COVID related death, which is markedly less than the two previous years which can be seen in the table below. 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

The most common leading causes of death for all of the 72 reviews completed in 2022/2023 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.

Leading Cause of Death	Number	Percentage
Aspiration Pneumonia	15	21%
Cancers	13	20%
Pneumonia	11	15%
Type 2 Respiratory Failure	5	7%

Our completed reviews tell us aspiration pneumonia is the most common leading cause of death for the learning disability community in Norfolk and Waveney. Combined aspiration and other pneumonias accounted for 36% of all leading causes of death in the 72 reviews completed in 2022/2023. This mirrors what was seen last year, although the percentage is much higher which could be accounted for by the drop in COVID related deaths. The cancer related death percentage has also increased for this year.

Cancers accounted for 20% of the 72 reviews completed in 2022/2023. There wasn't one leading cancer responsible for a majority of the deaths, but the varying diagnoses seen include breast, bowel, lung, lymphoma, womb and pancreatic cancers.

Figures on the three main national cancer screening programmes were recorded and are discussed more in section 10. These comprise cervical screening, breast screening and bowel cancer screening. Only 3 of the reviewed deaths from 2022/2023 were from a cancer that is currently nationally screened for, and only 2 would have been eligible by the current criteria. Of these 2, only 1 had been screened. The below table looks at the number of leading causes of death by ICD-10 Chapter. There were other chapters allocated 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	35	49%
Neoplasms (Cancers)	13	18%
Diseases of the Circulatory System	8	11%
Diseases of the Nervous System	5	7%

8.3.6 Underlying Causes of Death

The most common underlying causes of death for all the reviews completed in 2022/2023 are set out in the table below. 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 the top three have been listed.

Underlying Cause of Death	Number	Percentage
Cancers	13	18%
Pneumonia	11	15%
Cerebral Palsy	5	7%

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	16	22%
Neoplasms (Cancers)	13	18%
Diseases of the nervous system	10	14%
Endocrine, nutritional, and metabolic diseases	7	10%
Diseases of the digestive system	6	8%
Congenital malformations, deformations, and chromosomal abnormalities	6	8%

Learning identified from the reviewers:
Reviews have made it clear that prevention of respiratory illness, particularly pneumonia needs to be to be a focus for learning and action following this report. Respiratory illness is the primary leading and underlying cause of death for those with a learning disability and autism by a significant margin.
Due to diagnostic overshadowing and other issues in accessing healthcare, diagnosis is often delayed and not made until the person's disease is severe, meaning it is harder to treat and requires an extended hospital admission. Focus then is needed on preventative measures such as training for care staff in the use of Speech and Language Therapy (SALT) care plans and soft signs of deterioration. Further work to increase the provision and uptake of pneumonia vaccines is also required.

8.3.7 Avoidable Deaths

Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/Eurostat list of preventable and treatable causes of death[13] 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 66 Norfolk and Waveney reviews included in this definition 48% (*n*=32) were coded as avoidable, which is representative of the regional and national figures from their latest (2021) annual report. This still far exceeds the avoidable death rate of the general population of 23%.[14]

Appropriate classifications for causes of death are vital to ensuring these figures are accurate. ONS Guidance for the completion of MCCD[15] state that physical and intellectual disabilities and congenital syndromes which are not fatal in themselves should be avoided in Part 1. As seen above, from the completed reviews, classifications in the first part of the MCCD include Cerebral Palsy and Downs syndrome, which can lead to post-mortem diagnostic overshadowing. 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. Child Deaths

Child deaths are reviewed under the child death review (CDR) process. This is a statutory provision, which involves collection and analysis of information from known agencies who were involved with the care provision, before the child died. This is with a view to identifying any matters of concern affecting the health, safety, or welfare of children or any wider public health concerns.

Where the CDR team has a referral for a child or young person with a learning disability aged over 4 years, they invite the senior reviewer to the CDR panel and the Child Death Overview Panel (CDOP) to share in the review process and highlight any learning specific to the young person's learning disability needs.

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

The team has one senior reviewer, who is also a paediatric nurse dedicated to supporting the CDR team with these reviews. The reviewer will complete a referral on the LeDeR platform once notified. After CDOP the CDR team will share their review with the LeDeR team, which is then uploaded to the LeDeR system, and the review is completed.

There were 7 child death reviews shared with LeDeR in 2022/2023. Limited description of data can be given due to the small numbers and the need to protect anonymity. However, it can be shared that 75% of the reviews were for boys and over half of the young people had a Severe or Profound learning disability with multiple co-morbidities. Most young people died in hospital with other places of death including hospice and home. All our young people lived in their family home. Of the completed reviews for 2022/2023, the median age of death for children was 8.5 years old.

Learning identified from the reviewers:
Children's services differ significantly from adult provision, and this is most noticeable in the context of end-of-life care. Norfolk and Waveney are very lucky to have the services of East Anglia Children's Hospice (EACH) in Poringland, who provide Respite, End-Of Life and Bereavement support for children and their families. The provision of wrap around care including ReSPECT, symptom management, named nurses and expert clinicians on call are but a few of the factors that result in personalised and holistic end-of-life care.
Transitional care remains a difficult experience for young people and their family. New services including the Preparing for Adult Life team, acute transition nurses and navigator teams are working well to smooth out the process and support the move however greater collaboration between paediatric and adult services is needed and better preparation for families as to what to expect could be beneficial. Other areas of learning from these reviews have been included in the breakdown in Section 9.

10. 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 antipsychotic medications, provision of reasonable adjustments, cancer screening programmes and MCA assessments as well as end-of-life care.

10.1 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 screening[16]. 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. Including the ICB utilising Health Improvement Support Workers to mentor and provide training for surgeries in best practice for AHCs.

Performance for 2022/2023, across the different localities in Norfolk and Waveney, is measured and can be seen in the table below. Notably there is approximately a 20% difference between the best and worst performing areas, suggesting inequality across the region. However, 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.

Locality	# on Learning Disability Register	# AHC Declined	# of AHC completed	Percentage (without declines)	Percentage (including declines)
Great Yarmouth and Waveney	1734	114	1346	78%	73%
North Norfolk	1131	105	966	85%	78%
Norwich	1467	36	938	64%	62%
South Norfolk	1371	92	1061	77%	73%
West Norfolk	980	34	701	72%	69%
Total	**6683**	**381**	**5012**	**75%**	**71%**

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

In the above table there are two columns showing our percentage of completion. This is due to discrepancies in how NHS England and the ICB measure this data. The ICB count declines, as the person has been invited to their AHC, however NHS England only report on AHCs attended and completed.

Comparing this with the LeDeR reviews, out of the 64 completed for those who were eligible for regular AHCs (aged 14 years and over), 47 (73%) had been offered an AHC in the 12 months before they died. Our post review data collection is also able to tell us that 44 (69%) actually attended their AHC, in the last 12 months before they died. The percentages from LeDeR reviews are slightly behind the Primary Care and national figures. This may be explained by the fact our team have completed a few historical reviews in 2022/2023, for people who died before the improvement work of the health inequalities team started to show progress.

AHCs are a foundation of preventative care for people with a learning disability, and an essential part of managing co-morbidities and reducing mortality. Below, when discussing the main themes found in this year's review, AHC will be discussed to reflect how the attendance of a good quality AHC impacts a person's whole wellbeing. It's of note below that those with a mild learning disability are more likely to not have had an AHC compared to those with a more severe diagnosis.

Level of Learning Disability	AHC Completed (*n*=44)	% AHC Completed	AHC not Completed (*n*=20)	% AHC not Completed
Mild	7	16%	7	35%
Moderate	21	48%	8	40%
Severe	15	34%	5	25%
Profound	<5	xx%	0	0

Those who had had an AHC were 20% more likely to have had an annual medication review, 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*=44)	% AHC Completed	AHC not Completed (*n*=20)	% AHC not Completed
Recorded Annual Medication Review	35	80%	12	60%

The average BMI of those who did and did not have an AHC in the 12 months before they died was relatively similar. Reviewers find this to be more reflective of the quality of AHC and the need for proactive weight management in future, especially as the average BMI for both groups fall into the overweight category.

	AHC Completed (*n*=44)	AHC not Completed (*n*=20)
Mean BMI	26 kg/m2	25.5 kg/m2

Of those on an end-of-life pathway before they died, a higher percentage had not had an AHC completed. This is also true of those who had a completed ReSPECT document. This may be explained by the higher percentage of those without an AHC dying in hospital where ReSPECT documents and end-of-life pathways are more commonly used as demonstrated later.

On an End-of-Life Pathway	AHC Completed (*n*=44)	% AHC Completed	AHC not Completed (*n*=20)	% AHC not Completed
Total	26	59%	17	85%
<1 week	13	50%	8	47%
1-4 Week	8	31%	<5	xx%
1-6 Month	<5	xx%	<5	xx%
6+ Month	<5	xx%	<5	xx%

Place of Death	AHC Completed (*n*=44)	% AHC Completed	AHC not Completed (*n*=20)	% AHC not Completed
Usual Residence	20	45%	7	35%
Hospital	24	55%	12	60%
Hospice	0	0%	<5	xx%

	AHC Completed (*n*=44)	% AHC Completed	AHC not Completed (*n*=20)	% AHC not Completed
ReSPECT Document Completed	34	77%	16	80%

Learning identified from the reviewers:
Reviews are often done solely by nurses and allied health professionals, and there is no time spent with the GP, which is an essential part of the AHC process. Completed reviews can also appear to lack documentation of the conversations happening at the review, giving voice to the person, and showing the quality interactions happening during an appointment. As such an AHC can appear to be used as a "checklist" exercise. More thorough documentation would demonstrate the work being done and better example the quality of AHC. Primary care needs to increase the uptake for those with mild learning disability diagnosis as they are more to be overlooked. Coordination of care to include chronic condition reviews (e.g., asthma and diabetes etc) may be beneficial in the holistic assessment and planning for a person's wellbeing.

10.2 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 plan
- 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 44 completed reviews where there was an AHC in the last year of their life, 25 (57%) had evidence of a HAP in place. The information from data collected by the Primary Care Team for HAP completion in 2022/2023 is very different as seen in the table below. It is important to again note that LeDeR reviews have been completed this year for deaths as far back as 2018. As such current performance in some categories, such as HAP, is hard to measure as it doesn't consider the year-on-year improvements. For example, compared to this year's primary care figure of 70%, in 2021/2022 only 56% had a HAP.

Locality	No on Learning Disability Register	No of HAP completed	Percentage
Great Yarmouth and Waveney	1734	1276	74%
North Norfolk	1131	920	81%
Norwich	1467	841	57%
South Norfolk	1371	955	70%
West Norfolk	980	679	69%
Total	**6683**	**4671**	**70%**

Learning identified from the reviewers:
A completed HAP is difficult for reviewers to assess, as they are often demonstrated in the notes in different ways. Ideally a HAP will be created in the style of care plan with an identified need, the desired goal and then the SMART actions needed to achieve this. These will then be put onto one document which is shared with the person, any carers and a copy uploaded to their clinical notes. This is rarely seen by reviewers and evidence of a HAP is often seen in actions demonstrated as per the AHC consultation notes, for example a referral to the SALT team.
Primary Care agreeing to use a HAP template for across the ICS would be hugely beneficial. This would standardise practice for quality purposes and support its use across other services, for example dietetics and SALT.

10.3 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.

10.3.1 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 5 reviews with these eligibility criteria, none had evidence of a AAA screening being offered, despite 3 having had an AHC in their last year of life.

10.3.2 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. Despite the low numbers of cervical screening uptake as seen below, 13 of the 17 reviews evidenced an annual health check in their last year of life.

10.3.3 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, 12 of the 16 reviews evidenced an annual health check in their last year of life.

10.3.4 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 20 reviews, 12 evidenced an annual health check in their last year of life.

The table below shows engagement with national cancer screening programmes. Bowel cancer has the highest percentage of eligible people screened, of all three. 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 2022/2023. The refusal rate for this intervention was similar to breast cancer screening. The number of eligible people not invited for cervical screening is the highest percentage of the three programmes. Anecdotally reviews have shown health care professionals deciding screening is not appropriate as the person is not sexually active, and therefore deemed to be a low risk.

Attendance	Bowel (*n*=20)		Breast (*n*=16)		Cervical (*n*=17)	
	Number	%	Number	%	Number	%
Did not Respond	9	45%	<5	xx%	<5	xx%
Not Invited/Offered	<5	xx%	<5	xx%	5	29%
Screened	9	45%	6	38%	<5	xx%
Refused	<5	xx%	6	38%	6	35%

Learning identified from the reviewers:
Reviewers felt that more needs to be done to promote the cancer health screening programme, increase uptake and refer for early intervention and treatment as may be indicated. The value of AHCs in the uptake of cancer and other screenings cannot be underestimated, and the appointment should be used to try and engage the person in all the screening programmes they are eligible for. The Mental Capacity Act (MCA) should be used when someone declines screening for themselves or if someone attempts to decline on their behalf. Also, use should be made of support such as the community Learning disability teams where appropriate to support understanding and attendance.

10.4 Vaccinations

New data collection this year has enabled a closer look at the uptake of pneumonia vaccines for those eligible. Chapter 25 of The Green Book of Immunisations[17] states which comorbidities meet the eligibility criteria for the vaccine. Despite recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report[18], Learning Disability is still not included in in this.

Of the 26 reviews, where the persons cause of death was a pneumonia, 23 (88%) 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 these 23 reviews, only 3 had evidence of having a pneumococcal vaccine, meaning 87% didn't.

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 (including children and people with a learning disability) that puts them at risk of flu complications.

Uptake of the flu vaccine was much better, with 72% (*n*=52) of all completed reviews having evidence that the person had a flu vaccine regularly. 37 (71%) of those immunised had attended their annual health check (AHC) within the year before they died. This is in contrast with only 35% (*n*=7) who had not had a regular flu vaccine, highlighting the importance of AHC on public health initiatives and preventative care.

[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

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. 63 of the 72 completed reviews had a date of death after the COVID-19 vaccine roll out. Of those 63, 57 (90%) had had at least one dose. A second dose followed, with uptake starting towards the end of March 2021. 61 of the 72 completed reviews had a date of death after this time and 54 (89%) of reviews had evidence of the person having had the recommended 2 doses. A third dose was offered from the beginning of October 2021. 55 of the 72 completed reviews had a date of death after this time and 42 (76%) of reviews had evidence of the person having had the recommended 3 doses.

Learning identified from the reviewers:
Pneumonia vaccine uptake continues to be very poor amongst those who are currently eligible, and deaths from pneumonia are consistently the most common. Annual Health Checks (AHC) are an ideal opportunity to correctly identify someone as being eligible for a pneumonia vaccine. There is a clear willingness to engage in vaccination programmes from those with a learning disability, looking at the uptake for the flu and COVID vaccines. However, all declines to vaccines should consider the MCA for best practice including a robust capacity assessment and a best interest decision if appropriate.

10.5 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 poor diet and are more likely to be underweight or obese than people in the general population[19]. 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:

[19] https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance

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

Being underweight (malnourished) 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 64 adult reviews.

Gender	BMI (kg/m2)									
	<18	**%**	**19-24**	**%**	**25-29**	**%**	**>30**	**%**	**Unknown**	**%**
Males (*n*=35)	<5	xx%	16	46%	7	20%	<5	xx%	5	14%
Females (*n*=29)	<5	xx%	10	34%	6	21%	8	28%	2	7%
Total (*n*=64)	6	9%	26	41%	13	20%	12	19%	7	11%

In the 64 completed adult reviews both men and women mostly had a healthy BMI recorded. In men, this includes a higher percentage in the 19-24 than even the overweight and obese categories combined. For women however, a higher combined percentage were overweight or obese. There were also more women who were underweight than men. 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.

Learning identified by reviewers:
AHC and HAP need to be utilised to support people maintaining a healthy weight. Reviewers too often see weight highlighted as an issue, with no intervention or follow up to review progress. There needs to be earlier and more robust management at primary care level. Including referral to specialist dietician services to be utilised when needed. Supported living and care home environments need better staff training and a shift in focus to support better nutrition and build more exercise into social activities. Care commissioners should focus on weight management as a quality indicator and pick this up during quality visits and in reviewing provider performance.

10.6 BMI and Psychotropic Mediations

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 drugs[20]. Of our completed adult reviews, 59% (*n*=38) had evidence of psychotropic medications being prescribed.

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 adult reviews recorded as being on a psychotropic medication, 29% (*n*=11) had a BMI considered overweight or obese.

Long term psychotropic use with epilepsy is expected. This is often a first line treatment and effectively managing epilepsy is essential at avoiding SUDEP. However, 64% (*n*=7) who were prescribed psychotropics, had them for a mental health condition or to support in behavioural management, and 71% of those (*n*=5) had been on psychotropics for over 5 years.

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

STOMP[21] 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, mainly comprising psychotropic medicines.

58% (*n*=22) had a psychotropic prescribed due to an epilepsy diagnosis and the overwhelming majority of these cases (68% *n*=15) has been prescribed them for over 10 years, as expected with a chronic condition. The reviews evidenced that 91% (*n*=20) had a regular medication review.

42% (*n*=16) had a psychotropic prescribed due to a mental health diagnosis and/or for behaviour management, only 56% (*n*=9) had evidence of a regular medication review, which is markedly lower that those prescribed psychotropics for epilepsy.

29% (*n*=11) had multiple psychotropics prescribed for multiple diagnosis. Mostly this was a diagnosis of epilepsy with a mental health condition and/or behaviour management.

Most people prescribed psychotropics had a moderate learning disability, followed by severe and then mild. The table below shows the findings from completed reviews.

[20] https://www.bap.org.uk/pdfs/BAP_Guidelines-Metabolic.pdf
[21] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

Learning Disability	Mild	Moderate	Severe	Profound	Total
Psychotropics prescribed	7	17	13	<5	38
Percentage	18%	45%	34%	xx%	

Learning from the reviewers:
An AHC is an excellent opportunity to review a person's medication. With proper preparatory work with the person and/or their carer you can get a picture of how medication is being used, especially "as required" medication that may not be managing a chronic condition. Reviewers found psychotropic medications used for epilepsy were very well reviewed by the epilepsy team. However, medications used for mental health conditions or for behaviour management were not. A Norfolk and Waveney strategy for STOMP would be a welcome step to imbed its principles into all prescribing.

10.8 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 states[22]:

- 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 over the age of 16 would have required a capacity assessment at some point in their care. From the reviews 72% (*n*=46) had evidence of a capacity assessment being completed. This year we were also able to

[22] Section 1 of https://www.legislation.gov.uk/ukpga/2005/9/contents

document those where adherence to the MCA was variable, which accounted for 29% (*n*=12) of reviews. Only 6 reviews had no evidence of a capacity assessment having been completed at all.

Learning from Reviewers:
Compliance with the MCA is largely variable; with quality and accuracy of documentation being the most identified problem by reviewers. This was most apparent in acute settings. Improvement is needed to demonstrate a robust capacity assessment and best interest decision making. Both to evidence good practice but also to give to voice and representation to the person being discussed. An Independent Mental Capacity Advocate (IMCA) should be a better utilised service. It is expected that a referral should be made for any non-emergent capacity assessment where advocacy is needed. Reviewers see multiple missed opportunities for this. IMCA commissioners could also look at quality requirements for the service. For example, the time taken for an IMCA assessment and the need for a face-to-face meeting with the person before a decision is made.

10.9 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	20	31%
No	33	52%
Variable	<5	xx%
Not Applicable	9	14%

10.10 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, 43 (60%) had evidence of the person being on an end-of-life pathway before they died, however the length of time varied from a couple of days to over 6 months. A higher percentage of people who died on an end-of-life pathway, died in the acute setting.

	Place of Death					
End-of-life Pathway	Acute	Percentage	Usual Residence	Percentage	Hospice	Percentage
Yes	26	60%	15	48%	<5	xx%
No	14	35%	14	48%	<5	xx%

However, from all the completed reviews, most people died in the acute setting. Second highest was the persons usual residence including private residences and residential services. As with last year, we had a very low number of people dying in hospice care with the majority who did being children. There is no data available to indicate whether people's wishes were observed in all settings.

Place of Death	Number	Percentage
Acute	40	56%
Usual Residence	29	40%
Hospice	<5	xx%

Learning from the reviewers:
More people are dying in hospital than anywhere else, despite this not always being their preference. We have seen some excellent examples of care from residential homes, in supporting people to die at home. Also there have been examples of carers working in the acute setting when someone is at end-of-life to reassure and comfort them when care at home is not possible. However, there were also many examples of late admissions to hospital which potentially could have been avoided by better provision of collaborative end-of-life care.

Earlier referrals to palliative care and implementation of an end-of-life care plan would aid in symptom control for the deteriorating patient. Especially pain management, which poses extra challenges for care staff due to the lack of parent and/or carer advocacy, variability of communication and interpretation of pain indicators. Seizure management poses a challenge in community end-of-life care, which has been distressing for the person and their carers. Closer involvement with specialist epilepsy teams and those planning a person's end-of-life care could improve seizure management and react quicker to any deterioration.

We continue to see a lack of confidence in residential services (including care homes and supporting living) in supporting people to die in their home. More robust care plans and symptom management plans would help carers respond to symptoms and identify when escalation is needed. Better training for staff would also be beneficial in building knowledge and competence. Discharge planning from acute settings also needs improving, especially when a person is being discharged on palliative care. Better liaison is needed between the discharging team and the residential home to ensure they are equipped and prepared to deliver good end-of-life care.

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

The Recommended Summary Plan for Emergency Care and Treatment[23] (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 53 (74%) had evidence of a completed ReSPECT document at the time of their death, with most having died in hospital (62%). As previously mentioned, ReSPECT is a discussion which should happen as part of the AHC. According to reviews, 64% of those who had a ReSPECT document completed, had attended an AHC in the last 12 months of their life. Of the 43 people who were on an end-of-life pathway, 93% had a ReSPECT form completed. This is compared to only 45% of those who were not on an end-of-life pathway.

Learning from the reviewers:
ReSPECT document completion is often seen by reviewers however the quality and utility of these forms is not good and too often completed in hospital soon before the person dies. ReSPECT document education and training should be a focus for Norfolk and Waveney. Providers should support wider registered health care professionals becoming competent in completing and signing off ReSPECT forms, including registered staff in nursing homes and GP practices. Proper training will increase the number of staff able to complete the form, but also open it up to staff who know the person well and better able to advocate for their wishes.

10.12 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

[23] https://www.resus.org.uk/respect/respect-healthcare-professionals

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 52 (72%) patients had a DNACPR order in place before they died, with 66% of these being deemed appropriate according to the evidence available.

Learning from the reviewers:
DNACPR are seen in most reviews. This is likely due to high number of acute deaths, however with an increase in properly planned community care we may see a similar, if not a higher, percentage. Most DNACPR were seen as being appropriately put in place, however documentation of the decision-making process is often poor, including use of an IMCA, inclusion of those who know the person well and use of the MCA.

10.13 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	• Environmental controls such as side rooms and admitting straight to wards to avoid A&E. • Extended appointments to build relationships and encourage engagement. • Face to face appointments and home visits from primary care. • Use of hospital passports. • Acute Learning Disability Liaison Teams.
Communication	• Provision of communication care plans. • Adapted communication which meets individual needs.

	• Easy read communication to support with decision making. • Easy read information to support self-management. • Time allowed for processing.
Familiar Carers	• 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. • Staff are encouraged to attend appointments with people for support and advocacy.
Bespoke Care	• Collaborative needs-based care planning. • Good response to soft signs of deterioration. • Balancing of deprivation of liberty and risk assessment to make a best interest care plan. • Care provision commissioned based on what is best for the person. • Paediatric hospice provision. • Additional provision of 1:1 support where necessary to keep someone safe in the short term. • Support for people to meet their goals and aspirations.
MCA Principles	• Good and appropriate documentation of the MCA process and decision making by the ALDLT. • Involving IMCA where no advocacy is available. • Involving people in decisions made about them, using adapted means to communicate.

Theme	Examples of poor use of reasonable adjustments
Adapted Access	• No admission plans to avoid busy and distressing environments which can impact concordance with care. • Poor time allowance for someone to process instructions given for diagnostic imaging. • Lack of preparatory work to reduce stress and encourage engagement with interventions, for example blood tests and cancer screening. • Lack of appropriate equipment in acute settings to meet needs, for example hoists and adapted scales. • Inflexibility in prioritising face to face assessments for those at higher risk of diagnostic overshadowing.
Communication	• Lack of inclusion for people in decision making about their care.

	• Lack of adapted communication to aid and assess understanding. • Services not using or not having communication plans for people, which disadvantage people being invited to appointments or learning how to self-manage chronic conditions.
Familiar Carers	• No familiar carers provided during admissions by the person's home. • Acute hospitals not prioritising a small group of ward staff working with a person to help build trust and relationships.
Bespoke Care	• Personalised homecare packages have been difficult to put in place due to housing availability and available of suitable residential services.
MCA Principles	• Limited use of advocacy services. • Poor adaptive communication to best inform a person and assess understanding. • Best interest meetings may not always need to be strictly formalised, but documentation is required to evidence the work.
Service Availability	• Referral opportunities are missed for specialist learning disability and other universal services. • 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. • Quality monitoring of residential services can be limited and lead to poor outcomes.
Diagnostic Overshadowing	• Services not considering a person's vulnerabilities when setting a threshold to consider neglect and other abuse. • Recognition of the menopause for women with learning disabilities is poor. • Use of telephone assessments, even with carer support is not ideal when properly assessing an unwell person who may be unable to properly express what is wrong. • Inappropriate use of non-adapted measurement scales including pain and impairment of consciousness.

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. It is notable that more reviews demonstrated no examples of missed reasonable adjustments than reviews where no reasonable adjustments were seen. Overall,

there is definitely evidence of more use of reasonable adjustments than not. The table below shows the numbers of reviews with evidence of reasonable adjustments being made and reasonable adjustments being missed.

Theme	Number of reasonable adjustments seen	Number of reasonable adjustments required
Adapted Access	25	17
Communication	19	12
Familiar Carers	24	<5
Bespoke Care	22	<5
MCA Principles	5	8
Service Availability	0	13
Diagnostic Overshadowing	0	5
None	6	26

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.

10.14 Staff Training

10.14.1 Restore2™

Delayed recognition of deterioration is an area impacting on the quality of care. 'Train the trainer' in Restore2™ tool has been delivered to 15 people in the community learning disability teams across Norfolk and Waveney. From here the community learning disability team achieved its target of delivering this training to all care staff by 2023. Restore2™ is a tool designed to support care staff and health care professionals to:

- Recognise when a person may be deteriorating or is at risk of physical deterioration.
- Act appropriately according to the person's care plan to protect and manage them.
- Complete a set of physical observations to inform escalation and conversations with health professionals.

- Contact the most appropriate health professionals in a timely way to obtain the right support.
- Provide a concise escalation history to health professionals to support their professional decision making.

10.14.2 ReSPECT

All LeDeR reviewers have undertaken Level 3 ReSPECT training over the last year to ensure they are fully equipped to assess the quality and completeness of the forms we see, and the process undergone to complete them. As a major initiative for admission avoidance, Norfolk Community Health and Care NHS Trust (NCH&C) commenced ReSPECT Level 3 Education in 2020. This education package needs to be underpinned with comprehensive and on-going clinical support and governance. This would help prepare both competence and confidence in those registered clinicians wishing to hold ReSPECT conversations and complete ReSPECT documentation with the people they support, including those with a learning disability and/or autism.

In 2022/2023, the team delivering the training has supported 78 clinicians to complete this training, from across the ICS including primary care, social care, community services and the acute setting. It is hoped further sessions will be commissioned into 2023/2024 to continue this work.

10.14.3 Knowledge Anglia

A QR code has been shared below where providers can access resources to evidence based health and wellbeing from our NHS website Care Providers (knowledgeanglia.nhs.uk)

11. Safeguarding

Reviewing the deaths of people known to have a learning disability and/or people with autism helps 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, this year 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 document[24] and a structured process for referring for Safeguarding Adult Reviews (SAR). More recently, with the formation of the ICS Learning from Death Forum, the Senior Nurse Manager and LAC for the LeDeR programme will be presenting the findings of reviews every quarter to share key learning with representatives from the wider NHS providers and the ICB's Safeguarding Team. Over the last year our team has made three referrals for a SAR, following the agreed process. For LeDeR, the basis for a SAR is to learn lessons from particularly complex or serious safeguarding adult cases. This is where an adult has died, and abuse or neglect has been suspected due to services not working collaboratively to adequately safeguard the person. If the referral is accepted a detailed review is undertaken and recommendations are made to change or improve practice and services.

Learning from reviewers:
A general theme in all safeguarding referrals was the impact of poor collaborative working between services and professionals on a person's treatment and outcome. Also noted was poor use of the MCA in decision making for life changing interventions and procedures. Lastly was the provision of appropriate residential care in the community which protected the person from harm and met their basic care needs.

12. 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

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

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**.**

Samantha was a 34-year-old woman who lived at home with her family. Samantha liked horse riding and listening to music. She loved being with people and had a very busy social life, which unfortunately was impacted by the pandemic. Samantha had a very loving and involved family who adapted to keep her occupied and busy, but the isolation was hard for her to understand. Samantha had very complex chronic health needs which were managed both locally and with specialist teams at a tertiary centre. Samantha and her family had very different experiences of care between these environments. At the tertiary centre Samantha would often be given a side room to avoid the busy ward environment which she would find distressing and her family were also accommodated so they could stay with her, giving her an advocate and the reassurance of a loved one.

Locally Samantha's care was less well managed. There were difficulties for Samantha's family in getting appropriate housing solutions to meet her needs as well as issues in sourcing home care to fulfil her Continuing Health Care package. Sourcing appropriate equipment and consumables, which Samantha was prescribed to prevent ill health, was very difficult as this was not part of a commissioned service. Neither was their sufficient respite provision that could meet Samantha's complex health needs locally, meaning long waiting lists to attend.

Angela was a 19-year-old young lady who lived with her parents. Angela attended college three days per week and was supported via her Personal Health Budget to attend multiple clubs and groups. Angela liked the theatre and was learning braille. Angela had recently transitioned to adult services, which had been problematic. Most notably was a lack of coordination between the wide-ranging services that supported her. This caused delays in provision of care and duplication. Positively however, when the learning disability community nurses accepted the case, it appeared to join up some provision which improved things.

Angela also benefitted from the work of the Acute Learning Disability Liaison Team (ALDLT), who supported her with an emergency admission plan, supported her clinicians with best interest decision making and discharge planning and other reasonable adjustments such as a quieter side room. Also, despite having turned 19, Angela's end-of-life care was on the paediatric ward where she was familiar and knew the staff. Angela also had the support of a condition specific specialist nurse from a charity organisation. They were involved in supporting Angela and her family on almost a daily basis, even at weekends and advising health professionals, participating in therapy sessions and best interest meetings.

Jacob was an 81-year-old gentleman who lived in a residential care home. He loved nature and attended a farm day centre before the pandemic. He also enjoyed arts and crafts, getting out on the bus, and was described as having a great sense of humour.

Jacob had an excellent experience of care. His GP practice were very responsive to his needs, for example continuing with reasonable adjustments such as home visits, even during the COVID-19 pandemic. His care was proactive, and clinicians were aware of the risk of diagnostic overshadowing due to the impact of his limited communication, so in one case they ordered additional imaging for a minor ailment to rule out anything more serious.

Jacob had a few admissions to hospital in the last year of this life, and thanks to the meticulous work of the ALDLT, the Mental Capacity Act (MCA) was used well to make appropriate best interest decisions where Jacob's voice was heard. His ALDLT involved his community teams including the dieticians who knew him well and supported the collaborative care planning that happened.

Christine was a 69-year-old lady who lived independently, with the support of some close friends and neighbours who she described as being like family. Her neighbours were a huge practical and emotional support for Christine, especially towards the end of her life when she became less able to manage independently. This care ultimately allowed Christine to stay at home for as long as she did which was very important to her. Christine had been married and been widowed. She attended an activity centre twice a week which was a big part of her life and when at home she liked to knit and colour pictures.

Christine had not had an annual health check as he has never been put onto her surgery's learning disability register. However, Christine did have other annual reviews for her chronic conditions. Yet, despite being recognised as vulnerable by those that knew her, Christine was left by district nursing teams to arrange and order various consumables by herself. This was too difficult for Christine who did not understand what was being asked of her, especially as instructions were in letter format and Christine was not able to read or write.

Christine was unknown to the ALDLT until her referral for support at her cancer diagnosis. At her last admission the ALDLT were very attentive with Christine, building a relationship with her and visiting often to reassure her with a friendly face as she did not like being in hospital.

Harriet was a 32-year-old woman who lived in supported living. Harriet was very sociable and had close ties with her family who supported her to live as independently as possible. Harriet liked her routine and loved being out and about, meeting friends for a hot chocolate and spending time with her family. She loved life, was very happy and cheerful.

Due to her chronic health conditions, Harriet had regular hospital appointments and admissions. Despite having a hospital passport this was rarely referred to which could be frustrating as Harriet and her family frequently felt they were not listened to. Harriet's personal and skin care was a vital part of her daily routine and essential to keeping her well. This took time to complete, and Harriet could not do it independently, but was viewed as being a low priority for hospital staff. However, Harriet was included in decision making regarding her treatment and family were given open access 24/7 to visit her.

Harriet's GP continued to see her face to face throughout the COVID pandemic and provided information in advance to help her prepare for her annual health check. She was also supported with an appointment before her cervical smear test to prepare her for the procedure.

Barry was a 56-year-old gentleman who lived in a supported living environment. He was always laughing and joking with friends and carers, and he loved country music, watching television and spending time with his siblings. Barry had a few hospital admissions in the year before he died. His carers always made sure he went in with his hospital passport which was well used. The ALDLT supported clinical teams while Barry was on the wards and there were excellent examples of the MCA being used properly to make decisions in his best interest and with his voice heard.

It was recognised early that Barry was moving towards end-of-life and a ReSPECT form, and an end-of-life plan were completed early which supported Barry to stay at home and avoid any further hospital admissions, which is what Barry wanted. Barry avoided hospital for 12 months, despite having chest infections and requiring wound management. This was well managed by primary and community care in liaison with the care home. This working relationship continued when Barry died. The care home wasn't overly confident is supporting Barry to die at home, but with the support of the GP they supported his wishes.

Kathy was a 57-year-old lady. She had previously been married but was widowed so had moved back in with family. Kathy enjoyed going shopping and especially enjoyed car boot sales. Kathy had attended her annual health checks however management and response to her chronic conditions did not meet best practice and impacted on her health and wellbeing. Both on acute admissions and when at the GP, professional curiosity was lacking in assessing Kathy's safeguarding risk and appropriate referrals were not made.

Advocacy for Kathy was lacking, and this meant her medicines were not appropriately managed, and referrals were not made in response to chronic obesity and poor symptom control. They day before her death Kathy had attended the GP, but due to

diagnostic overshadowing necessary tests were not conducted which may have highlighted earlier, the underlying cause of her death.

Terry was a 59-year-old gentleman who lived at home with his family. Terry was described as great fun and a real character. Keeping Terry at home was important to him, and his family and community learning disability teams worked to support this.

The GP practice considered reasonable adjustments to Terry's care and completed home visits, even during the COVID period. They also conducted home visits to explain to everyone end-of-life plans and ReSPECT forms. Terry had attended for his annual health checks but did not have one in the year that he died. However, he had a lot of support from his GP in this year due to his deteriorating health including medication reviews and referrals for specialist support with symptom management.

Terry had a loving family who cared and advocated for him, and they were consulted in many aspects of Terry's care, along with social workers, to come to a best interest decision for procedures in hospital. However, there was little documentation of the use of the MCA and best interest decision making for Terry's vaccinations. There were records of his influenza and COVID vaccinations either being declined or not brought to invitations, with no follow up to explore why and attempt to encourage access to public health initiatives.

13. 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. Those which fit into current workstreams are fed into the appropriate working groups. Otherwise, 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 and is summarised below. Firstly, there are the projects undertaken by the working groups. Secondly the actions and work undertaken on behalf of the LIAG, and lastly other works completed by the LeDeR team to further the aims of LeDeR within Norfolk and Waveney.

13.1 Working Group Projects

13.1.1 LD Dietetic Weight Management Pack Pilot

Weight management was highlighted in last year's annual report so a nutrition working group was established with members representing organisations across the ICS learning disability services. We established there was already an excellent resource provided by the learning disability dietitians, for eligible referrals (Anyone with a BMI >25 with a weight related comorbidities or anyone with a BMI >30). This would be provided to the persons care staff or family with instructions on how to complete but progress was unmonitored and there was no follow up.

The working group wanted to see if more oversight and support using the weight management pack would give better results. The Local Authority Supported Living and Residential Review Team recommended one care environment to take part in a small pilot and 8 eligible residents were identified. The team also agreed to support the work by providing an assistant practitioner to collate progress forms for review.

There is dietitian oversight throughout, with a protocol formulated with safety netting for the provider on support services should they need it, for example SALT and Learning Disability Community Nurses (LDCN). The social prescribing team provided a prescriber to support the work and undertake assessments on all participants to suggest options to support their goals.

Capacity assessments were conducted jointly between an experienced LDCN, working as a reviewer, and the dieticians. Easy read supplements of the workbook and progress forms were reviewed and advised on by Opening Doors and shared with the home, once completed. A half day training package for key staff was completed by the Senior LeDeR Nurse Manager and the dietetic team to explain the pilot and fully inform them on the pack, how to use it and give them the opportunity to ask questions.

Following preparations the pilot began at the beginning of March 2023, with an anticipated 6 months run time. So far, the provider has started "Heathy Eating Meetings" which people are excited about and engaged in. They have been looking at topics including healthy foods, diabetes, and cooking. Sessions are varied have included collage making and use of IT for research as well as their workbooks.

People are becoming more involved in meal planning and cooking, using cookbooks to get ideas. Social prescribing has arranged 2 half an hour fitness classes per week with a personal trainer and Coopers Mill are doing a 3rd self-run fitness class. Making 3 per week. Plans are in progress to dig and care for a vegetable patch on the grounds.

The dietitian team attended the provider again in May to give a workshop to vary the programme delivery and help motivate the participants and explain the importance of monitoring measurements such as weights and waist circumference. We had our first monthly feedback meeting in April with feedback forms which do show a weight loss for most participants. Hopefully this trend will continue and if benefit can be shown then a case can be put forward for service change.

13.1.2 Residential Services End-of-Life Toolkit

Supporting residential services was highlighted in last year's annual report to better end-of-life care in the community and allow more people to die in a place of their choice. The end-of-life working group took on a project, to adapt a resource developed in Derbyshire, which had already been recognised as useful for carers, professionals, and families.

The toolkit charts the support available locally from diagnosis, through bereavement and into aftercare. The idea is to give as much information to providers as possible so they can plan and arrange appropriate services are in place to meet the persons need at home where possible.

The group worked with multiple professionals across the system to update and adapt the toolkit to reflect local information. There were also areas that were missing, which were included to better reflect the needs of people in Norfolk and Waveney. The toolkit has been finished and given to the ICB Communications and Engagement team for design and branding. Once complete the toolkit will be rolled out to providers, supported by the local authority.

13.1.3 Non-Invasive Long-Term Ventilation (NILTV) Care Pathway

Following the learning from Cawston Park, the focus of the respiratory working group has been improving NILTV care for people with a learning disability and autism. Locally, only one hospital in our system assesses, prescribes, and manages NILTV and progress here has been largely driven by the ALDLT Matron.

The outcomes of the project included:

- To improve training and education for care providers supporting someone being prescribed NILTV.
- Better care planning, to advise parents and/or carers when to respond to changes.
- Establishing pathways for servicing and consumables replacement.
- Better involvement from learning disability specialist teams.

Progress has been made firstly by establishing a Multi-Disciplinary Team (MDT) review to include the ALDLT prior to discharge when a person is started on NILTV. A pathway for referring to the dietetic team is in placed to review referrals when weight is a factor in the requirement for LTNIV. Education materials have been created by Baywater; a company commissioned by NSHE to develop accessible education materials for another region. The team arranged local focus groups and shared a survey on behalf of Baywater to gain feedback and coproduce localised information. Videos with local teams who would support a person newly prescribed NILTV have also been arranged including the CLDN, ALDLT and the respiratory team.

The respiratory and ALDL teams have created a more formal process for capacity assessments and best interest decision making when there is non-concordance. If a person is to be discharged from the respiratory team because NILTV is no longer a viable option, then suitable planning for end-of-life care is required including the acute and community learning disability teams.

13.1.4 Improving Uptake and Quality of Annual Health Checks (AHC)

A working group to look at improving AHC was arranged in response to last year's annal report, however its success in engaging primary care was limited. To better use resources, this group was disbanded and the team focused on supporting current pieces of work across the ICB.

Firstly, the health improvement team have been focussing their support on South Norfolk. This has included:

- Outreaching to patients (or their carers) who have not had their Annual Health Check for more than 12 months to support with attendance.
- Contacted 26 surgeries and visited 18 surgeries and trained 11 from South Norfolk and 3 from other localities.
- Called 158 patients from 8 surgeries and called patients who are not responding 2-3 times. Next step is home visits.
- Supporting surgeries with a learning disability register review to ensure its accuracy.
- Engaging care and residential homes to arrange visits to promote best practice and supporting residents with annual health checks.
- Representing AHC at Learning Disability events, including those targeting ethnic minorities.

The LeDeR team have also supported establishing a Point of Care Testing (POCT) Pilot, led by the Primary Care Commissioning Team. Following allocation of some resource from the NHSE Digital Team, a 12-month project was devised to demonstrate that the use of POCT can make every visit to general practice count and lead to improvements in overall patient experience and care for those living with a learning disability. It is hoped that General Practices will undertake the point of care blood tests as part of the AHC with the results available for clinical use shortly after to inform goals incorporated in the HAP.

The LeDeR team supported with clinical advice and the selection of an appropriate device which was done in collaboration with representatives from general practice. The pilot had a fantastic response from surgeries and more than expected signed up to the project. At the end, the team expects to know if POCT improves the quality of AHC and if so, look at how this can be rolled out across the system.

13.1.5 Learning Disability Notification of Admission Pathway Pilot

The acute working group has been focussing on improving the communication between acute and community services who support those with a learning disability including physiotherapy, occupational therapy, dietetics, and SALT. A pathway was proposed based on a model currently working between SALT in the community and one of the hospitals.

The proposed outcome of the pathway is that on admission, during admission and at discharge for someone with a learning disability and/or autism; the sharing of information could be improved to enable a better experience for patient and health care professionals. It would provide up to date care plans to services on admission to support acute teams in assessment and intervention. Also, on discharge so community teams can support continuity of care in the community setting.

By improving discharge planning and care this could reduce “failed discharges”. A communication network could allow a more holistic picture of a person’s experience to identify increasing hospital attendance, known risks, soft signs of deterioration and safeguarding concerns. Also, it could create a good professional network to encourage collaborative working for when MCA and best interest decisions are required.

A draft pathway has been developed between the community services and one acute hospital, once finalised and established this will be introduced to the two other hospitals in Norfolk and Waveney to deliver consistency across our area.

13.1.6 East Anglia Children’s Hospice (EACH) Hospital Passports

A piece of work which came out of a children’s review was considering how best to support an emergency admission from EACH for a young person having respite care. EACH support children and young people from across Norfolk and as such there is the possibility a child may be admitted to the closest hospital from their centre, despite this not being the child’s local hospital. As such they may not be familiar to staff or have an open access arrangement in place.

A task and finish group was arranged to explore sharing hospital passports and arranging for learning disability flags to be put into the system. It was agreed that it would be useful for every child who lives out of the catchment area of the hospital closest to EACH to have an Emergency Admission Plan and be registered digitally with a learning disability flag. It is hoped this will support staff in meeting their reasonable adjustments on admission, which would like to be through A&E while also notifying the ALDLT.

It was agreed that EACH and the ALDLT would work together to identify which children and young people are from out of area and access respite at EACH. A letter will be sent to each family to invite them to contact the ALDLT, should they wish to share an updated hospital passport and register with the hospital. EACH will also complete an EAP for all their respite children and share this with the hospital to be added to electronic records. In the case of an admission a paper copy will also be sent in with the discharge letter.

13.2 Learning into Action Group Work

Not all learning from completed reviews fits into current workstreams, nor is it big enough to warrant it. As such, if an action is identified it is allocated to the most appropriate person. Below is a selection of some of the work which has come out of LIAG in 2022/2023:

- Completing the governance arrangements for LeDeR including Terms of Reference and action plans with easy read versions for experts by experience.
- Establishing a safeguarding process including training needs, a safeguarding record log and supervision arrangements.
- Established close working with mortality leads with agreement for reviewers to attend all SJRs for those with a learning disability and/or autism.
- Working towards a collaborative model for SJRs across Norfolk and Waveney to ensure consistency and quality.
- A joint statement from the acute working group was shared describing concerns regarding MCA and BI use in the acute environment which was escalated to the NSAB who established MCA training led by social care and the ICB designated safeguarding team.
- Work to highlight some issues with the application and assessments of Disability Facilities Grants for those with progressive neurological conditions.
- LeDeR reviewers are now gauging IMCA quality in reviews to enable feedback of problems to the commissioning team.
- Working with ambulance services to confirm practise around DNACPR.
- Ongoing escalations regarding acute discharges and referral quality.
- Working with community healthcare provision to clarify that respite units have updated risk assessments and the current service provision post COVID, to better support families.

- Communicating with the transition networks regarding the importance of current diagnosis coding to protect learning disability registers and access to AHC.
- Supporting work between inpatient mental health wards and acute and community services to look at memorandums of understanding for staff escorting mental health patients into hospitals. This includes MDT practices for complex patients and ensuring annual health checks are completed.
- Noting and sharing of positive practice from reviews including letters to providers to celebrate success.

13.3 Other Work

The LeDeR team looks at any opportunity to share the learning from LeDeR and improve services wherever possible. The senior nurse manager has supported many workstreams in 2022/2023, some of which are mentioned below:

- Education sessions for colleagues within the ICS on the 2021/2022 LeDeR annual report including safeguarding leads, Continuing Healthcare Nurses, social care and community learning disability teams.
- University lectures for learning disability nursing students.
- Arranging and chairing the monthly primary care LD leads meeting with a varied training sessions agenda including SEND, Trauma Informed Practice, MCA/LPS, SALT, Portage and C(E)TRs amongst others.
- Supporting with testing for the new LeDeR review proforma on the platform.
- County National Power Outage and Rolling Power Outage Planning Working Group.
- Collaboration to share LeDeR learning with the LA to develop their residential care strategy.
- Liaising with the regional team to look at work in Menopause care for those with a learning disability.
- Providing placement experience for nursing students.
- Attending the regional Reasonable Adjustment and Digital Flag working group.
- Attending the regional Annual Health Check delivery and improvement group
- Attending and presenting learning to the ICB Learning from Death Forum.
- Contributing to the National Learning from Deaths definitions Task and Finish Group for Severe Mental Illness and Learning Disability.

13.4 Looking forward to 2023/2024

Some of the workstreams mentioned above will continue into next year and develop in response to any changes. However, from the reviews undertaken in 2022/2023, we know that we need to do more work in the following areas:

- Prevention of respiratory illness through better preventative and dental care.

- Increasing the uptake of screening programmes.
- Improving end-of-life care provision with earlier identification and better symptom management and care planning.
- Improving the quality and uptake in Annual Health Checks and Health Action Plans.
- Better provision in the care market to supply personalised care in a community setting.
- Increasing the awareness of LeDeR for those with autism and increasing our referrals for those who have died.
- Improve the co-ordination of care for people with learning disabilities and chronic health conditions and physical disabilities.
- Improve application of the Mental Capacity Act across our partner organisations.
- More comprehensive completion of ReSPECT documentation by a wider range of trained health professionals.

14. Local and Regional Partnership and Collaboration

14.1 Moving towards an Integrated Care Board

NWICB came into effect on 1st July 2022. New governance structures were finalised to support LeDeR delivery across the system.

14.2 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:

nwccg.haveyoursay@nhs.net Facebook Twitter

14.3 Educating Colleagues and the Future Workforce

Plans are underway to build LeDeR into the curriculum for all nursing and allied health professional studies at the University of East Anglia (UEA). Programme leads have been very supportive and working collaboratively with the LeDeR senior nurse manager to achieve this. The next step will be to establish similar relationships with the UEA medical school. Following the publishing of every annual report, the LeDeR team tours the ICS to share the learning from last year. So far bookings include talks with services including the Coroners, Norfolk Safeguarding Adults Board, Social Prescribing, Primary Care and community learning disability teams amongst others.

15. Conclusion

The last year has seen a dramatic change in the way LeDeR is delivered in Norfolk and Waveney; with performance, quality and learning into action improving significantly. Review data collation this year has given the team a wealth of information from which to identify what needs to change and what is working well. However, it does represent a reset, and our ability to look at historical trends with any accuracy is limited.

Our work is incredibly well supported by health and social care providers across the ICS. We are also very indebted to the contribution from experts by experience and people with lived experience. Collectively, we have developed many workstreams to action the areas of learning identified last year which have been well received by colleagues.

We continue to see improvements in the uptake of annual health checks, 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. We also have seen really good examples of widespread use of reasonable adjustment to support people to access healthcare.

We will endeavour to explore improving respiratory care and reducing respiratory related deaths, especially pneumonia. We will look to better listen to the voices of those we support through improved use of the Mental Capacity Act and advocacy. We hope to look at care coordination and develop collaborative working in care planning for those with chronic conditions and at end-of-life. We aim to better represent the experience of those with a sole diagnosis of Autism by outreaching into services, raising awareness and supporting 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, feeling 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: Public Health Strategic Plan

Date of meeting: 08 November 2023

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

Reason for the Report

There is growing evidence that proactive interventions focussed on prevention are both effective and cost-effective with good return on investment (RoI) and more affordable than simply focussing on providing reactive treatment and care. This can be done by promoting healthy living, seeking to minimise the impact of illness through early intervention, and supporting recovery, enablement, and independence.

The *Public Health Strategic Plan* is designed to support and enable the system to focus on prevention as a way of improving and sustaining good health and wellbeing by proactively identifying population health needs and prevention opportunities to accelerate health and social care integration and improve outcomes.

To use this strategy as a mechanism to engage with and influence system partners with a strategic approach that clearly articulates and sets out our ambition as part of the N&W Integrated Care Partnership.

Report summary

The Public's health is essential to the overall well-being and prosperity of our community. To help address the distinctive health challenges of Norfolk, a Public Health Strategic Plan has been developed for Norfolk: *Ready to Change, Ready to Act 2023*.

The plan describes the value, contribution and relevance of Public Health skills and capacity in achieving Norfolk County Council's vision for Norfolk to be the place where everyone can start life well, live well and age well, and where no one is left behind. Our mission is to improve the health and wellbeing of the people of Norfolk. Informed by best practice and evidence, we will lead the system in Norfolk to focus on prevention to improve and sustain good health and wellbeing and help reduce demand in the system.

We have designed our approach with the strategic ambitions of our partners and colleagues in mind. An outward facing strategy will provide a mechanism to engage with and influence system partners with a strategic approach that clearly sets out our ambition as a council.

Ten priority 'requests of system partners have been identified:

1. The Integrated Care Partnership is asked to **promote and communicate** the Public Health Strategic Plan within their organisations and consider what resources can be provided to support prevention.

2. Promote and work with us on **stop smoking initiatives**.

3. Identify staff groups and individuals within your organisation for **behaviour change training** to support and advise the people they work with to make a change to improve their health (i.e. Make Every Contact Count).

4. Promote and work with us on the **5 ways to wellbeing** (mental health promotion).

5. Promote the uptake of **NHS health checks** for staff and service users.

6. Work together to develop ways of **promoting best start in life** and healthy behaviours for children and young people.

7. Work with us to **identify and engage with individuals, groups and communities** who would most benefit from prevention interventions.

8. Actively participate and contribute to **collaborative partnerships**, such as Health & Wellbeing Partnerships, the Health Improvement Transformation Group, the Tobacco Control & Vaping Alliance, the Norfolk Drug and Alcohol Partnership, the Sexual Health Network.

9. Promote the **importance of good health** and more people actively engaging in thinking about their own health improvement.

10. Work with us to embed the use of **data and intelligence** in decision-making.

Recommendations

The ICP is asked to:

a) Endorse the Public Health Strategic Plan.
b) To promote the Public Health Strategic Plan within organisations and consider what resources can be provided to support prevention interventions.

1. Background

1.1 Although health in Norfolk is generally better than the national average there are areas where it could be improved due to intra-county health inequalities. People with pre-existing health conditions, older people, those from some ethnic backgrounds, people with caring responsibilities, those who are disabled or have a learning disability, can be at greater risk of ill health, isolation, and poor wellbeing, a situation highlighted by the pandemic.

1.2 Building on the 2016-2020 Public Health Strategy this new Strategic Plan (Appendix A) sets out our approach to improving the health and wellbeing of Norfolk's residents, with a focus on prevention, partnerships and place, children and young people, adults and older people.

1.3 As we move forward, we are shifting our focus to some of the wider, indirect health impacts highlighted by Covid-19, for example on mental health, healthy weight, children's health, and engagement with public health services. These areas are not new to Public Health teams, but their nature may have changed as a result of the events of the past two years.

1.4 We are exploring new ways of working with communities and our partners, to protect and promote good health and inclusion, taking a place-based approach to tackling the causes of poor health outcomes, such as quality of housing, air quality and limited access to green spaces. We will continue to develop and sustain existing and emerging partnerships at local, county, regional and national levels to support our leadership role in improving health outcomes, access to preventative health care support services and addressing some of the causes of ill health.

1.5 Our leadership is supported by health intelligence functions providing quality data and analytics. We have direct responsibility for spending the Public Health grant and invest over £33m a year on commissioned services including health visiting, drug, and alcohol services, stop smoking and sexual & reproductive health services.

2. The Public Health Strategic Plan

2.1 The strategic plan focuses on 3 main areas, prevention, partnership and place, adults and older people and children & young people.

2.2 **Prevention, partnership, and place**

2.2.1 Encouraging and supporting people to adopt healthy behaviours is important for health and wellbeing – both physically and mentally. This is an important element of demand reduction and for an affordable NHS and social care system in Norfolk.

2.2.2 We will continue to develop and deliver a range of preventative services which promote health and wellbeing for all residents, particularly those at highest risk of ill health and premature mortality. This will be done by working with under-served groups and wider communities to understand the impact of a range of factors on their health and how best to address them. We will ensure that when we commission public health services that target people who are most in need.

2.2.3 Creating healthy places can positively influence over 50% of the factors that affect a person's health. How we behave is also important and positive results become possible when people change their behaviour. For example, health benefits can be obtained from walking and cycling more, on better designed, safer routes and taking fewer car journeys.

2.3 **Adults and Older People**

2.3.1 We will lead the cross-system strategy on adult healthy lifestyle and behavioural change (primary prevention) to improve both physical and mental health and wellbeing for the local population.

2.3.2 As people live longer, it is important that older people have the best quality of life and health possible (i.e. *adding life to years, as well as adding years to life*) and are able to thrive into older age and we aim to empower and enable people to live independently for as long as possible through providing good quality information and advice which supports their wellbeing and stops people becoming isolated and lonely. We will work with our partners to develop and deliver a healthy ageing programme.

2.4 **Children and Young People**

2.4.1 Public Health shares the ambition that Norfolk is a place where all children and young people can FLOURISH. Using public health expertise in population health assessment and intelligence, we will support the work of the Children & Young People's Strategic Alliance by promoting evidence base interventions to improve health & well-being outcomes and reduce health inequalities for children and young people in Norfolk.

2.4.2 We will work with families and partner agencies to ensure that children and young people are as healthy as possible by ensuring that we have a whole system approach, including Family Hubs, to restore and adapt our children's health services and interventions as we recover from the pandemic.

2.5 **Evidence and reasons for supporting**

2.5.1 Preventative interventions are shown to be effective as well as more cost-effective to provide than later interventions. There is strong evidence that interventions focussed on prevention are both effective and more affordable than just focussing on providing reactive emergency treatment and care. To build a financially sustainable system means we must

promote healthy living, seek to minimise the impact of illness through early intervention, and support recovery, enablement, and independence.

Officer Contact

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

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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.

Norfolk County Council
Public Health

ready to change
your way to better health

Ready to Change... Ready to Act

Public Health Strategic Plan

Foreword

Welcome to the Public Health Strategic Plan. It describes how Public Health specialist staff within the council contribute to achieving Norfolk County Council's vision for Norfolk to be the place where everyone can start life well, live well and age well, and where no one is left behind.

We will lead the system in Norfolk to focus on prevention to improve and sustain good health and wellbeing. Preventative interventions are shown to be effective as well as more cost effective to provide than later interventions. There is growing evidence that proactive interventions focused on prevention are both effective and cost effective with a good return on investment and more affordable than just simply focused on providing reactive treatment and care.

We will identify population health needs, and proactively identify prevention opportunities to accelerate health and social care integration.

Councillor Bill Borrett
Cabinet member for Public Health and Wellbeing

Stuart Lines
Director of Public Health, Norfolk

Introduction

This strategic plan describes our vision, mission, and priorities. It outlines how we will deliver a wide range of positive health outcomes for Norfolk residents throughout their lives.

The population of Norfolk is growing. Since 2011, Norfolk's population has increased by an estimated 59,000 people to 918,300 people. The population is forecast to increase by a further 195,500 over the next 20 years. Most of the population increase will be in the older age groups, with those aged 65+ increasing by 77,000.

Although health in Norfolk is generally better than the national average there are areas where it could be improved due to intra-county health inequalities. People with pre-existing health conditions, older people, those from some ethnic backgrounds, people with caring responsibilities, those who are disabled or have a learning disability, can be at greater risk of ill health, isolation, and poor wellbeing, a situation highlighted by the pandemic.

As we move forward, we are shifting our focus to some of the wider, indirect health impacts highlighted by the pandemic, for example on mental health, healthy weight, children's health, and engagement with public health services. These areas are not new to Public Health teams, but their nature may have changed as a result of the events of the past few years.

In addition, we are exploring new ways of working with communities and our partners, to protect and promote good health and inclusion, taking a place-based approach to tackling the causes of poor health outcomes, such as quality of housing, air quality and limited access to green spaces.

We will continue to develop and sustain existing and emerging partnerships at local, county, regional and national levels to support our leadership role in improving health outcomes, access to preventative health care support services and addressing some of the causes of ill health.

Our leadership is supported by health intelligence functions which provide quality data and analytics. We have direct responsibility for spending the Public Health grant and invest over £33m a year on commissioned services including health visiting, drug, and alcohol services, stop smoking and sexual & reproductive health services.

Our Vision

Norfolk to be the place where everyone can start life well, live well and age well, and where no one is left behind.

Our Vision – Better Together for Norfolk 2022

Our Mission

To improve the health and wellbeing of the people of Norfolk and reduce health inequalities. Informed by best practice and evidence, we will lead the system in Norfolk to develop and focus a prevention approach to improve and sustain good health and wellbeing.

We will identify opportunities to accelerate health and social care integration to ensure that people remain healthy and independent for as long as possible.

We will work to improve and protect our population's health by promoting healthy lifestyles, supporting people to make healthy choices, working in partnership, and providing high quality public health service.

Our ambition

Ensure that prevention is at the heart of everything we and our partners do, ensuring that our population understand how to be healthy, and are encouraged and supported to put this into practice.

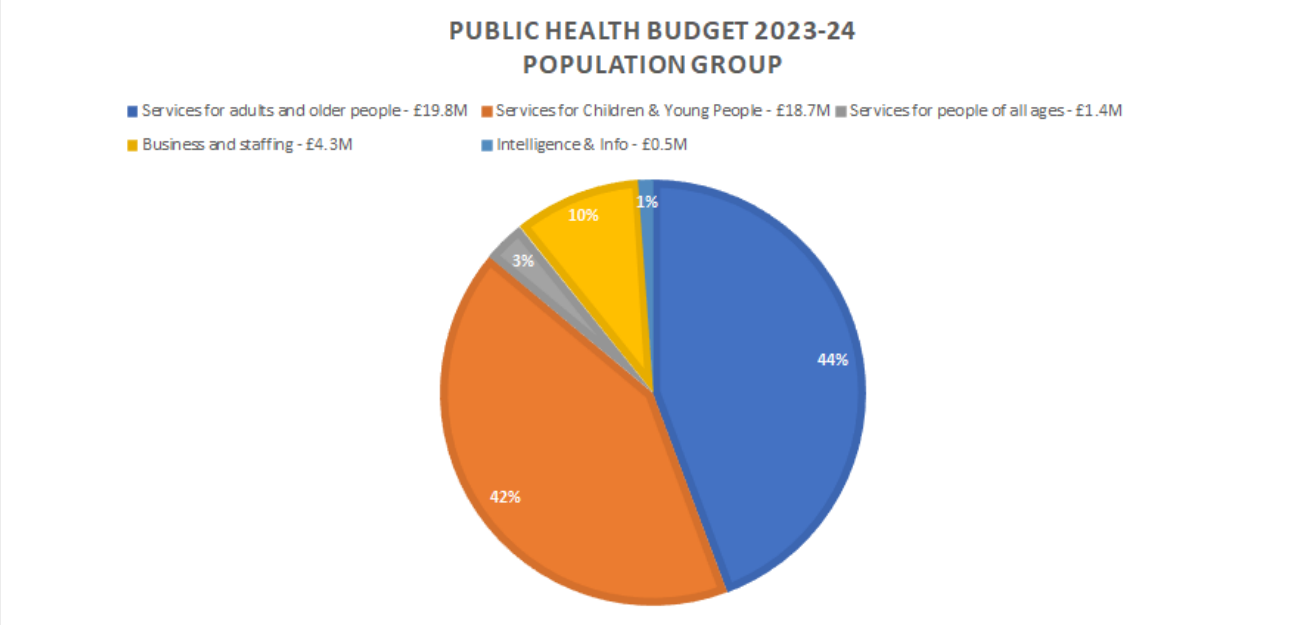
We want to increase access and take up of Public Health prevention services and support healthier living. We will do this by providing support through a variety of routes including digital platforms and community-based providers.

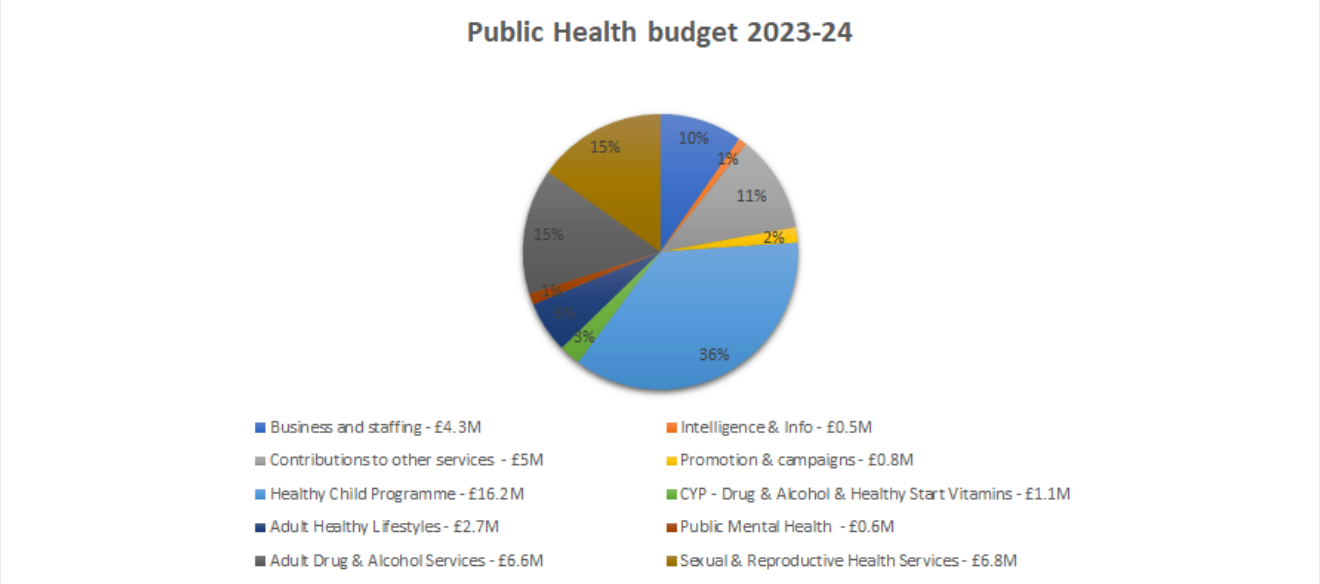
Our Investment

Norfolk's Public Health Service is funded via a government ring-fenced public health grant, which necessitates investment in purposeful public health activities. In 2023/24 we continued to invest in providing clinical and health & wellbeing services.

We are funding an ever expending range of primary prevention programmes services and campaigns and provide specialist support to the NHS and contribute to a range of services commissioned by other council services that achieve public health outcomes.

Looking to 2024/25, the government recently announced that Norfolk will receive £1.2m of additional funding to invest in stop smoking services, more than double our current level of spend.





Our approach

Public Health is guided by a number of principles which inform our ideas and guide the planning, delivery and evaluation of our work.

We will:

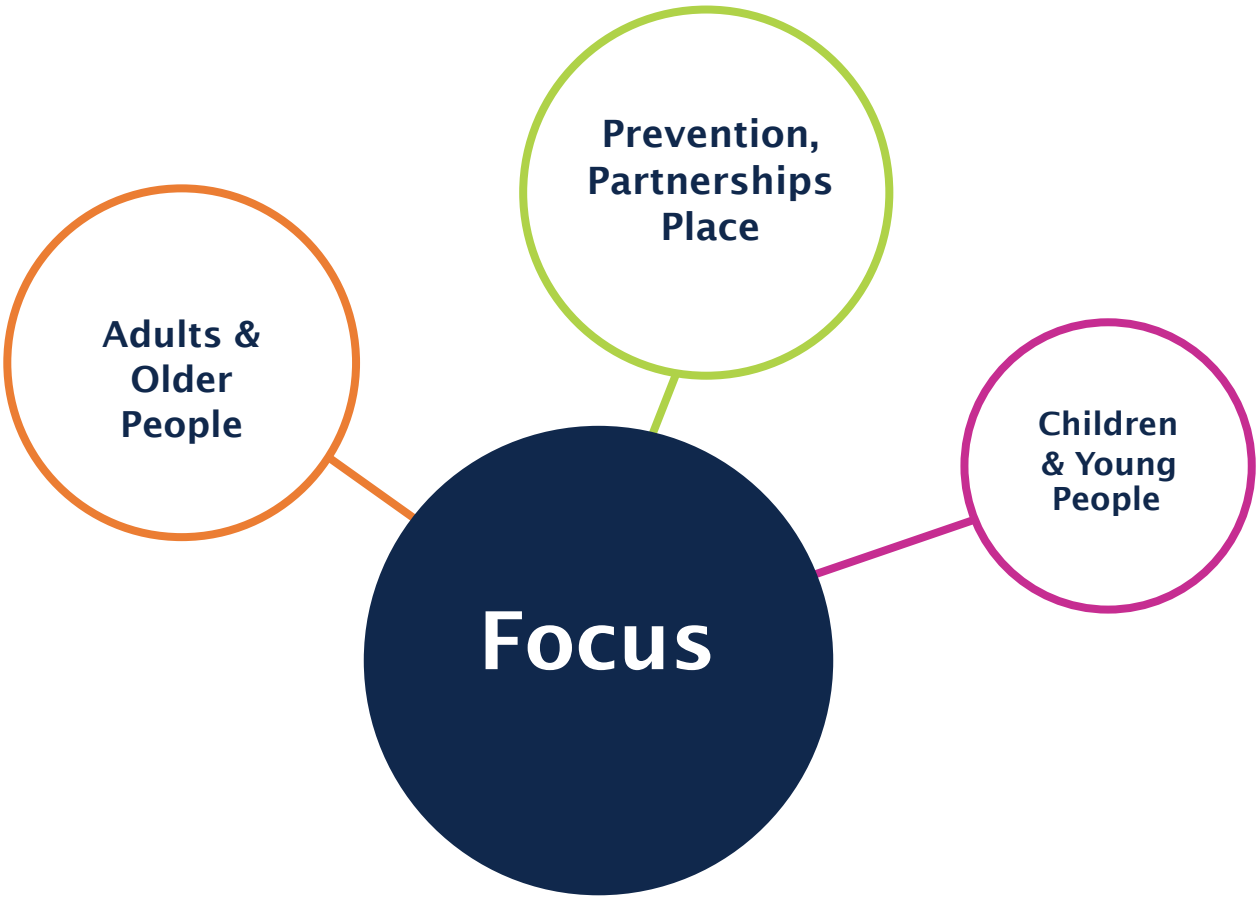
- ✓ Take a proactive approach to prevention identifying and tackling the issues that have a detrimental impact on poor health outcomes.
- ✓ Provide system leadership as the expert voice on population health, inequalities, and prevention.
- ✓ Provide expert advice on the promotion of healthy lifestyles informed by behaviour change approaches, driven by data and evidence and guided by a holistic view of health and wellbeing.
- ✓ Develop and sustain strong partnerships to improve access to better quality services such as working with districts to improve public health in their communities.
- ✓ Provide targeted support focused on places, communities, and individuals most affected by ill health and premature death.
- ✓ Embrace diversity and inclusion with a focus on reducing health inequalities.
- ✓ Manage our resource and capacity, achieving best value for money and carefully prioritised projects and programmes, based on good practice, sound evidence, and achievable outcomes.

Better Together for Norfolk Strategic Priorities:

We will actively pursue our ambitions through the priority themes in the County Council's corporate plan. This page shows the County Councils' ambitions and priority themes, and the key Public Health contributions to them.

Our Focus

In support of the Norfolk County Council's Better Together for Norfolk plan we have identified the following priorities for Public Health.



1. Focus on Prevention, Partnerships & Place

Prevention

Public Health is well placed to present clear offers of health and wellbeing to Norfolk residents and enable them to get the support they need.

We will continue to develop and deliver a range of preventative services which promote health and wellbeing for all residents, particularly those at highest risk of ill health and premature mortality. This will be done by working with under-served groups and wider communities to understand the impact of a range of factors on their health and how best to address them. We will ensure that when we commission Public Health services we target people who are most in need.

A holistic approach to health and wellbeing
Many factors influence and affect people's health and having access to a range of locally based support can play an important part in helping people to be healthy. We want to offer more opportunities for self-care by improving access to health and wellbeing information and services so that an individual's care is streamlined, co-ordinated and preseason-centred.

We will take action to improve integration across health and non-health organisations, through the development of referral processes (supported by holistic assessment tools) that make access to services easier and support people with complex or multiple behaviour lifestyle issues.

Places and Partnership

People's health and wellbeing often varies from one place to another and isn't only affected by what people do like eating healthy food and quitting smoking. It can also be affected by the places around us, like living in an area with low levels of crime, safe places to enjoy the outdoors, good jobs and quality housing. That's why it's important to look at what's needed in specific places to help people live longer and healthier lives.

The unequal distribution of the social determinants of health, such as education, housing, and employment, drives inequalities in physical and mental health, and reduces an individual's ability to prevent sickness, or to access treatment when ill health occurs.

While Norfolk's health statistics are mostly favorable when compared with the national picture, we know that there are persistent health inequalities especially in areas of deprivation. The leading causes of death among both men and women in Norfolk are also responsible for the largest gap in life expectancy and impact on the number of years people live in good health. They include cardiovascular disease, respiratory disease, cancer, and diabetes.

The COVID-19 pandemic has highlighted the impact that these inequalities can have on peoples' health and has led to many more people experiencing those inequalities through changed economic, employment or health circumstances. Throughout the pandemic, we saw communities rise to the challenges we faced. Services and individuals worked together to support each other and the most vulnerable in our communities. We want to keep this going and that is why we will continue to support places and partnerships including the Health and Well Being Partnerships in each local area.

We have designed our approach with the strategic ambitions of our partners and colleagues in mind. It is our ambition that all Norfolk organisations, whoever they may be, will have an opportunity to play a role. They include the NHS, district and borough councils, a wide range of voluntary, community and faith groups, social enterprises, and private sector services.

Public Health is a leading partner within the Norfolk & Waveney Integrated Care System (ICS) and we are working closely with the Integrated Care Partnership on long term action to improve health outcomes.

Our work supports the Health and Wellbeing Strategy created by the Norfolk & Waveney Health and Wellbeing Board where public health work with partners to set and achieve the overarching health and care aims for the county.

We will:

- ✓ Inform and support the ICS by providing expert advice for health improvement, prevention and health inequalities. Lead the Health Improvement Transformation Group subgroup of the ICS with its focus on prevention.

- ✓ Establish the Norfolk Drug and Alcohol Partnership as the strategic substance misuse partnership.

- ✓ Lead the development of the Norfolk Health & Wellbeing Partnerships.

- ✓ Lead the development of the Mental Health Transformation Prevention and Wellbeing Steering Group to improve individual mental wellbeing and resilience of residents.

- ✓ Provide leadership and direction on tobacco control through the Norfolk Tobacco & Vaping Control Alliance.

- ✓ Continue to work with partners on the environmental factors and action towards the Council's net zero and sustainability plans.

- ✓ Work with partners and communities to encourage and enable the development of local action to deliver clean air for all and other outcomes to protect human health with particular attention to understanding the impact on health and mitigating actions for affected communities.

- ✓ Influence planning by advocating and supporting health impact assessments and using our health protocols to design sustainable neighbourhoods which support health and wellbeing.

- ✓ Work with lead agencies and provide data insight and evidence to promote integrated approaches to road & water safety and domestic violence.

- ✓ Improve accessibility to our services for people with learning disabilities, mental health conditions, and people from ethnic minority groups.

- ✓ Support partners with their plans for addressing health inequalities by mapping existing health inequalities work across Norfolk, advise on gaps and duplication and develop a cohesive action plan for ourselves and partners.

- ✓ Promote clear and consistent messaging about health inequalities and how to include health in all policies, both internally and externally with partners.

- ✓ Jointly lead the ICS health inequalities work-stream, providing coordination for health inequalities initiatives and work with other health inequalities groups.

2. A Focus on Adults and Older People

Encouraging and supporting people to adopt healthy behaviours is important for health and wellbeing – both physically and mentally. This is an important element of demand reduction and for an affordable NHS and social care system in Norfolk. Public Health is well placed to inform and promote improved health and wellbeing support to Norfolk residents and enable them to get the support they need to live longer and more independently.

Physical activity and a healthy diet can prevent people from becoming overweight and to avoid or manage health conditions such as cardiovascular disease, cancer, diabetes, arthritis, and depression.

Smoking remains the primary cause of preventable death in Norfolk and some areas of Norfolk have a high rate of smoking in pregnancy.

Mental health and wellbeing is affected by individual, family, social, and environmental factors. Interventions at key periods of change in peoples' lives can prevent mental illness from developing and support recovery.

We will

- ✓ Lead the cross-system strategy on adult healthy lifestyle and behavioural change (primary prevention) to improve both physical and mental health and wellbeing for the local population.

- ✓ Promote the use of the new behaviour change digital platform (Ready to Change) to improve
self-care information and access to information on health and wellbeing offers.

- ✓ Extend our Public Health offer to support the wider health and wellbeing workforce in the role of prevention and behaviour change helping them to encourage people to talk about and take action to improve their health.

- ✓ Deliver a new programme of tobacco control and stop smoking initiatives to help people to stop smoking and create smoke free environments.

- ✓ Work with key organisations to develop a county-wide approach to mental health which promotes mental wellbeing and resilience, prevents ill health, and supports recovery.

- ✓ Invest in the delivery of health checks and explore new delivery methods.

- ✓ Enhance our prevention approaches to health improvement, healthy weight and nutrition, and sexual & reproduction health.

Older People – Promoting Independence

As people live longer, it is important that older people have the best quality of life and health possible (i.e. adding life to years, as well as adding years to life) and can thrive into older age.

Supporting older people to stay healthy as long as possible not only improves their own quality of life but adds value to the lives of those around them by the contributions they make to their families and communities.

Residents living into older age, but with complex health and care needs such as frailty and or dementia, need additional support from a range of services and community resources. Proactively identifying these people is the first step to helping them followed by introducing them to local community services to help them enjoy the best possible quality of life and remain safe and well at home.

By focusing on the prevention and early help element of the Councils' Promoting Independence Strategy we aim to empower and enable people to live independently for as long as possible by giving people good quality information and advice which supports their wellbeing and stops them from becoming isolated and lonely.

We will help people stay healthy, active and connected with others in their communities, tapping into help and support already around them – from friends, families, local voluntary and community groups. This will help their health and wellbeing (better mental health, more years free of disease, better mobility, fewer falls and increased companionship) and keep older people safe and well at home for longer. This reduces hospital admission and additional care, which has financial benefits to the NHS and adult care services.

Similarly, we need to ensure that carers receive the support they need to manage their own health. With an increasingly aging population, more people in Norfolk are carers for the elderly.

We will work with our partners to develop and deliver a healthy aging programme.

We will:

- ✓ Ensure older people and carers are supported to have a healthy lifestyle, that they are aware of and have access to appropriate health and wellbeing offers and support.
- ✓ Develop a collaborative approach to physical activity and mobility/strength-based exercise offers as part of maintaining strength and mobility and preventing falls.
- ✓ Ensure services are tailored to older people as appropriate and includes identifying and addressing frailty, dementia and social isolation.
- ✓ Support the development of a broad offer of community-based support and activities, which addresses social isolation and loneliness.
- ✓ Encourage older residents to understand the importance of keeping warm in winter and cool in summer, making sure they eat properly and are physically active. This is particularly important for extreme weather events such as freezing conditions and heat waves which are becoming more frequent.

Addiction

The percentage of people successfully completing drug treatment in Norfolk is below England average levels and there is a disproportionate number of drug related deaths in the Greater Norwich area.

We will:

- ✓ Lead the Norfolk Drug and Alcohol Partnership to increase our ability to respond to drug and alcohol issues by combining prevention, treatment and enforcement.
- ✓ Develop an improvement programme for adult drug & alcohol treatment services drawing on learning from Project Adder, focusing on improving access and the coordination of support across Norfolk.
- ✓ Implement effective local targeted and population level interventions and systems, which are coherently planned by local government, the NHS and criminal justice partners.

3. A Focus on Children & Young People

We work with families and partner agencies to ensure that children and young people are as healthy as possible and Norfolk County Council's Public Health, shares the ambition that Norfolk is a place where all children and young people can FLOURISH.

Using Public Health expertise in population health assessment and intelligence, we will support the work of the Children & Young People's Strategic Alliance by promoting evidence base interventions to improve health & well-being outcomes and reduce health inequalities for children and young people in Norfolk.

Our focus is on children and young people from 0-18 years and up to 25 years for young people who are care leavers or who have special educational needs.

The first years of life and particularly from conception to the age of 2 significantly impact health and wellbeing. During this period the foundations are laid for each child's social, emotional, and physical health development. Where there are concerns about the health of a child or young person, evidence shows that intervening early and/or prevention makes a significant difference to health outcomes.

We are one of the main funders of preventative health interventions for children and we will continue with our programme of work with partners to identify and respond to emerging need, targeting advice, supporting and delivering services to individuals and groups at higher risk of poor health outcomes.

We will:

- ✓ Work with partners to ensure that there is effective and joined up response to early years and emerging need including supporting the implementation of the Family Hub model.
- ✓ Work with our partner organisations to ensure a whole system approach to restoring and adapting our children's health services and interventions as we recover from the pandemic.
- ✓ Continue to invest in and support our Healthy Child Programme helping them to manage workforce risks to the service and develop a new service model.
- ✓ Ensure that addressing health inequalities is central to our work including tackling digital exclusion.
- ✓ Address the emerging mental health needs of children, young people and families by, working with partners to improve community based mental health and wellbeing support services, and work with those who work in schools to improve access to services for anxiety and low-level depression.
- ✓ Ensure that safeguarding of children and young people is paramount in all that we do.
- ✓ Work closely with Children's Services to ensure that the health needs of vulnerable children and young people are addressed, including Looked After Children and young people in the criminal justice system.
- ✓ Ensure that there is a joined-up pathway for tackling excess weight in children and young people.
- ✓ Support the Local Maternity System (LMS) to embed prevention to improve maternal and neonatal outcomes.

Strong Public Health Enablers

Health analytics and intelligence

Our aim is to continue delivering a joined-up evidence and intelligence function which facilitates evidence-based working across decision-makers, commissioners and providers.

The COVID-19 pandemic has highlighted the importance of a strong Public Health intelligence function for effective system wide strategy-setting and delivery.

We will:

- ✓ Provide the best quality of information that is possible through epidemiology and needs assessments to enable decision makers to focus on prevention.
- ✓ Drive change and improvement by embedding the use of population health analytics throughout Norfolk.
- ✓ Work with partners and a wide range of stakeholders to support public sector and wider partnership transformation through establishing improved data collection and availability, facilitating access to systems and technology to support collaboration, and working to develop analytical skills across the sector.
- ✓ Develop a new Joint Strategic Needs Assessment programme and refresh the website including the addition of a healthcare evaluation section.
- ✓ Develop a new Public Health Outcomes Framework
- ✓ Commission an independent assessment of the impact of COVID on health service activity and health outcomes and analysis to inform ICS priorities.
- ✓ Continue to undertake Public Health analysis of system data to identify prevention priorities and opportunities for system improvement.

Commissioning high quality services

We have direct responsibility for spending the Public Health grant and invest over £33m a year on commissioned services including health visiting, drug, and alcohol services, stop smoking and sexual & reproductive health services. Between March 2023 and September 2024, the majority of Norfolk Public Health's medium to large contracts are due for re-commissioning.

We will

- ✓ Work with our partner organisations to restore and adapt our Public Health services and interventions as we recover from the pandemic.
- ✓ Review and update our commissioning of services to reflect the new Provider Selection Regime which enables new ways of procurement and contracting giving more choice and flexibility on provider selection.
- ✓ Prepare for, and begin where necessary, the process of securing best placed providers to deliver our services in the future, working to local needs and priorities whilst observing national guidance and policy directives.
- ✓ Ensure that addressing health inequalities is central to our work in particular improving accessibility to our services.
- ✓ Actively seek the views of residents, service users, providers and other stakeholders about our current services and using their ideas to develop new services and delivery models.
- ✓ Publish our commissioning intentions.

Health Protection

Health protection seeks to prevent and control infectious diseases and other threats to the health of the population.

The Director of Public Health has a statutory responsibility to provide assurance that adequate arrangements are in place to protect the health of residents.

We will work closely with the Local Resilience Forum and other agencies to prepare for future health protection emergencies with an aim to ensuring that every person, irrespective of their circumstances, is protected from infectious and non-infectious health hazards and, where such hazards occur, to minimise their continued impact on the public's health.

We will:

- ✓ Manage COVID-19 like other respiratory illnesses and have a flexible health protection function that could be activated quickly to respond to any local outbreaks.
- ✓ Strengthen our preparedness for future health protection threats and support health sector preparedness and planning for emergencies.
- ✓ Work with health agencies to improve access and take up of vaccinations and immunisations.
- ✓ Work with resilience partners to identify and prevent exposure to hazards such as flooding, taking timely actions to respond to threats and acting collectively to ensure the best use of human and financial resources and scan for emerging threats and hazards to future bio-security, health and safety.

Achieving best value for money

We will meet the statutory duty to achieve best value for money and seek to continuously improve how we commission and deliver our services.

We will ensure that all the activities commissioned or delivered by Public Health will be underpinned by a commitment to achieving best value for money, working with both private and voluntary and community sector providers.

We will:

- ✓ Ensure that we combine financial information and health economics when looking at new opportunities and interventions.
- ✓ Actively seek the views of potential providers and other stakeholders about our ideas for developing new services and delivery models.
- ✓ Use digital and on-line services to support and achieve our priorities.
- ✓ Continually learn from previous experiences and local and national projects and services including cost comparisons.
- ✓ Develop arrangements for recovering our costs where appropriate.
- ✓ Develop new approaches for distributing funding to local community organisations.
- ✓ Ensure that contracted service providers and suppliers demonstrate how they will contribute to the wider health and care system, and support our sustainability and diversity ambitions and groups.
- ✓ Ensure that we use the national Quality Improvement frameworks for Public Health Services as part of continuing improvement.

Decision-making and review

This strategy will be delivered through a wide range of public health activities, and we will show that we deliver the best possible public health service for the people of Norfolk.

We will:

- ✓ Measure our progress using Public Health outcomes indicators and feedback from residents, partners and other stakeholders.
- ✓ Review our strategy annually.
- ✓ Use the national Public Health outcomes framework to ensure that we are continuously improving.
- ✓ Promote and utilize approaches such as self-evaluation, encouraging peer to peer learning.
- ✓ Use the Association Directors Public Health (ADPH) 'What Good Looks Like' frameworks to assure our working arrangements and continuously improve them.
- ✓ Lead and manage Public Health Sector Led Improvement Programme for the Eastern Region.

Ready to Change ... Ready to Collaborate

Ten priority 'requests' of partners have been identified:

1. Promote and communicate the Public Health Strategic Plan within their organisations and consider what resources can be provided to support prevention.

2. Promote and work with us on stop smoking initiatives.

3. Identify staff groups and individuals within your organisation for behaviour change training to support and advise the people they work with to make a change to improve their health. (i.e. Make Every Contact Count).

4. Promote and work with us on the 5 ways to wellbeing (mental health promotion).

5. Promote the uptake of NHS health checks for staff and service users.

6. Work together to develop ways of promoting best start in life and healthy behaviours for children and young people.

7. Work with us to identify and engage with individuals, groups and communities who would most benefit from prevention interventions.

8. Actively participate and contribute to collaborative partnerships, such as Health & Wellbeing Partnerships, the Health Improvement Transformation Group, the Tobacco Control & Vaping Alliance, the Norfolk Drug and Alcohol Partnership, and the Sexual Health Network.

9. Promote the importance of good health and more people actively engaging in thinking about their own health improvement.

10. Work with us to embed the use of data and intelligence in decision-making.

ready to change
your way to better health

Norfolk County Council
Public Health

www.norfolk.gov.uk/readytochange

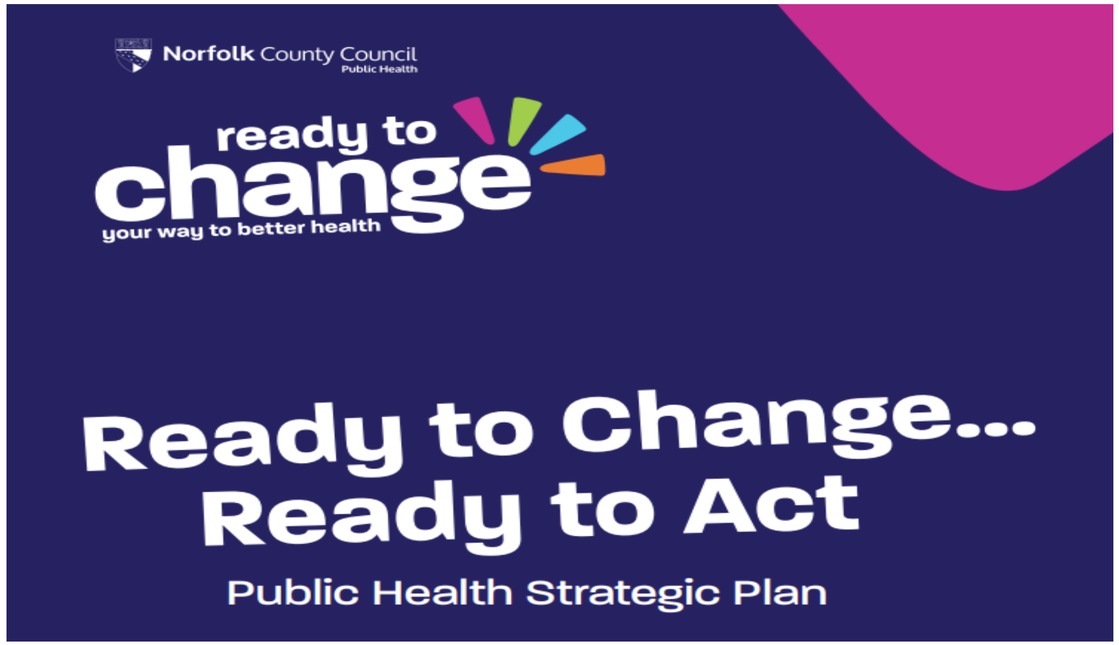
Norfolk County Council

Public Health Strategic Plan

Norfolk & Waveney Integrated Care Partnership

Chris Butwright, Assistant Director Prevention and Policy Public Health, Norfolk County Council.

8 November 2023



Public Health Strategic Plan

Vision

For Norfolk to be the place where everyone can start life well, live well and age well, and where no one is left behind.

Our Vision – Better Together for Norfolk 2022

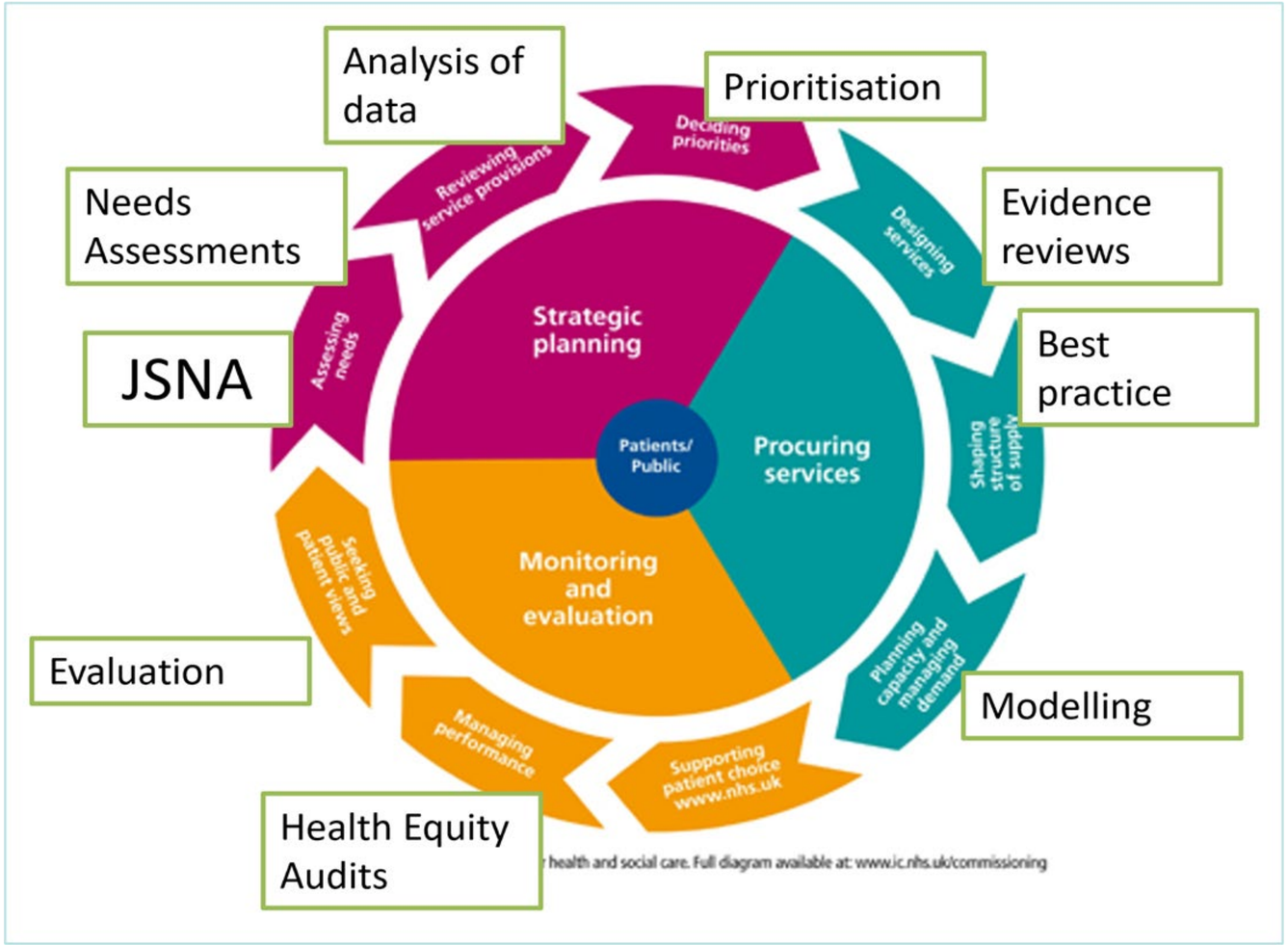
Mission

- To improve the health and wellbeing of the people of Norfolk and reduce health inequalities.
- To lead the system in Norfolk to develop and focus a prevention approach to improve and sustain good health and wellbeing.
- To identify opportunities to accelerate health and social care integration to help ensure that people are supported to remain healthy and independent for as long as possible.
- To promote healthy lifestyles and empower people to make healthy choices.
- To provide high quality public health services.

Ambition

- To ensure that prevention is at the heart of everything we and our partners do.
- To ensure that our population understands how to be healthy, and are encouraged and supported to put this into practice.
- To increase access and take-up of services that support and improve health and wellbeing.
- To provide support through a variety of routes, including digital platforms and through a range of community-based providers.

Public Health Role and Purpose



Our **intention** to focus on prevention, particularly in the context of children & young people and adults and older people

Ready to Change… Ready to Act

Public Health Strategic Plan

1. Focus on Prevention, Partnership & Place

- Inform and support the Integrated Care System (ICS) by providing expert advice for health improvement, prevention and health inequalities.

  i.e. Population Health Management

Lead the development of the Norfolk Health & Wellbeing Partnerships at Place.

- Lead on the development of a system-wide *Prevention approach* across a range of areas

  'Air pollution to Zoonoses' and 'Breastfeeding to Youth violence'.

- Collaborate on the development of the Norfolk Health & Wellbeing Partnerships at Place.
- Contribute to the development of the mental health and wellbeing initiatives to improve individual mental wellbeing and resilience of communities.
- Provide leadership and direction on tobacco control through the Norfolk Tobacco Control Alliance.

2. Focus on adults & older people

- Lead the cross-system strategy on adult healthy lifestyle and behavioural change.
- Deliver a new programme of tobacco control and stop smoking initiatives.
- Analysis of system data to inform ICS priorities with a focus on Population Health Management.
- Extend our public health offer to support the wider health and wellbeing workforce.
- Develop a collaborative approach to healthy aging with a focus on physical and mental health prevention initiatives to support living well in older years.
- Deliver specific services, such as for Substance Misuse and Smoking.

3. Focus on children & young people

- Contribute to the Norfolk Children and Young People Strategic Alliance and support ambitions of FLOURISH framework focusing on early childhood (First 1000 days) and wider preventative measures to improve children's health.
- Work with our partner organisations to ensure a whole system approach to ensuring the best start in life.

  i.e. mental wellbeing, childhood obesity
- Work with partners to ensure that there is an effective and joined up response to early years and emerging need, including supporting the implementation of the Family Hub model.
- Develop a new service model for the delivery of the Healthy Child Programme (Health Visiting and School Nursing).

Working in Collaboration 10 Priority Requests…

1. The Integrated Care Partnership is asked to **promote and communicate** the Public Health Strategic Plan within their organisations and consider what resources can be provided to support prevention.
2. Promote and work with us on **stop smoking initiatives**.
3. Identify staff groups and individuals within your organisation for **behaviour change training** to support and advise the people they work with to make a change to improve their health. (i.e. Make Every Contact Count)
4. Promote and work with us on the **5 ways to wellbeing** (mental health promotion).
5. Promote the uptake of **NHS health checks** for staff and service users.
6. Work together to develop ways of **promoting best start in life** and healthy behaviours for children and young people.
7. Work with us to **identify and engage with individuals, groups and communities** who would most benefit from prevention interventions.
8. Actively participate and contribute to **collaborative partnerships**, such as Health & Wellbeing Partnerships, the Health Improvement Transformation Group, the Tobacco Control & Vaping Alliance, the Norfolk Drug and Alcohol Partnership, the Sexual Health Network.
9. Promote the **importance of good health** and more people actively engaging in thinking about their own health improvement.
10. Work with us to embed the use of **data and intelligence** in decision-making.

In Summary…

- To use this strategy as a mechanism to engage with and influence system partners with a strategic approach that clearly sets out <u>our ambition.</u>

  ✓ relevance, value and contribution

  ✓ lead the development of a prevention approach

- Sets out <u>expectations</u> of a high-quality public health service, leadership and impact.

- To align with and contribute to the ICS Strategic aims.

  ✓ Driving Integration/Prioritising Prevention/Addressing Inequalities/Enabling Resilient Communities

- To review annually.

Report title: Department for Education Families First for Children Pathfinder Update

Date of meeting: 08 November 2023

Sponsor (ICP member): Sara Tough, Executive Director, Children's Services, Norfolk County Council

Reason for the Report

This report summarises the bid submitted to the Department for Education (DfE) on behalf the local safeguarding partners (Norfolk County Council (NCC), Integrated Care Board (ICB) and Norfolk Constabulary) to become a Wave 2 Pathfinder area in the Delivery of the Families First for Children programme, as part of the 'Stable homes built on love Strategy' following the Childrens social care review. The Families First for Children (FFC) Pathfinder is the delivery mechanism for testing implementation of some of the most significant reforms to how children and families are supported and protected by the system as a whole. This paper is intended as an update and the ongoing support from the Integrated Care Board (ICP) as if successful would place Norfolk at the forefront of testing the impact of these reforms.

Report summary

The report below sets out the key areas of reform that DfE are seeking to test as part of the FFC pathfinder work which are:

- Family Help
- Family Networks
- Child Protection; and
- Multi-Agency Safeguarding Arrangements

It sets out the timescales, funding parameters and partnership agreements required for the submission of a Pathfinder bid to the DfE.

Recommendations

The ICP is asked to:

a) Endorse the submission by NCC on behalf of the local Safeguarding Partners to become a FFC Pathfinder area.

1. Background

1.1 A report and presentation came to the HWB/ICP on the 21June 2023, setting out the children's reform agenda more broadly. The Pathfinder Opportunity and indicative support was received from the Board in relation to a local bid. The bidding process was launched by the DfE in October 2023, with a closing date of 6 November 2023, so it has been necessary for partners to work at pace to prepare for the submission. We have met separately with both the ICB and Norfolk Constabulary to present the opportunity and seek their support for the bid.

2. The Pathfinder Opportunity

2.1 The FFC Pathfinder provides local areas with the opportunity to be at the heart of work to transform family help, working together with central government to influence future reforms in safeguarding partnerships, family help, child protection, and family networks. The DfE are

providing revenue funding in 2024/25 to Local Authorities and their partners who are successful in bidding to be a Pathfinder area.

2.2 Indications are that although this a test and learn phase, this will reflect future government policy direction, even if there is a change of administration.

2.3 What are the reforms that FFC is seek to Test?

2.4 **Family Help:** Ensuring families can access the right support at the right time. Locally based, multi-disciplinary family help services providing welcoming, Seamless and effective support that is tailored to the needs of children and families.

2.5 **Child protection:** Dedicated and skilled multi-agency child protection teams comprising practitioners from a range of discipline, including social Workers with greater child protection expertise and experience. It will work closely with family help to protect children suffering or at risk of significant harm.

2.6 **Overarching system reform and multi-agency safeguarding arrangements:** Establishing a system-wide, 'families first' culture underpinned by clear and shared MASA and effective information-sharing. Strengthening the role of education at strategic level.

2.7 **Family Networks:** Greater use of family Networks, with earlier use of family group decision-making throughout family help and child protection, facilitated by targeted funding to enable more children to live safely at home or support a transition into kinship care.

Family help

Ensuring families can access the right support at the right time. Locally based, multi-disciplinary family help services providing welcoming, seamless and effective support that is tailored to the needs of children and families.

Child protection

Dedicated and skilled multi-agency child protection teams comprising practitioners from a range of disciplines, including social workers with greater child protection expertise and experience. It will work closely with family help to protect children suffering or at risk of significant harm.

Overarching system reform and multi-agency safeguarding arrangements (MASA)

Establishing a system-wide, 'families first' culture, underpinned by clear and shared MASA and effective information-sharing. Strengthening the role of education at strategic level.

Family networks

Greater use of family networks, with earlier use of family group decision-making throughout family help and child protection, facilitated by targeted funding to enable more children to live safely at home or support a transition into kinship care.

2.8 What are the opportunities for partners in Norfolk?

2.9 There is already considerable activity and partnership commitment in Norfolk behind all of the four areas of reform that places Norfolk in a strong position to offer an impactful and wide-ranging proposal building on what we already do well. Since July 2023 children's social care has piloted a Family Help approach in 2/6 localities, including testing a Child Protection Social Work Expert role, which would be considerably strengthened by closer alignment to police and health activity in this space, and Family Networks is also at the heart of many of our aspirations.

2.10 The four areas of reform clearly demonstrate the intent by the DfE to embed partnership working at the heart of how the system works to support families and children. This aligns well with our local ambitions and all the work which has taken place locally to deliver a system wide response where possible recognising that many of the families that need support will receive it from a number of partners depending on their unique needs and circumstances.

2.11 A successful bid would see Norfolk receiving up to £5m of funding to build sufficient capacity across our agencies to fully test and prove concept and would not require new investment from partners to test these new ways of working. What will be required is commitment to rapidly expanding the ambitions of our partnership working to deliver even better outcomes for children in the county.

2.12 The deadline for submission of the bid is 6 November 2023, with decision due from DfE in January. This must be countersigned by the ICB and Norfolk Constabulary. If successful, further development work will take place with the DfE to support the implementation of the pilot and ensure that it is a good fit for the local area before agreeing to go live.

Officer Contact

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

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