Who are we?

The Health & Wellbeing Board is the forum where representatives of the City Council, NHS and Third Sector hold discussions and make decisions on the health and wellbeing of the people of Brighton & Hove.

Meetings are open to the public and everyone is welcome.

Where and when is the Board meeting?

This next meeting will be held in the council chamber at Hove Town Hall on **(Insert Date)** starting at 4.00pm.

Health & Wellbeing Board

Date: **3 March 2026**

Time: **4.00pm**

Venue: **Council Chamber, Hove Town Hall**

Who is invited:

B&HCC members: Councillors: Baghoth (Chair), Helliwell and Alexander

Co-Opted members: Ian Smith (ICB), Tanya Brown-Griffith (NHS Sussex (Sussex Integrated Care Board)) and Adam Fazarkerley (Primary Care Rep)

Non-voting members: Deb Austin, Dr Nicola Lang, Steve Hook, Jess Gibbons, Professor Robin Banerjee, Nigel Sherriff (UoB), Kate Pilcher (SCFT), Peter Lane (UHSx), Dr Colin Hicks (SPFT), Alan Boyd (Healthwatch), David Norris (East Sussex Fire & Rescue Service), Tom Lambert (Carers Centre), Caroline Ridley (Impact Initiatives) and Spt Petra Lazar (Sussex Police)

Contact:

giles.rossington@brighton-hove.gov.uk

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This agenda and all accompanying reports are printed on recycled paper

Date of Publication - Monday, 23 February 2026

AGENDA

Formal matters of procedure

This short formal part of the meeting is a statutory requirement of the Board

Part One **Page**

33 DECLARATIONS OF SUBSTITUTES AND INTERESTS AND EXCLUSIONS

The Chair of the Board will formally ask if anyone is attending to represent another member, and if anyone has a personal and/or financial interest in anything being discussed at the meeting. The Board will then consider whether any of the discussions to be held need to be in private.

34 MINUTES **7 - 14**

The Board will review the minutes of the last meeting held on the 16th December 2025, decide whether these are accurate and if so agree them.

35 CHAIR'S COMMUNICATIONS

The Chair of the Board will start the meeting with a short update on recent developments on health and wellbeing.

36 FORMAL PUBLIC INVOLVEMENT **15 - 16**

This is the part of the meeting when members of the public can formally ask questions of the Board or present a petition. These need to be notified to the Board in advance of the meeting Contact the Secretary to the Board at penny.jennings@brighton-hove.gov.uk

37 FORMAL MEMBER INVOLVEMENT

38 LEARNING FROM THE LIVES AND DEATHS OF PEOPLE WITH A LEARNING DISABILITY AND AUTISTIC PEOPLE 2024-25 REPORT **17 - 66**

Report of NHS Sussex Integrated Care Board (copy attached).

Contact Officer: *Giles Rossington* *Tel: 01273 295514*
Ward Affected: *All Wards*

39 BETTER CARE FUND (BCF) MARCH 2026 **67 - 76**

Report of the Corporate Director, Health & Care and of NHS Sussex (copy attached).

Contact Officer: *Giles Rossington* *Tel: 01273 295514*
Ward Affected: *All Wards*

40 INTRODUCTION TO NEIGHBOURHOOD HEALTH AGENDA FOR CHANGE 77 - 96

Report of the Corporate Director, Health & Care, and of NHS Sussex (copy attached).

Contact Officer: *Giles Rossington* *Tel: 01273 295514*
Ward Affected: *All Wards*

41 NHS SUSSEX INTEGRATED CARE BOARD UPDATE

Verbal presentation

The Council actively welcomes members of the public and the press to attend its meetings and holds as many of its meetings as possible in public. Provision is also made on the agendas for public questions to committees and details of how questions can be raised can be found on the website and/or on agendas for the meetings.

The closing date for receipt of public questions and deputations for the next meeting is 12 noon on the fourth working day before the meeting.

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Date of Publication - Monday, 23 February 2026

BRIGHTON & HOVE CITY COUNCIL

HEALTH & WELLBEING BOARD

4.00pm 16 DECEMBER 2025

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

Present: Councillor Baghoth (Chair)

Also in attendance: Councillor Helliwell and Alexander

Other Members present: Tanya Brown-Griffith, Monica Fletcher, Dr Adam Fazakerley (NHS Sussex); Jenny Preece (UHSx); Professor Nigel Sherriff (UoB); David Kemp (ESFRS); Deb Austin, Steve Hook, Dr Nicola Lang (BHCC); Tom Lambert, Caroline Ridley (CVS), Alan Boyd (Healthwatch)

PART ONE

23 DECLARATIONS OF SUBSTITUTES AND INTERESTS AND EXCLUSIONS

23(a) Declarations of Substitutes

23.1 Monica Fletcher attended in place of Ian Smith (NHS Sussex Integrated Care Board); Jenny Preece attended in place of Peter Lane (University Hospitals Sussex NHS Foundation Trust); David Kemp attended in place of Hannah Youldon (East Sussex Fire & Rescue Service).

23.2 Apologies were received from Professor Robin Banerjee, Isabella Fernandez-Davis, Kate Pilcher and Superintendent Petra Lazar.

23(b) Declarations of Interest

23.3 There were none.

23(c) Exclusion of Press & Public

23.4 RESOLVED – that the press & public be not excluded from the meeting.

24 MINUTES

24.1 The minutes of the 16 September 2025 meeting were approved.

25 CHAIR'S COMMUNICATIONS

25.1 The Chair gave the following communications:

I would like to open the meeting by thanking all the colleagues that supported last month's Health & Wellbeing Board development session. It was great to bring together Board Members with other colleagues who are active in their leadership of our health & care partnership and start our work around the development of the Board and the refresh of our Health & Wellbeing Strategy.

I was encouraged by the results of our review of Board effectiveness, that partners felt we were good at delivering our statutory duties as a Board. It was also positive that partners felt we were effective at creating a strong sense of Place and ensuring our delivery had a strong local focus. I think this reflects our recent work around the health counts survey, our JSNAs and the evolving work of our local Integrated Community (neighbourhood) Team partnerships across the city. So, I am pleased that this work is part of our agenda today as we look at the progress on our Shared Delivery Plan objectives.

It was also important that we got constructive feedback that there is more we can do to support our joint working and strategic planning to improve the health and wellbeing of the local population. We have the Better Care Fund on our agenda today, as Chair I am keen to see us continue to improve our leadership of this important fund that should drive local integration ensuring that our plan and associated investment is driving improvement in local health outcomes and enabling the new neighbourhood health reform.

In our recent Board Development session, our work together on assessing our Board effectiveness led naturally into us considering the latest data we hold on the health of our local population and how this should inform the development of our Joint Health & Wellbeing Strategy. There were some consistent themes that emerged from our discussions on the data; one of these was the need for our strategy refresh to enable a more focused approach to targeting key population health priorities. There was a broad agreement that our strategy should have strong focus on prevention, local health inequalities and that Health & Wellbeing Boards are uniquely placed to focus on the wider determinants of health.

I know that colleagues will be using all the valuable feedback collected in our development session to produce a more detailed scope for our strategy refresh and a model of Board development for us to consider and work on at our next Health & Wellbeing Board development session in March.

I would also like to take the opportunity to welcome Monica Fletcher OBE to the Board. Monica is the ICB Deputy Chair and will replace Stephen Lightfoot at the Board. Monica brings with her a wealth of experience, having originally worked as a nurse, and latterly as an NHS manager and an academic. I'm sure she will be a valuable addition to our Health & Wellbeing Board.

Finally, just to note that there is a minor change to today's agenda. I've been asked to take Item 32 Shared Delivery Plan Progress Report ahead of Item 31 Better Care Fund: Assurance Against BCF Delivery.

26 FORMAL PUBLIC INVOLVEMENT

26.1 There were no public involvement items.

27 FORMAL MEMBER INVOLVEMENT

27.1 There were no member involvement items.

28 VIOLENCE AGAINST WOMEN AND GIRLS (VAWG) STRATEGY AND ACTION PLAN

28.1 This item was introduced by Anne Clark, Strategic Commissioner for Violence Against Women and Girls (VAWG) and by Cllr Emma Daniel, Cabinet Member for Children, Families & youth Services.

28.2 Ms Clark outlined the VAWG strategy, emphasising the significant contribution of VAWG to physical and mental ill health and to health inequalities. Cllr Daniel explained that, although Violence Against *Women and Girls* is the term used, the VAWG strategy in fact includes everyone. The biggest challenge is in shifting support from crisis to prevention whilst still meeting demand for crisis services. Priority areas include a focus on people who repeatedly feature at MARAC (multi agency risk assessment conference), delivering better staff training, and supporting the safe childhood campaign which targets the sharing and solicitation of explicit contact via smartphone. Cllr Daniel also told the Board that Cllr Sam Parrott has been appointed as lead member for VAWG.

28.3 Tanya Brown-Griffith noted that Health Counts data shows a worrying rise in the suicide rate for women and girls. Services are well aware that suicide is often links to VAWG. Ms Brown-Griffith asked what health partners can do to support VAWG work. Ms Clark responded that priorities would include a greater focus on suicide, recognising that VAWG prevention is also suicide prevention. For example, of the 6 current domestic assault related death reviews, 3 relate to suicides. A second priority would be to ensure that routine enquiry happens across health services.

28.4 Tom Lambert asked about VCSE input into MARAC. Ms Clark replied that there is considerable sectoral input. Precisely which VCSE organisations are involved will vary as it depends on which organisations are supporting or have referred individual clients, but the list includes Switchboard, CGL, RISE and the International Women's Network.

28.5 Alan Boyd asked what was done to pick up public voice when developing the strategy. Ms Clark replied, explaining that the VAWG team had worked with a wide range of groups to ensure that the strategy was informed by survivor experience.

28.6 Monica Fletcher asked how the VAWG work is informed by data. Ms Clark responded that the strategy is underpinned by data from MARAC and from individual services. However, better mechanisms are required for collecting data. Ms Fletcher commented that the Board needs to think about how the health and care system collects and uses domestic assault data.

28.7 **RESOLVED –** that the Board notes the Preventing and Tackling Violence Against Women and Girls, Domestic Abuse and Sexual Violence Strategy 2025–28, and progress in delivering the action plan for its implementation; and supports the proposed role for health partners in supporting delivery of the strategy, as set out in section 2.8 of this report.

29 BRIGHTON & HOVE SAFEGUARDING CHILDREN PARTNERSHIP ANNUAL REPORT 2024-25

29.1 This item was presented by Deb Austin, BHCC Corporate Director, Families, Children & Wellbeing. Sarah Smart, Local Safeguarding Children Partnership (LSCP) Business Manager was also present remotely.

29.2 Ms Austin explained some of the context for the work of the LSCP, noting that Brighton & Hove has seen a steep declines in the number of children living in the city but rising numbers of children eligible for free school meals, an increase in the number of education, health & care plans issued, and increases in school absence and NEET rates. However, school exclusions are below the national average. There were almost 20,000 initial contacts with safeguarding in 2024-25, leading to around 3000 referrals to social work. There are currently around 260 children in the city subject to a child protection plan.

29.3 All LSCPs were required to update their multi agency safeguarding arrangements, and this work has been completed locally. Education is now more represented in safeguarding work. Closer ties have also been developed with East and West Sussex safeguarding and a pan-Sussex approach to safeguarding has been adopted. Business priorities for 2025-26 include enhancing working with education partners, developing a new Neglect strategy, and delivering more safeguarding training. Other priorities include the development of a pan-Sussex learning and development strategy, the development of a child sexual exploitation strategy, and development of a young scrutineers programme.

29.4 Ofsted inspected children's services in 2024 and gave an overall ranking of outstanding. This included good scores for many aspects of safeguarding.

29.5 Cllr Halliwell asked why the point of intervention for school absence was set at under 30% attendance. Ms Austin replied that it is important to recognise that there are a range of interventions for school absences, most of which will tackle much lower levels of absence. The <30% is for safeguarding interventions only.

29.6 Cllr Halliwell asked about the Neglect strategy. Ms Austin responded that the refresh will seek to prioritise early stage identification of neglect, going beyond social workers to include professions such as health visitors and teachers.

29.7 Tanya Brown-Griffith asked where the gaps are in terms of health services. Ms Austin replied that it was particularly important that workers across healthcare are trained to be aware of safeguarding issues.

29.8 Monica Fletcher asked about young scrutineers. Sarah Smart replied that recruitment of a cohort of young scrutineers is progressing. They will be recruited from across the city and care will be taken to ensure that those chosen accurately represent the diversity of the city.

29.9 Cllr Halliwell asked about out of area care placements. Ms Austin replied that Rainbow Lodge has just been opened in the city. This provides residential places for children and young people with complex disabilities who would previously have been placed out of area.

29.10 Caroline Ridley noted that VCSE plays an important role in safeguarding. This may include providing training for staff and trustees as well as some organisations maintaining a register of issues raised that fall below the safeguarding threshold.

29.11 The Chair asked why city performance on school exclusions is so good. Ms Austin replied that this is largely due to excellent practice by city schools, particularly secondary schools. Patcham High should be particularly commended, but all city secondaries work effectively to minimise exclusions.

29.12 RESOLVED – that the Board notes the Local Children's Safeguarding Partnership Annual Report 2024-25.

30 JOINT STRATEGIC NEEDS ASSESSMENT PROGRAMME ANNUAL REPORT AND UPDATE 2025

30.1 This item was presented by Louise Knight, Senior Public Health and Research Specialist, and by Dr Nicola Lang, interim Director of Public Health.

30.2 Ms Knight told the Board that it was proposed that the current 3 year Joint Strategic Needs Assessment (JSNA) programme be extended for a further year. The membership of the JSNA Steering Group has recently been extended to include more partners involved with wider determinant issues such as transport. Other recently delivered work includes analysis of Health Counts data, including a recent HWB development event; development of a new communication plan; website refresh; and a greater focus on co-production with local communities. Going forward, priorities include using Health Counts data to develop area profiles, and completing the SEND, neurodiversity and learning disability needs assessment.

30.3 Cllr Alexander asked for more information about the Community Research Project. Ms Knight responded that public health is working with the Hangleton & Knoll Project and the Trust for Developing Communities to develop this project.

30.4 Tanya Brown-Griffith commended the JSNA and noted how important it is that the ICB's strategic commissioning intentions are underpinned by an understanding of health inequalities. Dr Lang agreed, stating that the team are working on developing a better understanding of how the wider determinants of health impact health inequalities and on developing neighbourhood level cuts of data to facilitate this. Much of this data is already available, but it is typically ordered by council wards and the ICB needs it at a neighbourhood level. Monica Fletcher commented that the system also needs to use this data to develop improvement metrics for the areas with the highest inequalities. This work needs to involve the communities, and this will require a bespoke rather than a standardised approach.

30.5 Jenny Preece noted that the recently developed University Hospitals Sussex Strategy had drawn on the Brighton & Hove and West Sussex JSNAs. Having data cut for neighbourhoods will be an important tool in delivering improvements, for example in terms of planning to reduce unnecessary admissions.

30.6 The Chair asked what the needs assessment priorities for the coming year were. Dr Lang replied that a detailed list was included in the report but that priority areas include TB, special educational needs & disability and Gypsy and Traveller health.

30.7 RESOLVED – that the Board notes the JSNA update and approves the updated proposed programme of needs assessments.

31 BETTER CARE FUND (BCF): ASSURANCE AGAINST BCF DELIVERY

31.1 This item was introduced by Chas Walker, Programme Director, Integrated Service Transformation. Also presenting were Steve Hook and Tanya Brown-Griffith.

31.2 Mr Walker told the Board that, NHS England (NHSE) approval for the local Better Care Fund (BCF) plan had been conditional as NHSE wanted to see more challenging targets set. Targets have subsequently been revised to NHSE's satisfaction. The Section 75 agreement that supports the local BCF has also been refreshed. BCF expenditure is on track at the end of Quarter 2. However, 2 key metrics are currently off-track: discharge delays and hospital admissions for people 65+.

31.3 Mr Hook told members that discharge rates are improving, with current performance better than last year and better than the start of this year. There is additional discharge support via the national BCF support programme; investment in therapists now means that many therapies are being delivered to people while they are still inpatients; and the Home First and Admission Prevention teams are working successfully to reduce unnecessary admissions and to speed discharge. Other initiatives include the introduction of personal health grants and a move to a 24/7 discharge model. Ms Brown-Griffith added that the development of a Neighbourhood Health Alliance would help target unnecessary admissions. The Alliance will work to identify and support the people at highest risk of admission.

31.4 Monica Fletcher asked about work on flu. Ms Brown-Griffith responded that the target is for a 10-15% increase in vaccination uptake. Performance so far this year has been positive.

31.5 Tom Lambert asked about CVS involvement in the Neighbourhood Health Alliance. Ms Brown-Griffith confirmed that this forms a key part of planning for the roll-out of the Alliance.

31.6 The Chair asked about reablement centres. Mr Hook replied that there are currently 2 centres which will support improvements in the reablement pathway. These are at Craven Vale and Ireland Lodge. Services are also looking at providing a reablement offer to people when they present for adult social care assessment.

31.7 RESOLVED – that the Board:

- Notes performance against the BCF Plan for Quarters 1 and 2;
- Notes the sign-off of the Section 75 agreement between the Council and NHS Sussex as one of the national conditions of the BCF;
- Agrees the revisions to 3 metrics targets in the BCF Plan for 2025/26 as part of the final approval of the 2025/26 BCF Plan; and
- Notes the latest information on the national guidance for BCF planning for 2026/27.

32 SHARED DELIVERY PLAN (SDP): PROGRESS REPORT

32.1 This item was introduced by Chas Walker, Programme Director, Integrated Service Transformation. Also presenting were Steve Hook, Tanya Brown-Griffith, Dr Adam Fazakerley, Tory Lawrence and Joanna Martindale (Hangleton & Knoll Project).

32.2 Mr Walker told the Board that, of the 13 Shared Delivery Plan (SDP) objectives 10 were on track, one had been delayed and 2 were off-track. Ms Brown-Griffith told members that one of the off-track objectives was the development of a women's health hub. There is a local pilot which ends in February and a city women's health hub model will be subsequently developed. The other off-track priority is young people mental health transition. Work required here includes the close alignment of mental health, learning disability and autism services; improvement in help & advice services; and the development of a 16-18 neurodivergent pathway. Steve Hook told the Board that the council has recently adopted a Transition Strategy and has some funding to employ a programme manager to help embed the strategy. Mr Walker said that there would be a detailed report on the off-track areas at a future Board meeting.

32.3 Dr Fazakerley explained how the East Brighton health hub operates. The hub has been a success. It has helped that University Hospitals Sussex NHS Foundation Trust has been extremely supportive and that funding has been provided by a local GP practice. Ms Martindale and Ms Lawrence explained how the West health hub operates, noting that this functions across a number of venues rather than from a single base.

32.4 Cllr Halliwell commented that there have been very different approaches to health hubs in the east and the west of the city. Ms Martindale agreed, noting that this was because the hubs had utilised the assets available within each area. For example, while the east hub was relatively focused, the west hub had to cover quite a large geographical area, stretching from Mile Oak to the Knoll, and it was decided that the best approach here would be to hold a series of events at different community locations rather than expecting people to travel to one site. There is no right or wrong health hub model, but to be successful a hub needs to adopt a model that reflects the needs and assets of its community. Dr Fazakerley added that there is a long term ambition to develop hubs in the east, west and centre of Brighton & Hove.

32.5 Cllr Halliwell asked how the hubs were publicised. Ms Martindale replied that GP patients were targeted. There was also a range of community engagement via social media, flyers and other means. To date, attendance has spilt around 50/50 in terms of whether visitors heard of health hubs from GP communications or community advertising.

32.6 The Chair asked about the percentage of communities who have attended health hubs. Mr Walker replied that this information is not available. There will be evaluation in terms of how effectively the hubs have engaged with the most at risk communities.

32.7 Cllr Alexander asked for more details on the women's health hub. Dr Fazakerley responded that this had initially been hosted within a GP surgery. However, demand had been very high, and the challenge is to develop a sustainable model that can be delivered at scale and over a long period of time.

32.8 Cllr Alexander asked about the number of appointments at the women's health hub compared to attendance at the hubs in East and West Sussex. Dr Fazakerley replied that it is difficult to compare the hubs in this way because of very different demographics. The sheer number of GP surgeries operating in Brighton & Hove also complicates the picture.

32.9 Cllr Alexander asked when the new transitions programme manager would be recruited. Mr Hook responded that the plan is to complete this recruitment in early 2026.

32.10 Tom Lambert noted that CVS organisations were critical to the success of health hubs. Ms Martindale concurred and added that it was important that the key role played by the sector was recognised.

32.11 Monica Fletcher noted that it was good to hear about the success of the Brighton & Hove health hub pilots. This is a key area of ambition for the ICB, which will be evaluating the performance of health hub pilots from across Surrey and Sussex. A particular positive from Brighton & Hove has been the active engagement from the acute trust.

32.12 Cllr Alexander enquired what is being done in other parts of the city. Mr Walker replied that there is also lots of work happening in the centre of the city. For reasons of time, it was not possible to include this work in the Board presentation.

32.13 The Chair asked how many women's health hubs would be needed across the city. Ms Brown-Griffith replied that this would depend on NHS England deciding on funding and the types of contracts it aims to award. However, it is clear that there is really high demand for holistic, non-medicalised hubs offering a range of medical and non-medical services across multiple sites, potentially with roving services also. Dr Lang noted that public health is committed to helping develop this model and is deeply involved in many women's health initiatives.

32.14 RESOLVED – that the report be noted.

The meeting concluded at 7.15pm

Signed Chair

Dated this day of

Brighton & Hove City Council

Health & Wellbeing Board Agenda Item 36

Subject: Formal Public Involvement

Date of Meeting: 3rd March 2026

The following question has been received from a member of the public:

1) Gary Vallier

In light of the final Cass Review, and the Supreme Court's clarification of the Equality Act in For Women Scotland versus Scottish Ministers, and the High Court's confirmation of the lawfulness of the interim guidance issued by the Equality and Human Rights Commission, and the DfEs draft 2025 update to Keeping Children Safe in Education .... will the Board confirm what steps it has taken, or will now take, to ensure that local safeguarding strategy, mental health pathways and partnership guidance across Brighton & Hove are aligned with this clarified legal and clinical framework?

Although a formal committee of Brighton & Hove City Council, the Health & Wellbeing Board has a remit which includes matters relating to the Sussex Integrated Care Board (ICB)), the Local Safeguarding Board for Children and Adults and Healthwatch.

Title: Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR)

Date of Meeting: 03 March 2026

Report of: NHS Sussex Integrated Care Board

Contact:
NHS Sussex
Email:
sxicb.leder@nhs.net

Wards Affected: all

FOR GENERAL RELEASE

Executive Summary

This report presents learning from the most recent year's (2024-25) reviews into the deaths of people with a learning disability and people with autism. The LeDeR programme reviews deaths in order to help identify the service improvements required to address the health inequalities experienced by people with a learning disability and people with autism. The report details the performance and progress of the LeDeR program in Sussex in 2024-25. This includes service improvement work undertaken across the Integrated Care System (ICS).

1. Decisions, recommendations and any options

1.1 That the Board notes the information provided in this report (Appendix 1).

1.2 That the Board approves the organisations represented on the Board utilising the learning from LeDeR and developing formal internal cascade processes in order to impact on the reduction of the mortality gap for people with a learning disability and autistic people.

2. Relevant information

2.1 LeDeR has been operational in Sussex since 2017, with the annual findings of LeDeR reported to the relevant service and service commissioners and shared with Sussex Health & Wellbeing Boards for information.

2.2 Appendix 1 contains the Sussex LeDeR Annual Report for 2024-25.

3. Important considerations and implications

Legal:

3.1 LeDeR is not a statutory function but a NHS policy led Service Improvement Programme. There are no specific legal implications arising from this report.

Lawyer consulted: Sandra O'Brien Date: 12 February 2026

Finance:

3.2 There are no direct financial implications arising from this report for Brighton & Hove City Council.

Finance Officer consulted: Sophie Warburton Date: 18/02/2026

Equalities:

3.3 The purpose of the LeDeR programme is to reduce the health inequalities people with a learning disability and autistic people face, by attempting to understand the determinants that underpin them. Sussex commits to the delivery of the LeDeR program which supports the protected characteristics of people with a learning disability and autistic people and works to support a target population of people within the Core20+5 group.

Sustainability:

3.4 No implications identified

Health, social care, children's services and public health

3.5 These implications are explored in the LeDeR Annual Report 2024-25 (Appendix 1)

Supporting documents and information

Appendix1: Sussex LeDeR Annual Report 2024-25

Appendix 2: LeDeR presentation slides

Appendix 3: Sussex LeDeR Annual Report 2024-25 easy read version

NHS Sussex

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

Sussex Annual Report 2024-25

Improving Lives Together

Contents

1 Introduction

1.1 LeDeR sets out a structured way to review the lives and deaths of people with a Learning Disability and Autistic people to share good practice and identify service improvements in order to promote living well for longer, ensuring the person, their family and their circle of support, are firmly at the centre of the work.

1.2 The LeDeR programme in Sussex is supported by a multidisciplinary team of reviewers who are registered learning disability and general nurses, and a social worker. Members of the team have additional skills in best interest assessing for the deprivation of liberty safeguards, autism support, patient safety and safeguarding adults.

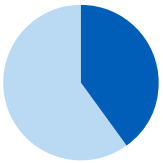
1.3 The programme is supported by a collaboratively developed and robust standard operating procedure with terms of reference for strategic and operational meetings. This ensures NHS Sussex meets the requirements of the national LeDeR Policy 2021.

1.4 The total population of Sussex is approximately 1.8 million people. Based on a Learning Disability prevalence of approximately 2.16%, 41,730 people with Learning Disabilities are likely to live in Sussex. The prevalence of Autism is approximately 1% of the population and 40% of Autistic people will also have a Learning Disability; this means approximately 7,200 autistic people (without a learning disability) live in Sussex.

1.5 LeDeR enables us to tell the story of important people within our Sussex communities. We have included the stories of some of these people to illustrate our work and we thank these people. Their names have been changed.

41,730
people with a Learning Disability

1%
approximate number of autistic people in Sussex



40%
of autistic people have a Learning Disability

2 Co-production

2.1 LeDeR cannot operate in isolation and continues to acknowledge the contribution our partners make under the current system pressures. These include:

- GP surgeries
- People and their families
- NHS Trusts
- Local authority duty desks
- Registered managers and their staff
- Governance group members who all have large portfolios in senior roles
- Panel members including those with lived experience

2.2 A LeDeR review is often the last words written about a person's life. Reviewers approach all reviews with compassion and sensitivity to develop rapport that often supports people in their loss, and to influence changes early in the process if helpful.

2.3 Working with families and carers is the most rewarding part of undertaking reviews and we are grateful for their candour and courage. Hearing the stories in LeDeR; both happy and sad, is a privilege.

2.4 When speaking with people with a learning disability, autistic people, their carers, families and service that support them, the message of "Living Well for Longer" is paramount. In all forums where we present our findings and service improvements the stark reality of inequalities that remain, are rightly pointed out. However, we are grateful to have the scope and capacity to be able to present the service improvement we drive, as a result of reviews undertaken in this report. LeDeR urges our stakeholders to develop their own service improvement plans as a result of reviews undertaken.

2.5 Most people with a learning disability have experienced care throughout much of their lives. For those that are autistic they may have had significant difficulties in accessing education and maintaining good mental health prior to their diagnosis. Almost all of these people will have experienced stigma and significant adversity and the subsequent trauma this causes. LeDeR is always reminded of their bravery.

3 Governance arrangements in the Sussex system

3.1 The Sussex LeDeR function has transferred from the Complex Commissioning arm of the NHS Sussex Integrated Care Board to the Chief Nursing Officer's remit. This was to enhance the clinical oversight of the programme and to bring it, along with the wider Learning Disability and Autism elements, to a single clinical management structure, that also oversees safeguarding.

3.2 The Sussex LeDeR Governance Group was established in 2021, in line with the Policy requirements, and is responsible for the governance and local implementation of the LeDeR programme.

3.3 Committed and consistent membership continues from the partner organisations in the Sussex integrated care system.

3.4 The LeDeR governance group in Sussex has benefited from a lay member who is an expert by experience with considerable knowledge and expertise in the LeDeR programme. This lay member left the programme at the end of this reporting period, and we pay particular thanks to them in this report.

3.5 Wider organisational governance routes include the Mental Health and Learning Disability Oversight Board, the Integrated Assurance Group, Quality and Patient Experience Committee and the NHS Sussex Board.

3.5 There are three Local Area Contacts, a national policy requirement, to support the work of the LeDeR programme by quality assuring reviews and chairing panels.

4 Ensuring compliance with policy and best practice

4.1 The LeDeR programme in Sussex continues to be fully compliant with the national LeDeR policy. The standard operating procedure is regularly reviewed and revised to ensure clear and up to date process and governance. This includes updating data protection impact assessments and data sharing arrangements with partners. Terms of reference have been agreed for the LeDeR governance group and focused review sign off panel, and these were reviewed and updated in September 2024.

4.2 Here is an example of how a member of the Sussex governance group implements learning from LeDeR reviews.

An example of LeDeR learning through the system:

A LeDeR Review takes place and learning identified.

The review is signed off and shared with stakeholders - in this case, the local authority.

The Head of Learning Disability Services at the local authority shares the learning and actions with the Services Managers at their team meeting, including their Directly Provided Services 'Compliance Officer' and Positive Behaviour Support Team.

The managers and compliance officer embeds the learning in the services and with their care officers,

The Compliance Officer said:

"LeDeR have been instrumental in my work as a compliance officer. They've not only highlighted key areas for learning but also shared valuable health initiatives, these insights have helped me feed back into our directly provided services and support the promotion of initiatives that lead to better health outcomes for the people we support."

5 Undertaking LeDeR for the death of autistic people in Sussex

5.1 It is essential to understand the significant difference in undertaking reviews into the deaths of autistic people in Sussex who do not have a learning disability. This population may have achieved high levels of independence and attainment whilst experiencing barriers to health care due to a lack of understanding of needs such as sensory processing difficulties and the consequences of masking.

5.2 LeDeR recognises that the number of deaths of autistic people notified to the programme is likely to be lower than actual deaths of autistic people in Sussex. Findings from undertaking reviews into the death of autistic people have been shared to inform the Autism strategies in different stages of development and implementation in Sussex.

5.3 LeDeR is a member of the Pan Sussex working group hosted by public health for suicide prevention.

A person's story

David lived with his parents until he was 42. His learning disability was quite mild, and he had needs associated with his mental health and autism diagnosis. David loved music and played air guitar to his favourite tunes. He particularly loved anything to do with airplanes.

David had experienced phobias that restricted him going out and about in his community. When he moved into his home 10 years ago, he developed trusted relationships with staff. This eventually enabled him to go on overnight stays to watch planes at airports which he thoroughly enjoyed.

David also had a fear of medical procedures including blood tests and blood pressure. These had not been possible despite lots of reasonable adjustments. Sadly, at the age of 52 David had a large stroke that he could not recover from. But his care staff wanted him to come home and die in a familiar environment with people who loved him.

David's LeDeR was a focused review as his care was funded by an area outside of Sussex.

The discharge was well co-ordinated, and his care staff were supported by the end-of-life care hub.

LeDeR identified that David received regular reviews, and these were comprehensive and personalised and enabled coordinated support. This was from the funding authority's Mental health team.

His discharge from hospital was described as "excellent" and his treatment in hospital was respectful and dignified.

6 Performance

6.1 National Health Service England (NHSE), sets key performance indicators (KPI) of:

- **100% of all reviews to be completed within 6 months.**
- **35% of all reviews to be undertaken as focused reviews.**

6.2 The following were locally agreed priorities for focused reviews in 2024 - 2025:

- Where a woman has died of breast screening age and mammography is not recorded as being undertaken.
- Where a person has a BMI of over 30.
- Where there is a diagnosis of type 2 respiratory failure.
- Where a person is placed into Sussex from another area.
- Where epilepsy is contributory to the cause of death.
- Where there are concerns about care co-ordination or the threshold was met for safeguarding.
- Where constipation is contributory to the cause of death.
- Where a person is a care leaver.

6.3 The following are national priorities for focused review:

- When the person is autistic (without a learning disability).
- When the person is from a minority ethnic community.
- Where a family member requests a focused review.

6 Performance (cont.)

6.4 Focused reviews enable reviewers to detail the specific physical and mental health conditions a person experiences, as well as considering the commissioning of their care contact with other services such as substance use and housing. Actions are agreed by a panel of senior decision maker across stakeholders in Sussex including an expert by experience and care provider.

6.5 **LeDeR has achieved 68% of reviews completed within 6 months. LeDeR has exceeded the 35% KPI with 41% of reviews being undertaken as focused reviews at the end of this reporting period. Further benchmarking of performance is given in Section 7 below.**

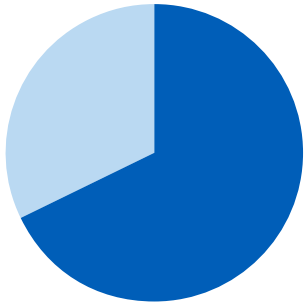
6.6 On audit it was found that 66% of 15 breeched reviews were signed off within 2 weeks of the 6-month target. We have therefore implemented an additional case load management tool to ensure that reviews are completed within 5 months.

6.7 Where reviews may not be completed within the required 6 months, risks are escalated and plans for completion devised.

6.8 LeDeR is not concluded until all statutory processes such as inquest or safeguarding enquiry have been undertaken. Where a statutory process is being undertaken LeDeR goes 'on hold' which stops the 6-month clock. After this, LeDeR will be completed within two months where possible. Regular audit of all reviews that are on hold is undertaken to ensure all reviews are appropriate to be on hold.

6.9 LeDeR tracks performance and collects data on high level themes for completed reviews. This is then segmented by provider. These themes are taken from both completed LeDeR initial and focused reviews.

6.10 On a quarterly basis LeDeR reports to Sussex system, Quality, Governance and Improvement Group (QGIG) and to the Integrated Assurance Group (IAG) and the Quality and Patient Experience Committee (QPEC).



68%

of reviews were completed within 6 months

Deidre

Deirdre was a 66 year old woman who lived in a care home. Deirdre grew up in the West Indies, she was a devout Christian who was described as a colourful and charismatic character often found knitting, dancing and gardening.

Deirdre had a history of serious mental illness, type 2 diabetes, abdominal swelling and constipation.

Deirdre hadn't attended cervical screening.

Deirdre often agreed with what people said and didn't 'make a fuss'.

Review Analysis

Deirdre hat numerous medical appointments and exploration of symptoms over two years, however she was diagnosed with a likely advanced malignancy with metastases (intraabdominal, ovarian and umbilical cancer) at a very late stage resulting in a terminal prognosis and palliative treatment pathway.

The review found that whilst there was lots of oversight and care for Deirdre, amongst other things there were issues around:

- Diagnostic overshadowing
- Recognition of deterioration
- Delayed diagnosis and missed opportunities in annual checks

Outcomes

The GP surgery was asked to complete a significant event review process using an intersectional lens. The care home manager and deputy attended 'Stop Look Care' training and implemented the toolkit in all homes.

We shared easy read information on diagnostic overshadowing, and this was discussed in the home's team meeting. The care home manager agreed to discuss screening needs for all residents with the GP on their next call. The care home contacted the health facilitation team about meeting their resident's health needs.

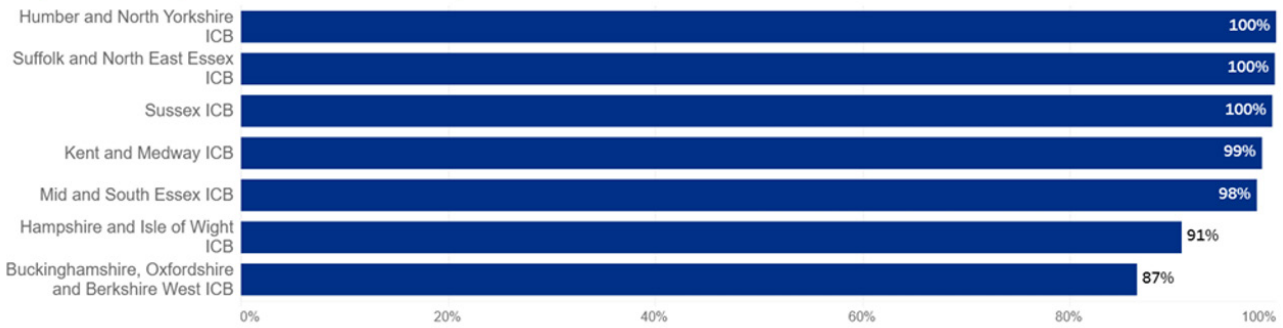
7 Benchmarking

7.1 NHSE hosts the national LeDeR reporting dashboard. This shows relative performance with peers.

This page shows the closing position of LeDeR in Sussex against comparable systems, over a rolling period of 6 months.

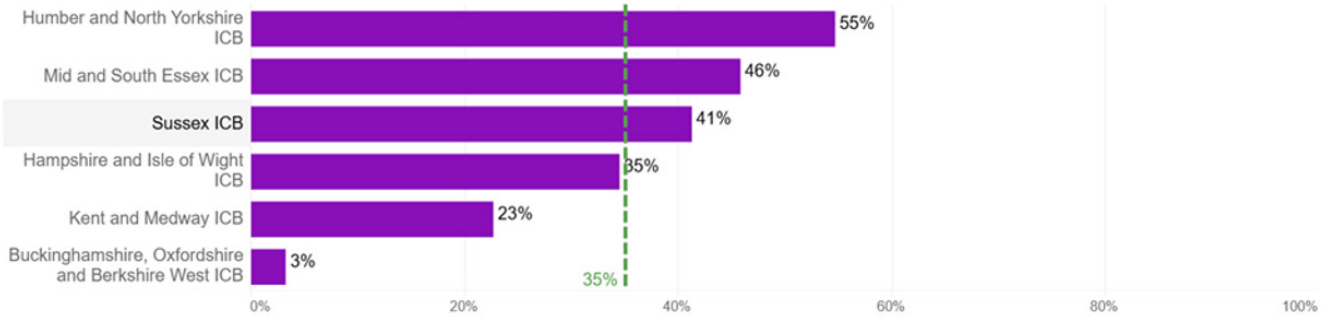
Proportion of eligible reviews that are completed

ICB breakdown - March 2025, All



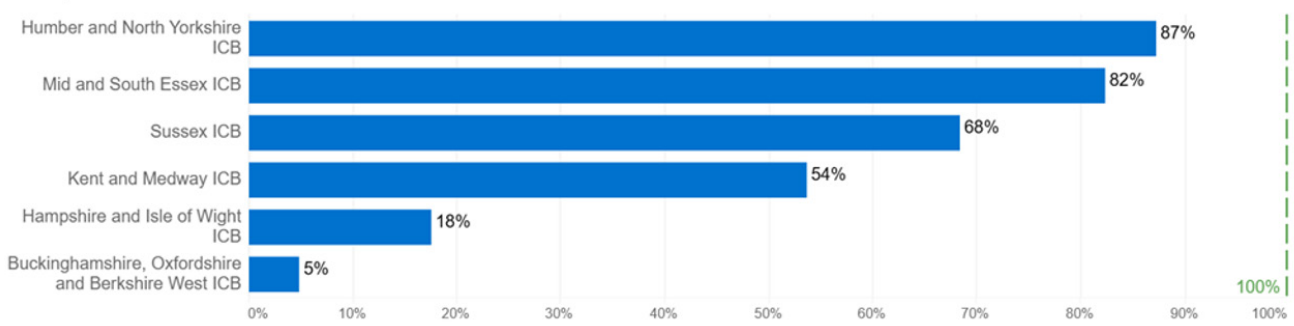
Proportion of completed reviews that were focused (6 month rolling period)

ICB breakdown - March 2025, All



Proportion of all reviews completed within 6 months of notification (6 months rolling period)

ICB breakdown - March 2025, All



8 Analysis

8.1 Equality impact

The purpose of the LeDeR programme is to reduce the health inequalities that people with a learning disability and autistic people experience, by attempting to understand the determinants that underpin them.

8.2 Four domains of analysis

The next part of this report focuses on the analysis of all the reviews received and completed in the reporting period.

These domains are:

- **Demographics of all notifications received: age, gender, ethnicity.**
- **The cause of death as recorded on the death certificate of completed reviews.**
- **Health conditions in order of prevalence and levels of multiple morbidities.**
- **Themes identified in the recommendations made in completed reviews.**

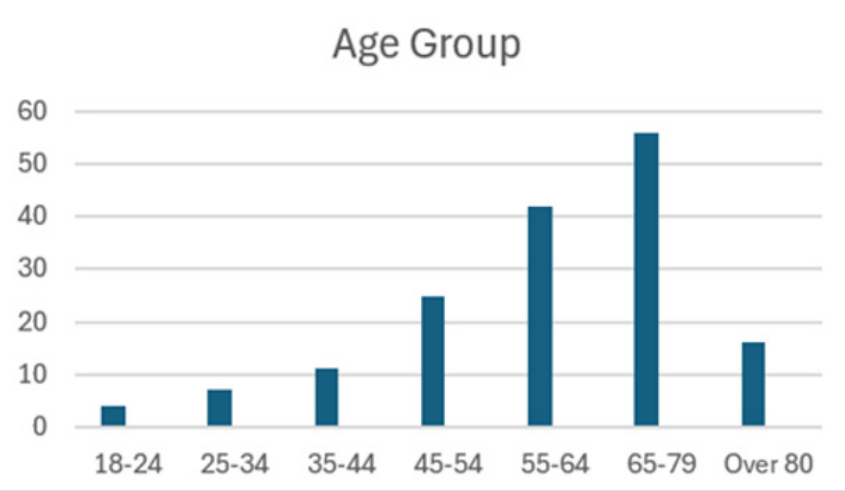
8 Analysis (cont.)

8.3 Age

158 deaths were notified to LeDeR during the reporting period.

This is an increase of 20 from the last reporting period and confirms a year-on-year increase in notifications received.

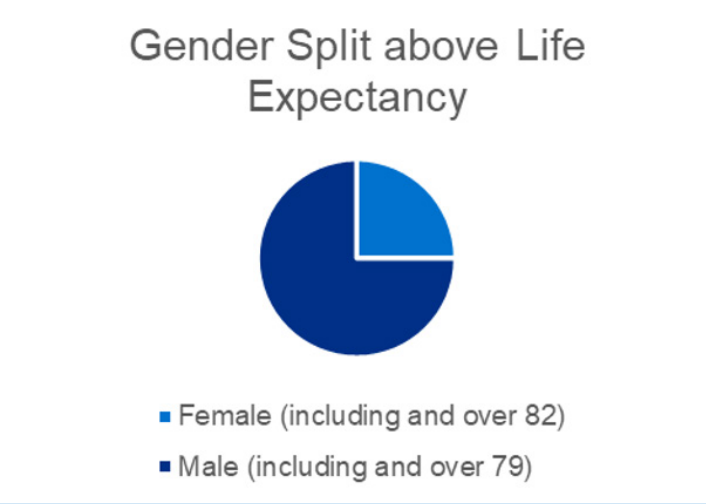
- The range of age of death was 19-91.
- The median age of death was 62.



8.4 Gender

- 77 females died in the reporting period.
- 79 males died in the reporting period.
- 2 autistic people who identified as non-binary died in this reporting period.

More people with a learning disability lived to their life expectancy and below shows the gender split of those with a learning disability who die in old age.

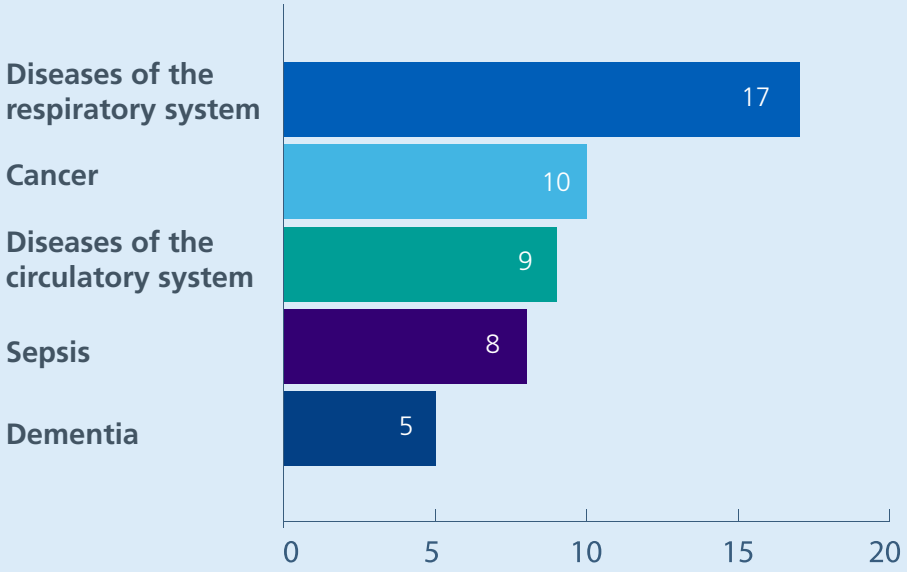


8 Analysis (cont.)

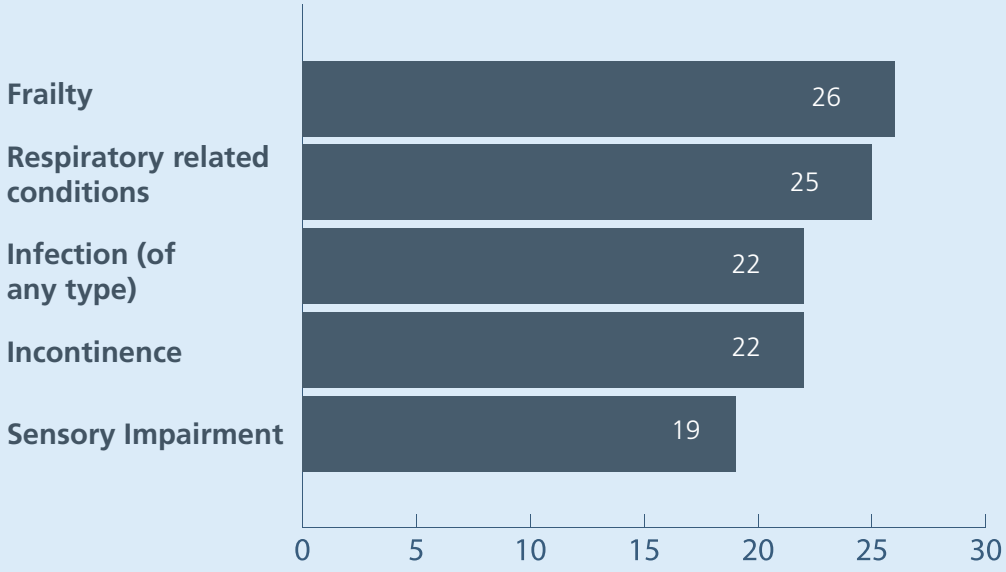
8.6 Cause of death

The top 5 causes of death in Sussex have remained consistent since reporting began in 2019.

Causes of death - Top 5



Most common health conditions- Top 5



8 Analysis (cont.)

8.7 Recommendations made in completed reviews

163 reviews were signed off as completed in this reporting period with 63% undertaken as initial reviews. This increase in focused reviews was enabled by a change in process. The break down for the reasons focused reviews were undertaken are shown on this page (chart 2).

Sussex collects aggregated themes on the learning and actions in initial and focused reviews. The LeDeR platform groups actions by themes and below is the analysis of grouping of action by theme (chart 1).

Chart 1 **Themes**

- Professional practice and the provision of care - **94**
- Care Pathways - **25**
- DNACPR recommendations and EOL care - **22**
- Safeguarding including MCA - **19**
- Training on Specific Conditions -**14**
- Learning Disability Awareness - **12**
- Involving the Coroner - **3**
- Family and Carer Awareness of Support - **2**
- Deterioration - **1**

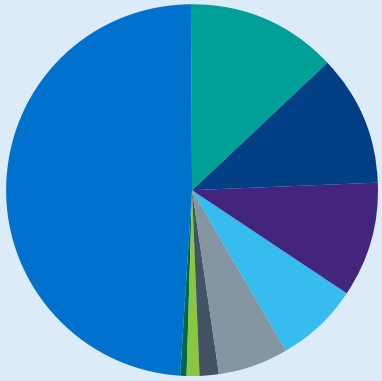
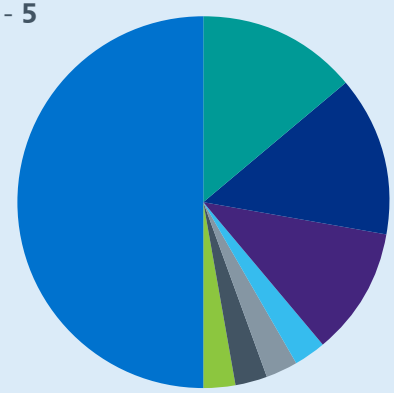


Chart 2 **Reason for focused review**

- Out of Area Placement - **18**
- Black and Minority Ethnic Background - **5**
- Autistic Person - **5**
- Reviewer Judgement - **4**
- Lack of mammography - **1**
- Care Experienced - **1**
- Epilepsy linked to COD - **1**
- Type 2 Respiratory Failure - **1**



9 Action from learning: system learning identified within completed LeDeR reviews

9.1 Impact

Sussex has a long track record of developing and delivering service improvements across the health and social care system, some of which are detailed below. These service improvements would be unsuccessful without the collaboration of stakeholder including Voluntary, Community and Social Enterprise sector (VCSE) and people with a learning disability.

A National LeDeR report has yet to be published for 2024 but a Sussex LeDeR report was produced in full and easy read. The LeDeR team in Sussex created a briefing of these reports delivered and presented into:

- Sussex Integrated Care System (ICS) mental health, autism and learning disabilities board.
- Safeguarding adults' boards.
- Learning disability partnership boards.
- Sussex Health and Wellbeing boards.
- Chief nursing directorate meeting.
- Local authority social work teams.
- Shared lives carers teams.
- Autism partnership boards.
- Medical examiner services and teams.
- Adult social care provider forums.
- Self-advocacy groups.
- Suicide prevention boards.
- Sussex Safeguarding fortnight focusing on out of area placements.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

LeDeR also continues to create a quarterly newsletter which is published on the NHS Sussex and local authority websites here and distributed to a wide circulation list in Sussex.

LeDeR seeks to influence the system work force in understanding the barriers people with a learning disability and autistic people experience, in order to overcome them. 176 people or agencies are on the circulation list and a printable poster has been devised based on feedback received.

9 Action from learning: system learning identified within completed LeDeR reviews

9.2 Outcomes

Some of the highlights of the year include:

On 24 June, Tom Cahill, National Director for Learning Disability and Autism visited Sussex to meet those across the ICS involved in service improvements as a result of LeDeR. This visit had been initiated by Sussex presenting their work at a national health inequalities event. Tom said this about his visit:

> "I came away feeling both inspired and excited by the work you are doing and the potential there to make such a difference to the local population".

Tom's visit featured in the NHSE Mental Health, Learning Disability and Autism Bulletin with this picture, of our colleagues who developed our cardiovascular disease prevention and management resources.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

On 15 October, Sussex hosted Clive Parry, England Director for the Association for Real Change (ARC), who had co-chaired the initial event with Tom. He reflected that he was unaware of LeDeR influencing other ICS's in the same way and particularly saw the benefit of Stop Look Care (a tool developed to identify deterioration and adapted for use in care settings for those with a learning disability) to adult social care. This was subsequently presented by Sussex at an ARC national registered managers event.

Four teams in Sussex continued to deliver this 90-minute virtual training sessions on a rota basis. Hard copies of the booklet have been produced with a plan for distribution developed.

Numbers of people trained in Stop Look Care for those with a learning disability:

- **2022-23 (3 sessions) -** 263
- **2023-24 (4 sessions)-** 575
- **2024-25 (4 sessions) -** 595

There are already 4 identified dates for this training in 25/26 and booking has commenced.

The Sussex LeDeR team delivered a two-hour workshop at the Safeguarding Fortnight event in November 2024 titled 'LeDeR: Supporting your Work in Safeguarding Adults'.

The workshop focused on the prevention principle of safeguarding adults and utilising resources developed because of LeDeR reviews, such as Stop Look Care and our Cardiovascular Disease Prevention and Management (CVDPM) films, in addition to national resources such as the Clive Treacy Checklist (tools for supporting the safety of people with a learning disability and autistic people with epilepsy).

Break out room sessions focused on the learning gleaned from focused reviews completed for those people that died and were placed from authorities outside of the Sussex area. LeDeR had learned that services may not understand the risks in placing people away from family advocates and networks, where referral pathways for additional support may not be known and the oversight from a person's funding authority is limited. Adults may not come to the attention of the hosting authority until they have experienced, or are at risk of experiencing, abuse or neglect.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

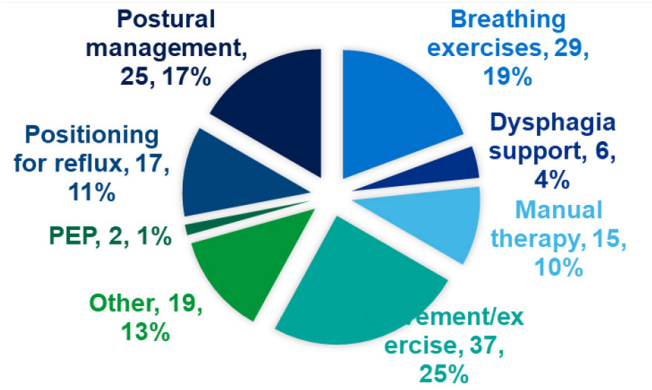
There was good attendance at the workshop from across Sussex, including VCSE, primary care, local authorities and district and borough workers. Over 70 people attended, and feedback included:

"The faciliator was really knowledgeable and passionate about the topic of service improvement. The inclusion of people with learning disabilities in resources helped to reinforce the importance of the programme and the ethos of the programme. I learned lots of valuable information."

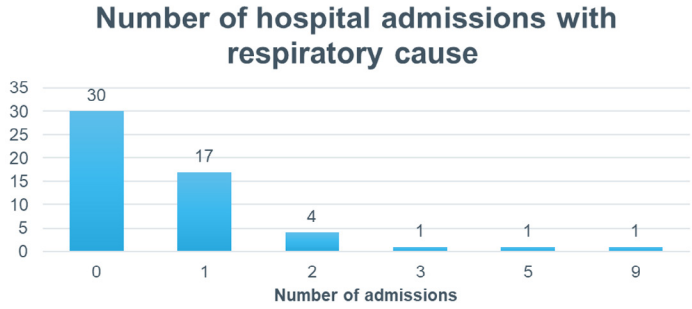
"My role has some strategic elements through training and policy development. I will certainly be using information from this course when I train others around organisational harm and neglect."

We asked the group for one or more new things learned from this training, presented here as a word cloud:

Extensive work continues with the community learning disability physiotherapy teams on their respiratory pathway, for those usually with profound and multiple learning disability, who are at the highest risk of premature mortality due to pneumonia. Below details the interventions and reduction in hospital admission. Of the 59 referred into the service, two followed the pathway into secondary respiratory services. Baseline scores in respiratory assessment determined intervention.



The interventions were then able to evidence better outcomes particularly regarding hospital admission avoidance as below:



9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

Last year, money was secured from the Sussex prevention board to develop resources to support people with a learning disability and autistic people to stop smoking. This was due to LeDeR identifying that whilst records stated, "smoking cessation advice offered", referrals for onward support were not seen and cessation rates were nil unless a person became too ill to smoke.

Utilising a tobacco dependency service (TDS) that was already established within an NHS Trust, a project plan was developed to:

- Undertake focus groups with both adults with a learning disability and autistic adults to inform adjustments into the service.
- Co-deliver training to skill TDS advisors.
- Provided training to specialist staff supporting those with a learning disability
- In the importance of onward referrals and available support.
- Co-produce a set of accessible resources including films with branding similar to that of previously produced cardiovascular disease prevention and management resources.
- Co-deliver training to universal prevention services providing tobacco dependency services, including public health, social prescribing and community pharmacies.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

The TDS developed a set of standards on good engagement based on what they heard. Approximately 70 people joined an online training event co-delivered by people with a learning disability.

Here are some of the feedback comments received:

"An action I'll take from this training is to me more aware of the environment we're in - sensory requirement."

"Loved the fact that the training also comprised of people sharing their experiences which made things so much more useful to understand."

"Excellent training. Informative and lovely to meet Expert by experience."

"Going forwards I'll be more mindful of barriers and find ways to ask about reasonable adjustments."

This work has been shared at the Sussex ICS Prevention Board and all resources are available online with the agreement that providers can add their own logos as needed. Local health facilitation teams have also worked with their public health TDS to ensure that the resources are made available.

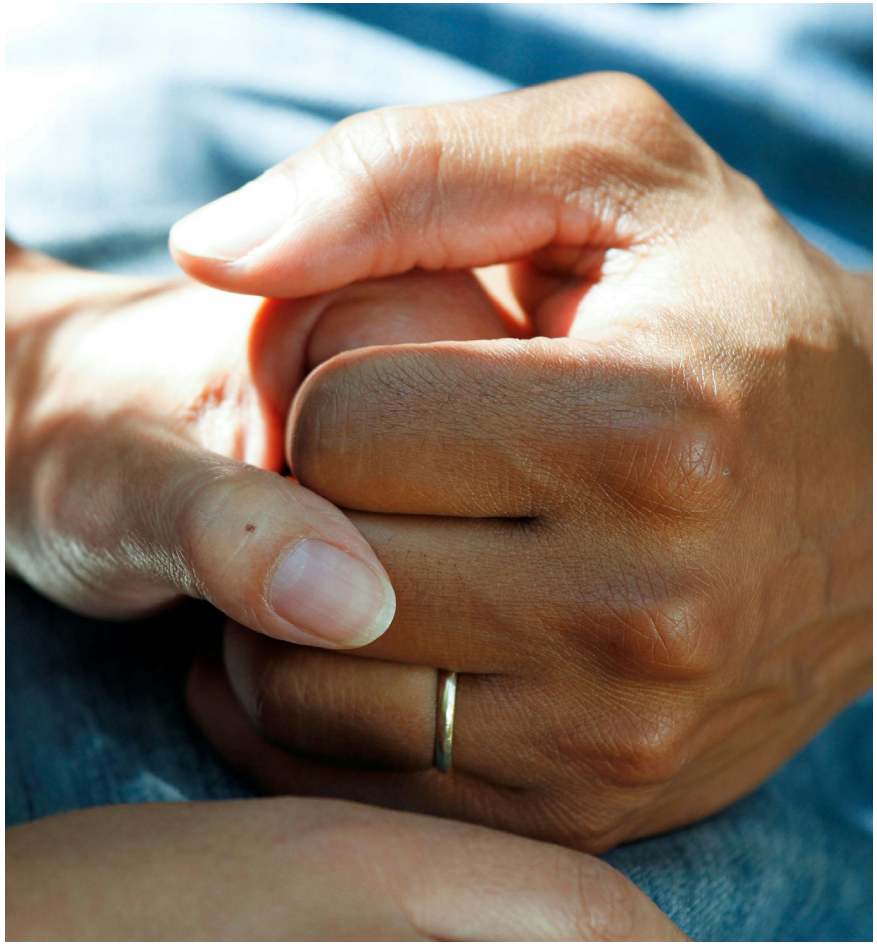
9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

LeDeR is an active member of the Sussex Palliative and End of Life oversight group and has contributed to the submission to NHSE of the Palliative and End of Life care ambitions for people in Sussex.

LeDeR is also a member of the Learning Disability Palliative Care Link Group, established due to learning from a LeDeR review, and in this period our contributions included:

- LeDeR provided a briefing on the annual report.
- LeDeR presented on grief and bereavement for people with a learning disability.
- LeDeR presented on the importance of Life Story Work
- LeDeR increased the membership and reach of the group.
- LeDeR circulated and shared learning from the group.

LeDeR has undertaken subsequent reviews where plaudits have been made regarding palliative and end of life care due to learning and relationships developed in this group.



10 How did we do? Achievements against local priorities for delivery in 2024-25

"LeDeR has identified that women with a learning disability continue to die of breast cancer when they are of screening age but have not attended for the mammogram. We are working with the Surrey, Sussex and Frimley cancer alliance to deliver training across primary care to reduce the barriers to mammography for woman who have a learning disability or are autistic."

- Focused reviews have been undertaken for women of screening age who have not received mammography to better understand the barriers. Health facilitators in Sussex are members of the newly established Inequality Group as part of the Surrey and Sussex Screening and Immunisation team who share learning on the barriers to this screening process.
- Sussex has met with a service in Somerset which is specifically commissioned to increase the uptake of screening for those with a learning disability and has shared this learning with our system.
- The Sussex provider collaborative has 'closing the mortality gap and health inequalities for people with a learning disability and/or mental health disorder' in their list of four priorities. LeDeR has met with the director in order that mammography is included in this priority.

"LeDeR continues to identify a gap in understanding of the health inequalities autistic people in Sussex experience. We will work hard to undertake LeDeR as soon as possible to ensure we have better information to make service improvements."

- Sussex awaits the outcome of NHSE pilots expected by April 2026, in combined learning disability, serious mental illness and autism annual health checks in order to mobilise this learning. With regards to mental health, NHS Sussex is undertaking a transformation plan to increase the resource of their post diagnosis support which has shown to reduce admissions to a mental health hospital setting and to considerably decrease the length of hospital stays if admitted.
- In relation to suicide prevention, LeDeR has shared case studies into autism partnership boards and suicide prevention boards. The specialist mental health provider has co-developed and delivered a presentation at a national event called Neurodivergence and Suicide Prevention. NHS Sussex has established the Lived Experience Advisory Group to inform their transformation programmes.

10 How did we do? Achievements against local priorities for delivery in 2024-25 (cont.)

LeDeR has identified that a lack of structured education and support is provided to people with a learning disability and autistic people who are obese and/or have type two diabetes or non-diabetic hyperglycaemia. LeDeR will support work already underway in the mapping and improvement of these services by informing Integrated Care Board (ICB) colleagues of the barriers identified in reviews.

- LeDeR will work with stakeholders to increase the use of continuous glucose monitoring in line with NICE guidance. Health facilitators in Sussex are members of the Health Inequities Group established as part of the Surrey and Sussex Screening and Immunisation team where this information is shared.
- 'D2day', is an initiative across Sussex to better understand the barriers that result in Type 2 Diabetes being diagnosed before 40, when outcomes are known to be poorer. LeDeR has flagged an increased risk of those with a learning disability who are on psychotropic medication or have specific chromosomal disorders. LeDeR has provided case studies and support on how to adjust education to be inclusive of those with a learning disability. LeDeR has shared guidance regarding the use of continuous glucose monitoring (CGM) for those on insulin, and has seen their use and trial in reviews.

Sepsis continues to result in many deaths of those with a learning disability or who are autistic. We will work jointly with NHS Sussex and other ICS stakeholders to deliver training to those supporting people with a learning disability or who are autistic in identifying sepsis.

- LeDeR has facilitated the co-development and delivery of a webinar on the prevention of sepsis in people with a learning disability. Targeted at the adult social care workforce the training was co-developed with health facilitation teams, a nurse with over 10 years working in the emergency department now working with adults with a learning disability, a registered nurse: learning disabilities who is the registered manager of a supported living provider and a registered manager of a residential home for those with profound and multiple learning disabilities.
- The webinar was attended by over 100 people and was well received. The edited version of the webinar is available on you tube and the Sussex ICS website.

10 How did we do? Achievements against local priorities for delivery in 2024-25 (cont.)

"LeDeR will develop and implement a communication plan to promote the use of the Victoria and Stuart toolkit to support advance care planning for those with a learning disability."

- This toolkit on advanced care planning, has been circulated widely via the developed communication plan. It has been included in the LeDeR newsletter, the hospice link forum and in training for Stop Look Care. It has also been presented at the Sussex ICS Palliative and End of Life Oversight Group. Sussex looks forward to an evaluation of its use and benefit at a national conference later in the year. LeDeR has also influenced the submission to NHSE of the ICS's Palliative Care Ambitions in order that the needs of those with a learning disability, based on learning from LeDeR, are represented.

"LeDeR will increase its reach and influence through active engagement into our minority ethnic communities with the support of ICB colleagues. This will enable LeDeR to understand the intersectional barriers experienced and ensure notifications are in line with the demographics of Sussex in order to result in culturally informed service improvements."

- Dying Matters week 2025 adopted the theme "The Culture Of Dying Matters". This saw the launch of the 'Respecting Faith and Culture in End-of-life Care Handbook'. LeDeR supported the development of this resource to ensure that it included the needs of those with a learning disability from our minority communities who may be approaching the end of their lives. Learning from LeDeR reviews on the inequalities that people with a learning disability from a minority ethnic background experience, was detailed in Dying Matters Week, alongside the launch of this handbook.

A Case Study - Janet

Janet was born with tuberous sclerosis and had a severe learning disability and epilepsy. She lived at a residential home and was described as happy and full of life.

In March 2021, Janet's carers noticed a distortion of her breast, which then returned to normal.

In June 2022, a further lump was found and following a biopsy, breast cancer was confirmed. Janet had surgery and hormone therapy.

In November 2022, Janet's breast cancer returned with widespread metastases.

Janet collapsed at home and died, at the age of 66, a few months later, on the day the hospice was due to visit her to plan her end-of-life care.

Background

In 2010, Janet attended a "disabled screening clinic" and was deemed not suitable for mammogram due to non-cooperation.

In 2012, Janet attended for a mammogram, but it was not completed. A breast screening disclaimer was completed.

In November 2020, a breast care letter was sent to the surgery but was returned.

In January 2022, the care provider asked the family to sign a disclaimer regarding withdrawal from mammography screening, stating it was unfair to continue when it causes upset.

As a result, Janet was removed from the breast screening programme without appropriate application of the Mental Capacity Act 2005 (MCA).

Learning

The application of the Mental Capacity Act (MCA) is a legal requirement for all those involved in the care of a person who may not be able to provide consent.

- Principle 2 – Capacity must be maximised using reasonable adjusted information and experiences.
- Principle 4 – Decisions made about a person who is unable to consent must be made in their best interest under the MCA.
- Principle 5 – Any best interest decision made must be of the less restrictive means.

Service improvement

- As a result of the LeDeR process, the review was shared with all services undertaking mammography screening to be used as a case study regarding the application of the Mental Capacity Act (MCA) and reasonable adjustments.
- The case and learning were presented to 153 nationwide healthcare professionals working within a Breast Cancer Screening setting during the Surrey and Sussex Cancer Alliance Breast Cancer Education webinar by LeDeR.
- A film was commissioned on applying the MCA to cancer screening programmes.
- Resources regarding cancer screening and follow-up appointments were shared across provider forums.
- Cancer screening programmes were asked to consider reviewing those who have been 'opted out'.

11 Our priorities for 2025-26

1. To ensure that system partners have a formal approach to utilising the learning from LeDeR reviews to reduce the mortality gap for those with a learning disability and mental illness. That these are shared in the quarter 4 LeDeR governance group.
2. To increase the number of notifications of the deaths of Autistic people to the LeDeR programme to ensure an accurate picture of this population in Sussex. This will be demonstrated in next year's annual report.
3. To seek assurance via the Mental Health, Learning Disability and Autism Transformation Programme regarding the care of autistic people in community and inpatient mental health.
4. To ensure that learning from LeDeR is included in the commissioning, and de-commissioning of all NHS services in Sussex and included in health inequalities impact assessments, by linking to this report on the NHS insight bank when published.
5. LeDeR will develop and implement accessible information to support improved hydration as part of the Hydrate to Feel Great initiative by the end of quarter 3.
6. LeDeR will work with prevention and dental services to ensure accessible resources are available to promote better oral health in those with a learning disability and autistic people.

12 Conclusion

This report demonstrates that health inequalities for people with a learning disability and autistic people remain. LeDeR commits to continue striving to reduce these inequalities.

People with a learning disability and autistic people, their families and their carers all tell us that they want to live for a long as possible, and as well as possible.

In hearing the stories of the lives of incredible people in Sussex, LeDeR is committed to informing service improvements across the whole health and care system.

This report serves to highlight the need for all health and care services to be aware of inequalities that are consistently reported and the times when things go well in order that they are shared and replicated.

We all have a duty under the Equality Act to ensure services are accessible but it is the barriers to these services that results in inequalities. LeDeR hopes that this report is of use to all services when considering how they meet the needs of those with a learning disability or who are autistic, as they are legally required to do so.

12 Conclusion (cont.)

Finally:

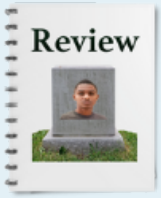
Julie had down's syndrome and was very frail due to her Dementia. LeDeR found that she had been cared for by her stepmother who also had Dementia. Their needs were not seen holistically or well understood by Julie's carers. Julie died in hospital when she would have preferred to die at home with those who cared about her. Julie's sister wanted LeDeR to know that her sister was insightful and emotionally articulate. Prior to developing Dementia, she was a talented poet. She wrote this poem in her 50's in memory of her father's birthplace, that she visited as a child.

The distant hills are calling.
They are far away.
I can't remember where they are.
Yes I do now.
Blue sky.
The rolling hills are soft and green and gentle.
I know where they are…..on the moors where I love to be.
They are calling me to come to the place where I belong.
In the distance, the soft wind is blowing.
I'm the only one there, only me.
I love the sounds.
I am free and the gentle wind is blowing my hair.
It's just nice to be out there.
I look around.
What a sight!
I walk about or run, I just love to be free.
I see the hills in the distance, soft and gentle.
I sit down.
I hear something or is it calling?
I don't remember.
I lie there still.
I think I must be in a dream, only I am not in a dream.
I was still there.
I wake up, I am still in a dream.
I hear voices, the Northern accent.
Soft Lancashire voices, they have a sense of humour which I like.
I listen quietly.
I thought I heard someone I know.
It was Molly!
She recognises me.
She said, "Come on, we'll go home, lass, and have a mug of tea and cake."
Good old Lancashire.
They do make good cakes and a good mug of tea.
The cobble streets.
All you see are lots of houses in a row.
They are back to back, but I am not too sure where the shops are.
Some have the loos at the bottom of the garden.
They cook a lot of meals.
The coal fire. The kettle is on.
The damp cold air outside.
Good old Lancashire.

Thank you for taking the time to read this report.

NHS
Sussex

LeDeR 2024 - 2025
NHS Sussex Report



Learning from the Lives and Deaths of People with a Learning Disability and Autistic People

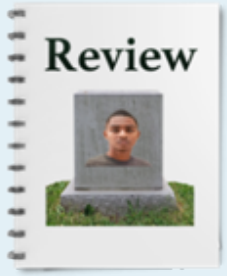
An easy read guide

made with photosymbols®

BRIGHTON & HOVE INDEPENDENT ADVOCACY
SPEAK OUT

NHS Sussex

What is LeDeR?



LeDeR is the name for the programme that Learns from the Lives and Deaths of People with a Learning Disability and Autistic People.

It finds out why people with a learning disability or autistic people have died. It does this to make improvements for future.

This report is about people with learning disabilities and autistic people who died in Sussex from April 2024 until April 2025.

Why is this important?

We believe everyone has the right to good health. Getting the care you need is very important.

Unfortunately, people with learning disabilities and autistic people are more likely to have health problems.They die at a younger age than other people.

Working together

People with learning disabilities, autistic people, families and carers know most about the care they need. We listen and learn from them carefully.

The LeDeR programme also works with other organisations in the health service - GP surgeries, NHS trusts, the Council, care home managers, and experts by experience.

How we work

The LeDeR programme in Sussex reports to the NHS Sussex Integrated Care Board. We follow the national LeDeR policy on how we should work.

One person on our board is an expert by experience who knows a lot about LeDeR. They left this year, so we wanted to say a big thank you to them in this report.

We work with health services in Sussex to share the learning from our reviews, so that they can learn and make improvements.

An example of really good healthcare

We did a focused review of a man called David.

David loved music and watching airplanes.

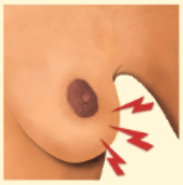
He didn't like medical procedures.

David had lived at home with his parents until he was 42. He had phobias that stopped him going out, but when he moved into his new home he built good relationships with the staff that helped him to start to go out more.

Sadly, David had a large stroke that he could not recover from at the age of 52. But his care staff wanted him to come home and die in a familiar place with loved ones. Everyone worked together to make this happen.

An example of unequal healthcare

We did a focused review of a woman called Janet. She was described as being happy and full of life. In 2021 Janet's carers noticed her breast looked strange, but it then returned back to normal again.



In 2022 they found a lump and found out Janet had breast cancer. She had surgery and treatment. But a little later on in 2022, the breast cancer returned and spread throughout her body.

Janet later collapsed at her home and died at age 66.

Janet had been seen as not suitable for a mamogram to screen for breast cancer in 2010 because she did not cooperate. We found that Janet had been removed from breast screening programme in the wrong way.

Are we working well and meeting our targets?

We have national targets for how quickly we review the death of someone, and what things we should look at in each review.

We are meant to complete all reviews within 6 months of the person dying. This year, we completed nearly 7 out of 10 of our reviews within that 6 month deadline.

Of all of our reviews, at least 3 out of every 10 should be ‘focused reviews’, meaning they look at more detail than the other reviews. This year, 4 out of every 10 of our reviews were ‘focused’ reviews.

The facts for 2024 - 2025

We were told about 158 deaths. This is 20 more deaths than we were told about last year. This doesn’t have to mean more people are dying, just that more people are learning to tell us about deaths so we can review them.

Age

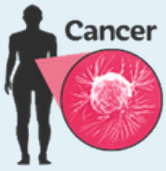
- Age of death ranged between 19 - 91.
- Many people died in their early 60s.

Gender

- 77 females died
- 79 males died
- 2 autistic people who were ‘non-binary’ died. Non-binary means they don’t see themselves as male or female.

Main causes of death

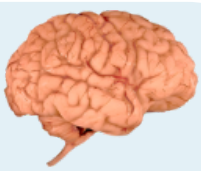
Respiratory diseases - Diseases of the lungs and breathing systems.



Cancer - this is when the cells in your body go wrong and start to make you sick.

Diseases of the heart and blood systems

Sepsis - Sepsis is when your body fights too hard against an infection and damages itself.

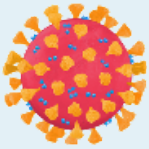


Dementia - a disease of the brain that stops it from working properly.

Most common health issues

Frailty - Frailty is when your body becomes weak due to age or health condition. It makes it harder to recover when you become ill.

Respiratory conditions - Issues with the lungs and breathing systems.

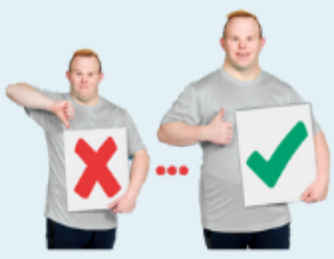


Infection - any type, like a UTI or a virus.

Incontinence - Incontinence is when you cannot control your bladder, so that pee can leak out when you don't want it to.

Sensory impairment - This means that one of your senses does not work well or at all. For example, trouble seeing or hearing.

What we have been doing



Our LeDeR programme works hard to learn from the reviews and make changes to health services as a result. We do this by working with others, including charities and people with learning disabilities.

We tell people about our learning and service improvements through talks and newsletters.

The ‘Stop Look Care’ tool and training

We worked with our Health Facilitation colleagues to create a tool for staff in care homes to use to spot if anybody is getting really unwell.

595 people were trained this year on how to ‘Stop Look Care’. There are 4 more trainings booked in for 2025 and 2026.

We have shown care staff other resources they can use, like the Cardiovascular (or Heart Health) films we helped to make last year, and epilepsy resources.

Support to stop smoking

Continuing a plan we started last year, we worked with a Stopping Smoking service to improve these services for people with learning disabilities and autistic people.

We helped to create easy read resources to help people stop smoking. We sent these out to other areas of the country so that they can use the resources too.

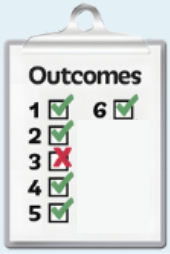
We helped to train 70 different healthcare staff about stop smoking resources and how they could improve their services for people with learning disabilities too.

Planning for the end of life

We have been working with the 'Sussex Palliative and End of Life Oversight' group and the 'Learning Disability Palliative Care Link Group'.

Palliative care is the care and treatment for people living with serious or longterm illness to make them more comfortable.

Did we achieve our goals for last year?



We had 6 goals, or priorities, from last year's report. In this section we will track what we have been doing to achieve each one.

Breast cancer

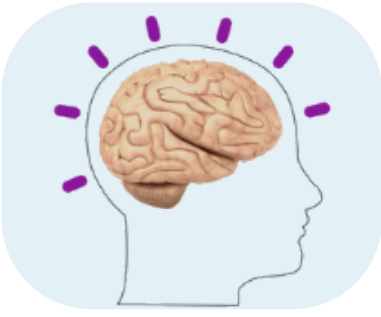
We wanted to learn more about women with a learning disability who died from breast cancer, especially if they could have had screening to catch the cancer earlier.

We did ‘focused’ reviews into these deaths to work out what the main issues are stopping women from using breast cancer screening.

We have helped start a new group of healthcare professionals to work together to address the issue in Surrey and Sussex.

We met with a breast cancer screening service in Somerset that is for people with learning disabilities to learn from them. We have shared this with the services in Sussex.

Health inequalities for Autistic people



We wanted to focus on the health inequalities that autistic people face in Sussex around their physical and mental health, neurodivergence support and suicide prevention.

We are still waiting on a trial of doing annual health checks for autistic people.

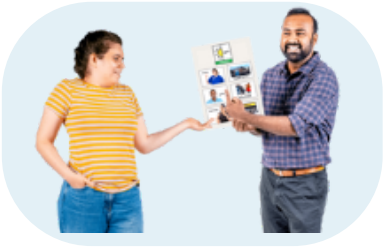
We are focusing on helping people after a mental health diagnosis. This should reduce mental health hospital admissions or make stays shorter.

We are working with local suicide prevention and autism partnership boards. The local specialist mental health provider delivered a national presentation on Neurodivergence and Suicide Prevention.

Obesity and diabetes

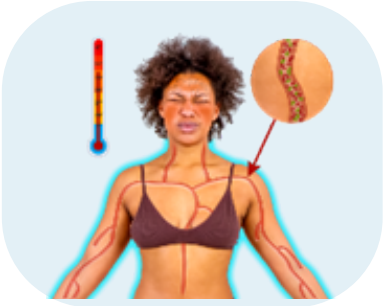
We are working with different healthcare staff to tell more people with learning disabilities learn about ‘continuous glucose monitoring’, which is a device that lets diabetics check their sugar levels without pricking their finger.

We have been working with a Sussex programme that is trying to understand why some people are getting Type 2 diabetes before they are 40, beacuse we know getting it early makes the disease more deadly.



We helped them understand what happens for people with learning disabilities, and how to make their resources accessible for them.

Sepsis



Sepsis is when your body fights too hard against an infection and damges itself. It is one of the main causes of death for people.

We have helped to train over 100 people on how to prevent people with a learning disability from dying of sepsis. This was mainly adult social care staff.

Planning to die how you would like to

We have been sharing a toolkit that was developed to help people with learning disabilities plan for the end of life. It is called ‘The Victoria and Stuart Project’.

We have also been working with healthcare staff in Palliative Care and End of Life Care to make sure they understand what people with learning disabilities need.

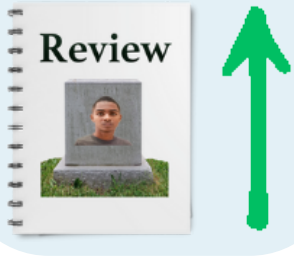
Supporting people from ethnic minorities

We know that we don't understand as much we would like to about people with learning disability for minority ethnic communities. We want to improve this.

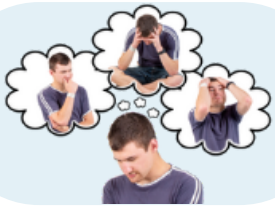
We helped to make sure that a new resource called 'Respecting Faith and Culture in End-of-Life Care Handbook' included the needs of people with learning disabilities too.

What we are going to focus on over the next year

We will make sure that healthcare providers have a formal system to learn from LeDeR reviews to stop people from dying earlier.



We will work to hear from more autistic people who should be entitled to a proper review of their death.



We will look into the community and hospital mental health care for autistic people.

We will make sure LeDeR learning is used to help make the decisions about which NHS services are funded or not funded.

We will make accessible information about how to drink enough and stay hydrated.

We will work with dental care services to make sure there is accessible information about having healthy teeth and gums.

To finish

This report shows that people with learning disabilities and autistic people still face health inequalities. We need to do better.

One of the people who died was Julie. Julie had to die in hospital, even though she would have preferred to die in her home. Her sister wanted to share Julie's talent for poetry. Here is a piece of a poem she wrote.

The distant hills are calling.
They are far away.
I can't remember where they are.
Yes I do now.
Blue sky.
The rolling hills are soft and green and gentle.
I know where they are.....on the moors where I love to be.
They are calling me to come to the place where I belong.

Although a formal committee of Brighton & Hove City Council, the Health & Wellbeing Board has a remit which includes matters relating to the Integrated Care Board (NHS Sussex,) the Local Safeguarding Boards for Children and Adults and Healthwatch.

Title:
Better Care Fund Report

Date of Meeting:
3 March 2026

Report of: Steve Hook Director Health & Adult Social Care & Tanya Brown-Griffith NHS Sussex Director for Joint Commissioning and Integrated Community Teams – Brighton and Hove

Contact: Chas Walker

Email:
Chas.walker@brighton-hove.gov.uk

Wards Affected: All

FOR GENERAL RELEASE

Executive Summary
The report covers:

1. Background information on the Better Care Fund
2. Quarter 3 performance against our Better Care Fund (BCF) Plan for 2025/26 sets out that we are meeting all the national conditions, that we are on track on only 1 out of the 3 BCF core metrics and that we are in line with our planned expenditure profile
3. National BCF Planning Framework for 2026/27

Decisions, recommendations and any options

Brighton & Hove Health and Wellbeing Board is recommended to:

1. Note performance against BCF Plan for Quarter 3
2. Note the requirements of the BCF planning framework for 2026/27

1. Background & context

1.1. Since 2014 the Better Care Fund (BCF) has provided a mechanism for joint health, housing and social care planning and commissioning, focusing on personalised, integrated approaches to health and care that support people to remain independent at home or to return to independence after an episode in hospital. It brings together ring-fenced budgets from NHS Integrated Care Board (ICB) allocations, and funding paid directly to Local Government, including the Disabled Facilities Grant (DFG) and the Local Authority Better Care Fund (formerly called the Improved Better Care Fund).

1.2. The BCF has two core policy objectives:

- Reform to support the shift from sickness to prevention
- Reform to support people living independently and the shift from hospital to home

1.3. As set out in the policy framework, HWBs will be expected to agree goals against three headline metrics as part of their planning return:

- Emergency admissions to hospital for people aged 65+ per 100,000 population.
- Average length of discharge delay for all acute adult patients, derived from a combination of- proportion of adult patients discharged from acute hospitals on their discharge ready date (DRD), for those adult patients not discharged on DRD, average number of days from DRD to discharge.
- Long-term admissions to residential care homes and nursing homes for people aged 65+ per 100,000 population.

1.4. Supporting indicators aligned to the metrics will be:

- Unplanned hospital admissions for chronic ambulatory care sensitive conditions.
- Emergency hospital admissions due to falls in people over 65.
- Patients not discharged on their discharge ready date (DRD), and discharged within 1 day, 2 to 3 days, 4 to 6 days, 7 to 13 days, 14 to 20 days, and 21 days or more.
- Average length of delay by discharge pathway.
- Hospital discharges to usual place of residence.
- Outcomes from reablement services.

1.5. Local authorities and ICBs must agree a joint plan, signed off by the HWB, to support the policy objectives of the BCF for 2025 to 2026. The development of these plans must involve joint working with local NHS trusts, social care providers, voluntary and community service partners and local housing authorities.

1.6. The NHS minimum contribution to adult social care must be met and maintained by the ICB and was increased by 3.9% in each HWB area for 2025/26. Local authorities must comply with the grant conditions of the Local Authority Better Care Grant and of the Disabled Facilities Grant. HWB plans are also subject to a

minimum expectation of spending on adult social care related schemes, which are published alongside the BCF planning requirements. HWBs should review spending on social care, funded by the NHS minimum contribution to the BCF, to ensure the minimum expectations are met, in line with the national conditions.

1.7. Section 75 of the NHS Act 2006 allows partners (NHS bodies and councils) to contribute to a common fund which can be used to commission health or social care related services. This power allows a local authority to commission health services and NHS commissioners to commission social care and relates specifically to the pooled fund element of the BCF.

1.8. We can confirm to the Board that the Council and NHS Sussex agreed a new section 75 agreement and executed the agreement in line with the national conditions of the BCF

2. Performance Against 2025/26 BCF Plan Quarter 3

2.1. **National Conditions**- We can confirm to the Board that we reported full compliance with the national condition requirements of the BCF which are

- We have a jointly agreed plan
- That our plan meets the national objectives of the BCF
- We complied with all the grant conditions including maintaining the NHS minimum contribution to social care
- That we complied with the governance and oversight requirements of the BCF

2.2. **The national BCF Metrics** - For 2025 to 2026 there are 3 core metrics:

- Emergency Admissions – for quarter 3 we are off track to meet our planned targets for the year
- Average length of discharge delay- for quarter 3 we are off track to meet our planned targets for the year
- Residential admissions- for quarter 3 we are on track to meet our planned targets for the year
- It is important that the Board notes that for quarters 3 & 4 we were required to stretch our BCF metric targets as part of moving from conditional to full national NHS approval of our BCF plan. We were not meeting the Discharge Delay or Avoidable Admissions original targets in quarters 1 & 2, so the new stretched targets will create an additional challenge in meeting these two metric targets
- Appended to this report is a more detailed update on the work to improve performance on our Discharge & Avoidable Admission metrics

2.3. **Emergency admissions** to hospital for people aged over 65 per 100,000 population

- Our average monthly planned performance target was 1,364 admissions per 100,000 of the population for people aged over 65 this equates to an average of 543 admissions a month. This reduced to 1,191 admissions per 100,00 of the population for people aged over 65 this equates to an average of 482 admissions a month when we revised our metric targets for quarters 3 &4

- We are still waiting for national validated data for this quarter, but based on our local data we are seeing further increases in avoidable admissions for quarter 3 rising from 6% in quarters 1 & 2 to 14% in quarter 3 above our metric target. This increase in the percentage of admissions above our metric target is influenced by the new stretched target for quarters 3 & 4 and the early onset of this winters flu season.

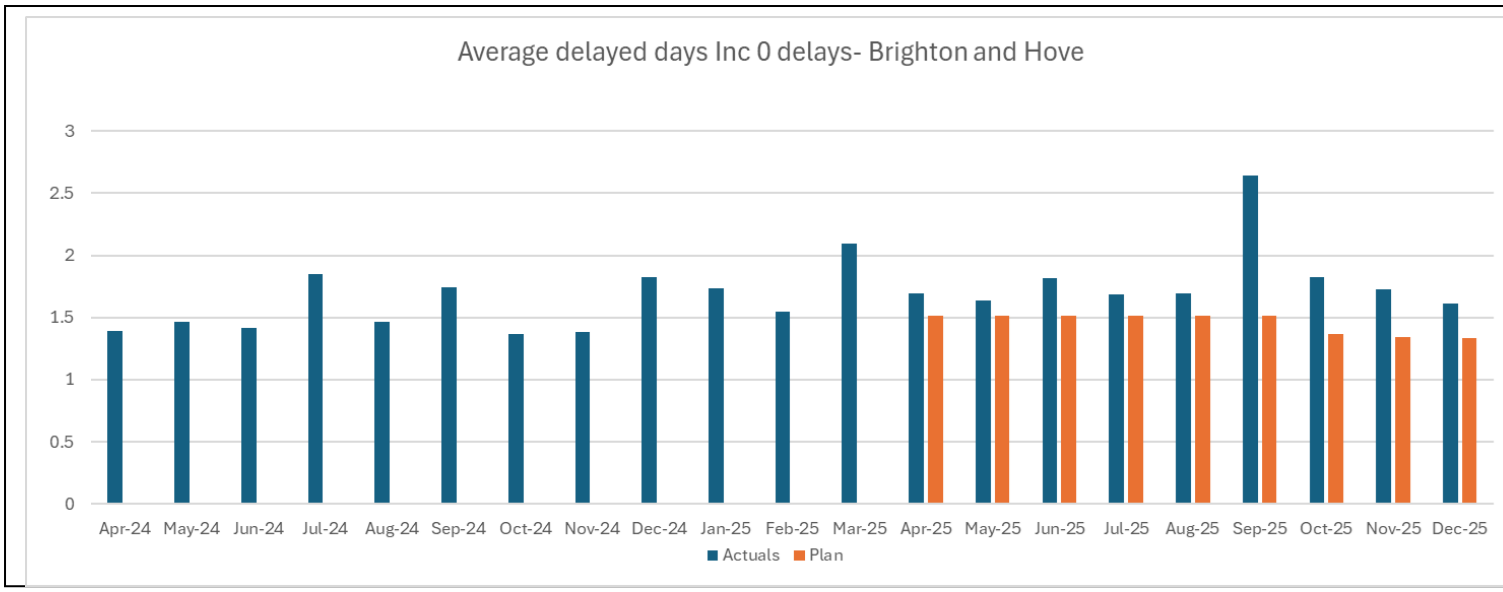
- See appendix below for more detail on our partnership work to improve the Avoidable Admissions metric performance

2.4. **Average length of discharge delay** for all acute adult patients, derived from a combination of: proportion of adult patients discharged from acute hospitals on their discharge ready date (DRD). For those adult patients not discharged on their DRD, average number of days from the DRD to discharge

- Our planned target is 87.9% of patients are discharged on their DRD. For patients with a delayed discharge this will be an average of not more than 12.51 days giving an overall average for all patients of 1.51 days average length of discharge delay. With the revision of our metric targets for Qtr's 3 &4 this will be an average of 11.1 days giving an overall average for all patients of 1.33 days average length of discharge delay.

- This quarters performance is an average of 84% of people were discharged on their discharge ready date. With an overall average discharge delay for all patients of 1.72 days

- The graph below provides a visual of the overall average discharge delay over past 2 years and against this years planned targets. See appendix below for more detail on our partnership work to improve the Discharge Delay metric performance



2.5. **long-term admissions to residential care homes and nursing homes** for people aged 65 and over per 100,000 population

- Our rate for the year is 706.3 per 100,000 of the population, which equates to 281 residential admissions. Our revised metric target we have submitted to NHSE is the equivalent of 623 per 100,000 of the population, which equates to 248 admissions over a year.

- Currently we are on track to meet the target with the last Qtr we recorded 53 admissions so well within the 12 month rolling target.

2.6. **Expenditure**- below is the table that set outs current expenditure against the agreed plan for year. By the end of quarter three we should be close to 75% of the BCF funds being spent. The current position shows 75% spent at the end of quarter three.

	2025-26		
Source of Funding	Planned Income	Updated Total Plan Income for 25-26	DFG Q3 Year-to-Date Actual Expenditure
DFG	£2,869,975	£2,869,975	£2,152,481
Minimum NHS Contribution	£28,150,986	£28,150,986	
Local Authority Better Care Grant	£11,669,360	£11,669,360	
Additional LA Contribution	£404,140	£404,140	
Additional NHS Contribution	£0	£0	
Total	**£43,094,461**	**£43,094,461**	

	Original	Updated	% variance
Planned Expenditure	**£43,094,462**	£43,094,462	**0%**

		% of Planned Income
Q3 Year-to-Date Actual Expenditure	£32,320,846	**75%**

2.7. We would like to bring the Boards attention to the changes in our contracted community equipment services provider. In the autumn our existing provider notified us of impending bankruptcy. The provider works at a national scale and Local Authorities came together to consider potential mitigation. In the end the provider went into liquidation, and we were fortunate to be able to quickly agree a new contract with the provider used by East and West Sussex. They took on the

existing service maintaining a basic level of delivery and have now moved to full delivery of the community equipment service. To date there has not been an overspend on the original community equipment budget as the new provider started with a more limited catalogue of equipment as they got up to speed. There is additional cost requirements connected to the new contract which we will start to see come through on Quarters 3 &4 and we are currently working on an assumption of not more than 5% overspend on the original budget. The over all pooled budget can support this overspend through the utilisation of the winter pressures budget we build into our overall BCF plan.

3. BCF National Planning Framework 2026/27

3.1. To be added if national planning framework released in time or presented at the meeting

4. Important considerations and implications

Legal:

4.1. It is a requirement that the Better Care Fund is managed locally though a pooled budget. The power to pool budgets between the Council and the ICB is set out in the NHS Act 2006 and requires a formal Section 75 Agreement. Regulations prescribe the format and minimum requirements for a Section 75 Agreement. A new Section 75 Agreement was agreed in 2025 to support the 2025-26 plan.

Lawyer consulted: Sandra O'Brien Date: 18/02/2026

Finance:

4.1. The Better Care Fund is a section 75 pooled budget which totals £43.094m for 2025/26. The ICB contribution to the pooled budget is £28.151m and the Council contribution is £14.943m. The planned expenditure as at quarter 3 is in line with the original overall budget.

4.2. The Better Care Fund informs budget development and the Medium-Term Financial strategy of the partner organisations, including the council. This requires a joined-up process for budget setting in relation to all local public services where appropriate, and will ensure that there is an open, transparent and integrated approach to planning and provision of services. Any changes in service delivery for the council will be subject to recommissioning processes and will need to be delivered within the available budget.

Finance Officer consulted: Sophie Warburton Date: 18/02/2026

Equalities:

4.3. The BCF plans set out in the narrative submission specifically how the schemes invested in will support the equalities and health inequalities of their local population. Individual EHIAs are carried out for specific new schemes as they are developed. All schemes funded by the NHS are required to apply EHIA processes to of all services commissioned. The plans and strategies have been developed jointly based upon detailed population analysis, reflecting the Place based plans that are informed by EHIAs and the local JSNAs. There is not a formal public and engagement process supporting this annual process, but individual schemes will be informed by views of patients and public.

Sustainability:

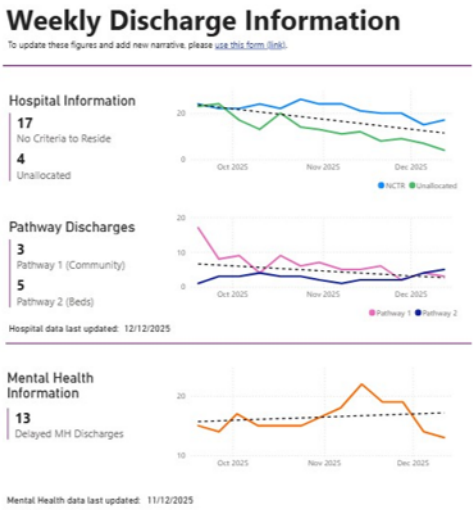
4.4. None

Health, social care, children's services and public health:

4.5. The BCF plans set out in the narrative submission specifically how the schemes invested in will support equalities and health inequalities policy and requirements of their local population. The development, agreement and delivery of the plan is the responsibility of the local Health and Wellbeing board.

5. Supporting documents and information

Better Care Fund Plan- Metric Performance Assurance
Discharge Delays



- National Oversight and external support - Consortium 24 via the Better Care Fund Support Programme
- **Increased investment-** senior therapists (physical & mental health), in Hospitals. Home First Team reorganised and co-located in Transfer of Care Hub, 24/7 discharge model being implemented in A&E.
- **Removing barriers**- personal health grants, new self-funder service launched October, increased use of volunteers in A&E supporting nonclinical needs – "Helpforce"
- **Better support for complex needs-** improved support for carers, homeless and recovery in reach teams
- **Consortium 24-** working with senior BHCC and NHS Sussex leaders, & frontline clinicians in the hospital. Work underway to increase co-location and integration of data – one set of data
- **Discharge performance is now improving**- 4000 people have received extra support 62% (2,500+) of those have gone directly home from A&E via Admission Prevention Team & 129 people into short term recovery services

Improving Lives Together

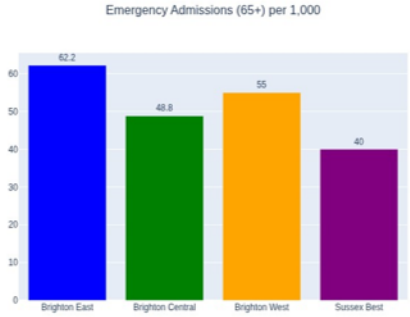
Better Care Fund Plan- Metric Performance Assurance
Emergency Hospital Admissions Over 65

NHS Sussex Neighbourhood Health Alliance

- NHS Sussex commissioning intentions 26/27
- Part of a 1% Transformation Fund
- ICT dashboard and performance metrics
- 10% reduction in Avoidable admissions by March 2027
- 10-15% improvement in vaccination and screening rates

NHS Sussex's Highest & Ongoing Needs Programme

- Part of the wider Sussex Neighbourhood Health Plan
- Focuses on shifting care from hospitals to the community through Integrated Community Teams (Brighton West, Central, East ICTs)
- Using data to proactively identify and support frail elderly, those at risk of admission, and people with complex needs
- Using pro-active joint care planning to enhance community health & care offer with the aim of reducing unnecessary hospital admissions
- Our ICTs have set up 5 Multidisciplinary Teams, SCFT have recruited 3 Coordinators, and the delivery has started this month



- Refreshed Place-based Falls Plan
- Winter Collaborative partnership
- ICT leadership Groups focusing on increasing vaccination and screening up take in line with NHS Sussex Commissioning Intentions 10% improvement target

Health & Wellbeing

Although a formal committee of Brighton & Hove City Council, the Health & Wellbeing Board has a remit which includes matters relating to the Integrated Care Board (NHS Sussex,) the Local Safeguarding Boards for Children and Adults and Healthwatch.

Title:
Introduction to Neighbourhood Health Agenda for Change

Date of Meeting:
3 March 2026

Report of:
Steve Hook Director Health & Adult Social Care,
Tanya Brown-Griffith- Director for Joint Commissioning,
NHS Sussex

Areas of the report will be presented by representatives from the Neighbourhood Health Alliance (NHA) – Jess Thom, Katherine Saunders and Kate Pilcher.

Contact: Chas Walker

Email:
Chas.walker@brighton-hove.gov.uk

Wards Affected: All

FOR GENERAL RELEASE

Executive Summary
The report covers:

From what we know from the new NHS long-term plan Health and Wellbeing Boards (HWBs) will have an important role to play in delivering the ambition for neighbourhood health reform. This will include owning neighbourhood health plans and ensuring strong alignment across the NHS, social care, public health and other

areas that affect health outcomes. With HWBs being responsible for signing off neighbourhood health plans, and retaining a role in the sign-off and oversight of reformed BCF plans, Boards will play a critical part in driving prevention, integration and place-based delivery.

This report provides the Board with an introduction to:

- The national neighbourhood health plan
- The Sussex Neighbourhood Health Framework
- The new Sussex Neighbourhood Health Alliance
- The expectation of Health & Wellbeing Boards in delivering the national neighbourhood heath agenda

Decisions, recommendations and any options

Brighton & Hove Health and Wellbeing Board is recommended to:

1. Note the report

1. Introduction to the national neighbourhood health plan

1.1. The National Neighbourhood Health Plan refers to a coordinated national effort to transform how health and care are delivered in England—shifting from a hospital centric model to community based, integrated neighbourhood health services.

1.2. It is embodied through the National Neighbourhood Health Implementation Programme (NNHIP) and related government initiatives that support local "neighbourhood health teams" across England.

Core Purpose

1.3. The plan aims to:

- Move care closer to home and reduce reliance on hospitals.
- Support people to live healthier, more independent lives by addressing both clinical and wider social determinants of health.
- Tackle health inequalities, particularly in areas with low life expectancy and high deprivation

Key Features of the Neighbourhood Health Model

1.4. Integrated, Multi-disciplinary/ Neighbourhood Teams that bring together

- GPs
- Community nurses
- Hospital doctors
- Social care workers
- Pharmacists, dentists, optometrists
- Paramedics
- Social prescribers
- Local government and voluntary sector partners

1.5. These teams provide end to end, coordinated care, reducing fragmentation and duplication across services.

1.6. Prevention & Early Intervention

1.7. Services focus on:

- Preventing deterioration of long-term conditions
- Early identification of risk factors

- Addressing root causes such as housing, education, employment, and social support
- Community Powered Care

1.8. The plan promotes a shift from “institutional power to community power,” emphasising:

- Co design with communities
- A biopsychosocial approach
- Strength based models of care

National Programmes and Rollout

1.9. National Neighbourhood Health Implementation Programme (NNHIP)

1.10. A large scale programme supporting places across England to adopt neighbourhood health approaches.

1.11. Uses learning from areas already demonstrating improvements (e.g., reduced emergency admissions and improved self management).

1.12. From September 2025, 42 pilot sites were selected to accelerate development with national support and shared learning (for Sussex this was Hastings & Rother) .

1.13. Government Backed Rollout

1.14. Initial focus: people with highest and ongoing health needs and long term conditions (diabetes, arthritis, hypertension, MS, epilepsy), especially in deprived areas.

1.15. Link to the 10-Year Health Plan

1.16. Neighbourhood health forms a central pillar of the government’s 10 year strategy, aiming to:

- Shift resources from hospitals into the community
- Improve integration between NHS, local authorities, and voluntary/community organisation

Anticipated Outcomes

1.17. The plan intends to deliver:

- Improved patient experience through joined-up, personalised care
- Reduced emergency hospital admissions
- Greater patient agency in managing their own conditions

- More sustainable health and social care systems
- Reduced inequalities across regions and communities

In Short

1.18. The National Neighbourhood Health Plan is a major structural reform of English health and care services, built on integration, prevention, community partnership, and local empowerment. It aims to create healthier communities and deliver care that is more timely, more personal, and closer to home.

2. The Sussex Neighbourhood Health Framework

2.1. NHS Sussex has developed a Sussex Neighbourhood Health Framework which sets out a commissioner-led model in which the Integrated Care Board (ICB) defines the outcomes, standards and enabling infrastructure required for neighbourhood delivery, rather than specifying operational models. Strategic commissioning is expected to enable neighbourhood health by establishing a consistent framework including population cohorts, agreed outcomes, and an expectation that delivery is data led through population health management.

2.2. Appended to this report is a more detailed summary of the Sussex Neighbourhood Health Framework.

2.3. Neighbourhood health is about care centred around population needs and care shifting from acute hospitals to community settings. The ethos is to support people to live healthier, more independent lives for as long as possible through integrated working across NHS, local government, social care, hospices, VCSE, and other partners as the norm, not the exception.

2.4. The ICB's role includes commissioning and maintaining system enablers such as risk stratification, shared care records, and neighbourhood-level metrics dashboards, alongside place-based facilitation and coordination to support implementation. The framework is explicit that strategic commissioning should ensure equity of ambition and consistency of expectations across Sussex, while allowing flexibility in local delivery, with accountability focused on improved population outcomes.

2.5. The co-produced and published NHS Sussex Commissioning Intentions 2026-27 reinforce strategic commissioning for neighbourhood health and is explicit that commissioned neighbourhood services must deliver a proactive core offer for people with high and ongoing needs, address health inequalities, and contribute to measurable reductions in avoidable emergency admissions.

2.6. The ICB is delegating delivery responsibility for neighbourhood health to the Neighbourhood Health Alliance by commissioning it as the vehicle responsible for organising and delivering the neighbourhood health

framework. The ICB sets a clear expectation that Integrated Community Teams (ICTs) will contribute to a reduction in avoidable emergency admissions of 10% by 30 March 2027, using October 2025 as the baseline, with each ICT required to submit trajectories for review and approval by the ICB. Additionally is expected to contribute to a 15% increase in uptake of vaccinations & screening in underserved communities.

3. Introduction to the new Sussex Neighbourhood Health Alliance

3.1. Key leaders in the new Sussex Neighbourhood Health Alliance will attend the Board meeting and support the agenda item. Appended to the report is Neighbourhood Alliance Integrated Community Teams implementation update and Neighbourhood Alliance Delivery Plan 2026-27

3.2. The Sussex Neighbourhood Health Alliance (The Alliance) is not a single formal organisation, but rather the collective system-wide approach across Sussex to redesign health and care around neighbourhoods. The Alliance is still a very new structure and so in its formation stage.

3.3. The Alliance approach seeks to transform how care is organised so services are: Integrated across organisations, reducing fragmentation and duplication. More preventive, shifting from reacting to ill health to supporting wellbeing and early intervention. Delivered closer to home, reducing reliance on hospitals and long inpatient stays. Responsive to neighbourhood-level needs, with planning shaped by local population data

3.4. The Alliance is made up of the following NHS organisations as core members:

- Sussex Community Foundation Trust
- East Sussex Health Trust
- Sussex Partnership Foundation Trust
- Sussex Primary Care Collaborative (collaborative structure for primary care across Sussex)

3.5. It is the intention of The Alliance to enter into a Management of Understanding with the three upper tier Local Authorities in Sussex, Sussex Hospice Alliance and the Sussex Voluntary Sector Alliance, so all community partners that are part of the Sussex Integrated Care Partnership have a level of representation on The Alliance

3.6. The work of The Alliance is delivered primarily through 15 Integrated Community Teams (ICTs) that bring together health, social care, community services, and voluntary sector partners to provide joined-up,

proactive, local care at a neighbourhood level (a neighbourhood is defined as populations from (50,000 to 100,000)

3.7. It is anticipated that the Alliance will formally be contracted by the ICB to deliver the NHS Sussex commissioning Intentions for Neighbourhood Health and the formal structure for this will emerge as the new Surrey and Sussex ICB takes shape.

3.8. Over the last year the Alliance has focused on:

- Building stronger collaborations across NHS partners and with Local Authorities and the Sussex Voluntary Sector Alliance
- Leading the development of the Sussex Highest & Ongoing Needs Programme

3.9. Looking forward over the next 12 months, the Alliance will be focused on

- Supporting the delivery of the NHS Sussex Commissioning Intentions to reduce avoidable admissions by 10%. The Alliance will do this through delivering the aims of the Sussex Highest & Ongoing Needs Programme
- The Alliance will support the development of the 15 Integrated Community Teams across Sussex measured through the Maturity Matrix approach
- The Alliance will finalise the Management of Understanding with Local Authorities and Sussex Voluntary Sector Alliance to ensure inclusion of all core partners in the delivery of the Sussex Neighbourhood Health Framework
- The Alliance will oversee the neighbourhood health transformation fund detailed in the NHS Sussex Commissioning Intentions

4. The expectation of Health & Wellbeing Boards in delivering the national neighbourhood heath agenda

4.1. Detailed national guidance on the delivery of neighbourhood health reform, as set out in the new NHS Long-term Plan, has not been published, but is expected in the spring. This guidance will provide far more detail on the formal role of Health & Wellbeing Boards (HWB's) in the local governance and delivery of neighbourhood health

4.2. What we are expecting is that HWB's will need to produce a Place-based neighbourhood health plan, working closely with wider System partners like The Alliance and the new Surrey & Sussex Integrated Care Board.

4.3. We know that the Better Care Fund will also be reformed becoming the Integrated Care Funding Framework in 2027/28 and will be expected to align with HWB's Neighbourhood Health Plans to ensure appropriate

direction of these resources to support the Neighbourhood Health reform agenda.

4.4. The Brighton & Hove HWB is already preparing for these changes. We have engaged the LGA to support Board development, and we will be refreshing our Health & Wellbeing Strategy for the city in line with the national priorities for neighbourhood health and building on the evolving work of our local Integrated Community Teams.

4.5. Through the recent assessment of the maturity of local ICTs across Sussex, our three neighbourhood ICTs scored well showing good momentum and growing maturity across the local partnerships. All three ICTs are in a process of developing local neighbourhood plans for their areas of the city and it is anticipated that these plans will feed into the requirement for a Place-based neighbourhood plan

5. Important considerations and implications

Legal:

As described in the body of this report, neighbourhood health reform is one of the key elements of the new NHS 10-year Health Plan. National guidance emanating from the Plan has yet to be published but is expected to specify the requirements of the HWB on the delivery of neighbourhood health reform. This introductory report is for noting only by HWB

Lawyer consulted: Sandra O'Brien Date: 18/02/2026

Finance:

The Neighbourhood Health Reform and Neighbourhood Health Plan will ensure strong alignment across the NHS, social care, public health and community services. It's aims include delivering care that is more timely, more personal, and closer to home.

This will inform priorities, budget development and the Medium-Term Financial strategy of the partner organisations, including the Better Care Fund. This requires a joined-up process for budget setting in relation to all local public services where appropriate, and will ensure that there is an open, transparent and integrated approach to planning and provision of services. Any changes in service delivery for the council will be subject to recommissioning processes and will need to be delivered within the available budget.

Finance Officer consulted: Sophie Warbton Date: 18/02/2026

Equalities:

Health inequalities are a significant priority across all neighbourhood health plans

Sustainability:

N/A

Health, social care, children's services and public health:

Are all partners in the Integrated Care Partnership and will have shared accountability for the delivery of a Place-based neighbourhood plan

6. Supporting documents and information

- Sussex Neighbourhood Health Alliance Integrated Community Teams Programme Implementation Update
- Sussex Neighbourhood Health Alliance Delivery Plan 2026-27

Appendix 1

Neighbourhood Alliance Delivery Plan 2026/27

In line with Sussex ICB commissioning intentions, partners within the Sussex Provider Collaborative have agreed to work together under the name of the Neighbourhood Alliance to deliver the specific asks of the commissioning intentions 2026/27. The Neighbourhood Alliance reflects our joint approach and shared purpose, rather than a formal organisational entity.

Neighbourhood Alliance Delivery Focus

- Deliver preventative and proactive care for high-need populations.
- ICT-led targeted interventions.
- Achieve 10% reduction in avoidable emergency admissions by March 2027.
- Achieve a 15% increase in uptake of vaccination and screening in underserved communities.
- Contribute to health inequalities and Children & Young People (CYP) programmes.

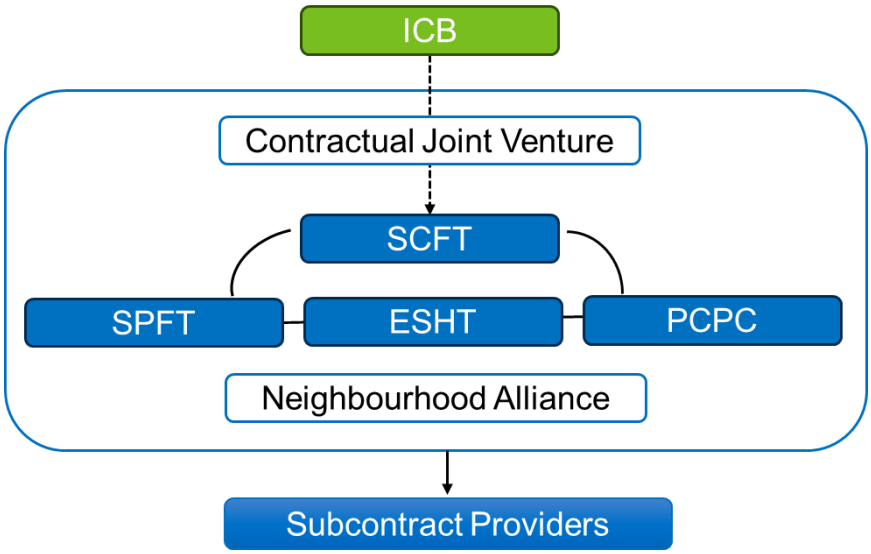
Neighbourhood Alliance Formation

Sussex ICB intends to contract with; SCFT, SPFT, Primary Care PC and ESHT NHS providers to deliver the commissioning intentions 2026/27 aims. This group of providers have agreed to a **Contractual Joint Venture (CJV) contractual model with SCFT acting as the lead-pass through provider.**

The expectation is that the CJV partners (known as the Neighbourhood Alliance) will have the ability to **subcontract at an ICT level to deliver elements of the specification**.

The Neighbourhood Alliance recognises the importance of wider system deliver partners to achieve the aims and objectives of the commissioning intentions. Therefore, **the Alliance will form an MoU partnership agreement that includes the SVLA, Hospice Alliance, and the three Local Authorities**. This will ensure design, development, and delivery at ICT level.

Fig.1 Contract Model Illustration



Transformation Funding

Sussex ICB has confirmed that the commissioned activity outlined in the Commissioning Intentions for the Neighbourhood Alliance will be supported by a Transformation Fund, created from a 1% reduction in acute non-elective costs. In addition, an ICT Innovation Fund (total £3m) will be available for ICTs to bid for, all aimed at reducing avoidable emergency admissions.

Programme Infrastructure and Delivery Approach

To maintain continuity of the current delivery programme (Highest and Ongoing Needs), the infrastructure process will:

- Sustain and streamline governance to ensure stability while enabling flexibility for emerging requirements.
- Integrate updated governance and contractual obligations into programme design in preparation for the new contract.
- Embed the ICT programme within this framework, using interoperable systems and secure data-sharing to support local care delivery.

This approach will:

- Enable a smooth transition from current operations to future requirements.
- Keep services reliable while creating space for innovation and improvement.

Key Components

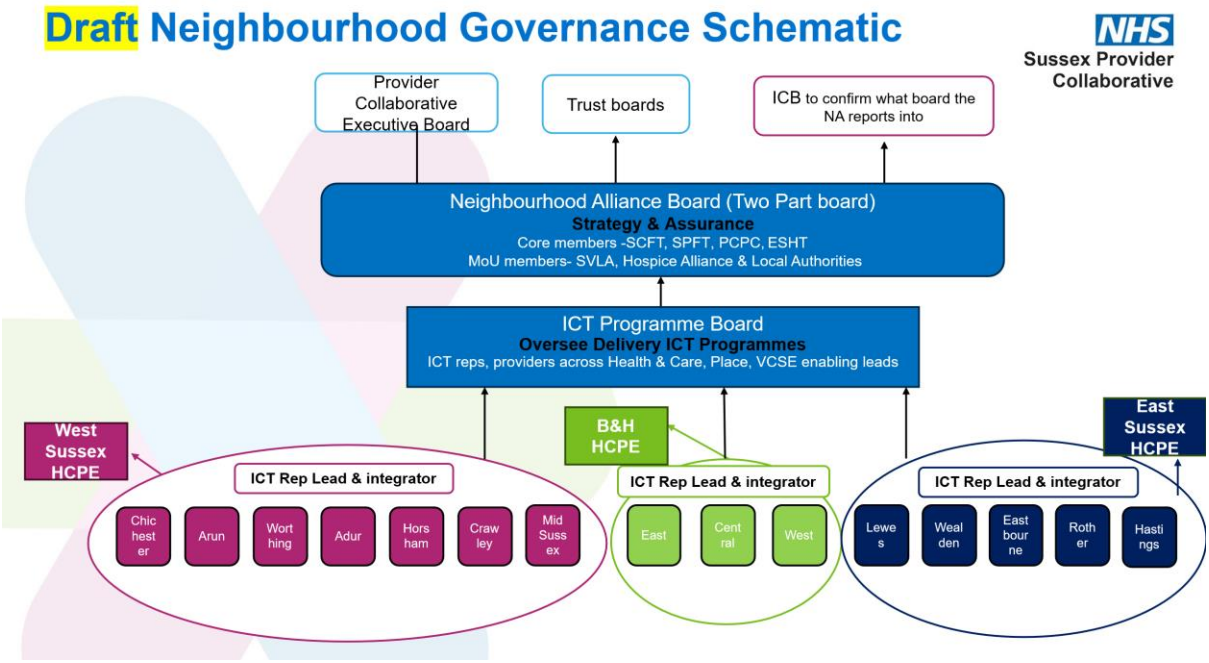
- Programme Design: Incorporate direct input from ICTs to ensure responsiveness to local needs.
- Governance: Align and streamline governance to:
  - Position the Neighbourhood Alliance ICT programme as the primary delivery model.

- Embed place-based partnerships and Health & Wellbeing Boards (HWBB) planning.
- Include place-based representatives within the Alliance Board, Programme Board, and ICT structures.
- Leadership: Support ICT cluster leadership and ensure clear reporting into programme governance.

Alignment with MoU Principles

This approach aligns with commitments in the Neighbourhood Alliance MoU, prioritising ICT design and development and supporting ICTs to evolve as self-organising, accountable entities capable of direct commissioning.

Fig.2 Draft Neighbourhood Governance Schematic



Neighbourhood Alliance Board Membership

NHS Sussex Provider Collaborative

Organisation	Members
CJV Core Members- Part A	
SCFT	Siobhan Melia, CEO (Chair)
CJV Exec Leads	
SCFT	Kate Pilcher
PCPC	Katherine Saunders
ESHT	Steve Aumayer (Also Acute Alliance Rep)
SPFT	Colin Hicks
PMO	
SCFT	Matt White
Provider Collaborative	Jess Thom
Admin	TBC
MOU- Part B Members	
West Sussex County Council	Alan Sinclair
East Sussex County Council	Mark Stainton
Brighton & Hove County Council	Steve Hook
Sussex VSCE Leaders Alliance	Jess Summer
Hospice Alliance	Nick Bottomley &/or Colin Twomey

Appendix 2

NHS
Sussex Provider Collaborative

Neighbourhood Alliance: ICT Programme

Implementation update for SHCPE

February 2026

A partnership of NHS organisations

1. Purpose

This paper sets out the proposed implementation approach, governance, resource plan, and next steps for delivery of the Neighbourhood Alliance ICT Programme, aligned to the Sussex Provider Collaborative Delivery Plan 2026/27 and Sussex ICB commissioning intentions.

2. Background

The Sussex Provider Collaborative (SPC) is delivering transformation under the Neighbourhood and Acute Alliances, in alignment with ICB commissioning intentions for 2026/27.

The Neighbourhood Alliance brings together SCFT, SPFT, Primary Care, and ESHT who are developing a Contractual Joint Venture (CJV), with SCFT as the lead provider.

Commissioning intentions require delivery of:

- Preventative and proactive care for high-need populations
- ICT-led interventions
- 10% reduction in avoidable emergency admissions by March 2027
- 15% increase in uptake of vaccinations & screening in underserved communities

The Programme is in active mobilisation with a February 2026 RAG status of Amber (off-track but with plan) based on current risks relating to MoU approval, integrator role definition, funding certainty and contract formation.

3. Programme Objectives

- Deliver neighbourhood led proactive and preventative care
- Standardise and deploy MDT models across all neighbourhoods.
- Reduce avoidable emergency admissions by 10%
- Increase vaccination and screening uptake by 15%
- Embed new contractual and performance frameworks for 2026/27

4. Implementation Approach

4.1 Governance & Oversight

The CJV governance model aligns with the revised SPC governance framework:

- **Neighbourhood Alliance Board** – strategic oversight, chaired by SCFT CEO
- **ICT Programme Board** – operational oversight, ICT Chairs, Workstream Leads (to be established March 2026)
- **Programme Groups** – monthly delivery oversight

- **Integrated governance model** linking into HWBs, place-based partnerships, and CJV partners-based partnerships, and CJV partners

Next Steps

- Redraft the MoU & TOR for approval by **early March**
- Confirm roles and responsibilities aligned to the CJV principles- **March**
- Set up ICT Chairs & SMEs as the Programme Board membership- **March**

4.2 Service Design & Specification

Work to finalise **the ICT Service Specification** is underway.

Key tasks:

1. **Review the MDT Core Offer spec draft (Feb)** and identify required elements for ICT Specification.
2. **Develop the ICT Service Specification** reflecting broader ICT requirements - **March**
3. **Engage Exec Leads and relevant groups** on the draft specification - **March**
4. Align the spec to contractual and performance frameworks- **by end of March**

Dependencies:

- HoNs learning and outputs **(due end of March)**
- Core Offer modelling relating to emergency admission targets- **end of Feb**

4.3 Contractual & Commissioning Model (CJV)

The developing CJV arrangements outline:

- SCFT as lead provider
- Sub-contracting ability to organisations outside of the CJV operating at community or neighbourhood level
- Resource and risk-share model
- Clear principles for shared accountability

Immediate work:

- Drafting ways of working- **Feb- March**
- Developing contractual structure- **Feb- March**
- Defining resource requirements and completing negotiations with CJV partners- **by end of March**

Decision Required:

ICB to confirm expectations for:

- Contract schedules
- Risk-share principles

4.4 Performance Framework

Design work is underway but dependent on datasets being finalised between ESHT, UHSx, SASH.

Key elements:

- Alignment with avoidable admissions metrics
- Incorporation of MDT outputs and ICT specification
- Monthly system reporting linked to the NA Board

Next Steps:

- Finalise data model to support the core offer- **March**
- Present for agreement at NA & ICB meeting **(25th February)**

4.5 Workforce & Programme Resourcing

The Programme requires a new structure including:

- Integrator roles (profiles drafted but not yet agreed)
- Programme team posts (recruitment to commence)
- Support for ICT leadership and programme functions

Next Steps:

- Move forward with recruitment process- **Feb- March**
- Agree host for integrator roles- **Feb**
- Finalise recruitment/resourcing timescales- **Feb- March**

5. Risks & Mitigations

Risk	Mitigation	RAG
Delay in MoU/ToR sign-off	Redrafted docs to be agreed by March	Off-track (with plan)
Integrator roles undefined	Finalise profiles and confirm recruitment	Off-track (with plan)
Funding commitments not fully quantified	Workstreams to confirm needs and develop framework	Off-track (with plan)
Finalised ICT specification	Integrate core offer draft and finalise	On Track
Dependency on key appointments	SPC MD supporting stand-up	On track

6. Interdependencies

- MDT Core Offer → shapes ICT Specification
- Performance Framework → Core Offer and avoidable admissions modelling
- Contractual framework → legal review & partner sign off
- HoNs learning → ICT model, service design
- Recruitment timelines → Programme Director + integrator roles

7. Implementation timeline (High Level)

Date	Milestone
Feb 2026	NA meeting on 25/02 to confirm Core Offer performance framework
Feb–Mar 2026	Redraft MoU/ToR and complete workstream alignment
March 2026	Final HoNs learning to inform design
March 2026	Establish ICT Programme Board
March–April 2026	Recruit programme resource and integrator roles
April 2026	Commence contractual mobilisation and implementation
April 2026 onwards	Live delivery, monitoring and monthly reporting

NHS
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