



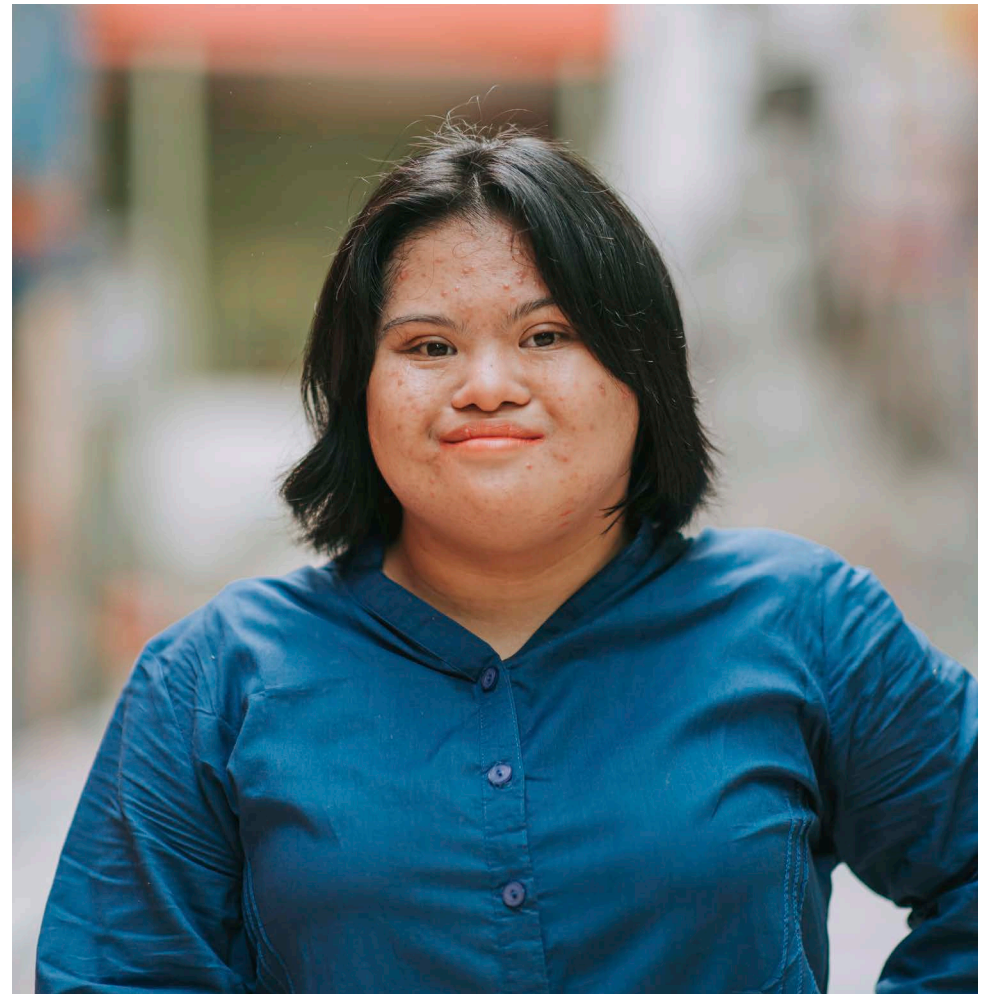
# Learning Disabilities Mortality Review (LeDeR)

Sussex CCGs Annual Report 2021-22

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# 1 Executive summary

- 1.1** The Sussex learning from the lives and deaths of people with a learning disability (LeDeR) programme wishes to acknowledge the continued support of families, services and professionals across the Sussex system and thank them for their involvement, especially during this time of continued challenge due to COVID-19.
- 1.2** This is the third 'LeDeR Annual Report' to be published by the Sussex CCGs' LeDeR programme. All previous reports can be found on the CCGs' [website](#).
- 1.3** The LeDeR programme receives notifications for all deaths of people with a diagnosis of a learning disability, over the age of four. Following notification, a review is completed which looks at the person's life and death to identify good practice or areas for improvements; these are then shared with relevant stakeholders to influence service developments.
- 1.4** Since the start of the LeDeR programme, Sussex has been committed to ensuring people with learning disabilities live well, by acting on the learning identified by LeDeR reviews. The programme has expanded this year to include autistic people, with the LeDeR platform accepting notifications from 1 January 2022 for the deaths of autistic people with no learning disability.
- 1.5** This year has seen considerable change in the LeDeR program, following the publication of the National LeDeR Policy and the withdrawal of Bristol University as host of the LeDeR platform and programme. While the migration of the system has been challenging and seen some inevitable delays in data being reported, there have also been positive updates to the review process and the development of improved governance both locally and nationally.
- 1.6** This report details the progress of the LeDeR programme in Sussex between 1 April 2021 and 31 March 2022. It serves to highlight the link between the learning identified in LeDeR and the continued service improvements we are seeing across Sussex. This year we have also seen an increase in the system-wide commitment to addressing the health inequalities experienced by people with learning disabilities and autistic people.
- 1.7** During this reporting period, cardiovascular conditions were the most common cause of death of someone with a learning disability in Sussex. Cancer and respiratory conditions are joint second with COVID-19 now reduced to fourth, having been the primary cause in 2020/21. Not enough data has been collected yet to report on themes for autistic people, as only one notification has been received.
- 1.8** In-line with the LeDeR Policy this annual report celebrates the change in focus from performance to sustained quality improvements. The 'learning into action' section details the priorities for quality improvement for 2022/23. These are based on the aggregate learning from the reviews completed in previous years and are aligned to the Sussex LeDeR Health Inequalities Strategy.



## 2 Introduction

- 2.1** LeDeR continues to be an important tool in addressing the health inequalities experienced by people with a learning disability and autistic people.
- 2.2** 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 live in Sussex who do not have a learning disability.
- 2.3** Since 2017 Sussex has been reviewing the lives and deaths of people with a learning disability to identify areas of both good and poor practice, with the aim of reducing the significantly worse health outcomes experienced by people with a learning disability, who continue to die on average 27 years earlier than the general population.
- 2.4** The LeDeR policy set outs a structured way to review the lives and deaths of people with a learning disability and now autistic people, to identify the service development needed to address the health inequalities that are leading to premature death.



# 3 Acknowledgements

**3.1** Considerable acknowledgement and thanks go to all those who provided information when requested, especially considering the additional pressures faced during the last year. These include:

- GP surgeries
- Families
- NHS Trusts
- Local authority duty desks
- Home managers and their staff.

**3.2** Further thanks go to the reviewers for their compassion when completing the reviews, keeping the person at the centre of the process, in order to identify learning and share good practice. This includes the Northeast Commissioning Support Services (NECS), who have continued to complete a small number of reviews to support Sussex.

**3.3** At the core of LeDeR are the people and their families, so our thanks go to the incredible carers, families and friends of those who have died, for sharing their stories, sadness and fond memories. We give special thanks to the families who gave permission for the Pen Portraits of their loved ones to be used in this report.



**3.4** Finally, and by no means least, it is of course the people whose lives our reviewers were permitted to review that we thank the most. People who may have experienced care for the duration of their lives; people who were taken from their loving families' too early; people who throughout their lives often faced adversity with bravery. LeDeR in Sussex is indebted to the extraordinary people, from whom we are able to learn so much.

# 4 Implementation of the National LeDeR Policy in Sussex



- 4.1** The new LeDeR platform was expected to go live on the 1 June 2021; however, delays meant the platform was not accessible until the 16 June 2021, following which there was still limited functionality. This remains an ongoing issue and the reporting function, which allows health systems to draw data from the platform, is currently not operational. This has impacted some of the central information available for this report which has, instead, been collected locally.
- 4.2** Further delays were experienced with being able to open reviews on the new platform and with the necessary training being accessible for reviewers to complete. Following escalation, this was resolved, and the LeDeR team are now able to access the platform as needed.
- 4.3** A number of reviews were carried over from the previous University of Bristol platform; and any notification made in the early stage of the new platform, only became visible to the Sussex reviewers on 2 July 2021, four weeks later than expected. Notification made in this time were reported as 'stacked reviews'. This caused some delays in the allocation of the LeDeR reviews, which has been reflected in recent quarterly performance.
- 4.4** 'Stacked reviews' have been transferred to Northeast CSU (NECS) for completion. This was commissioned by NHSE to avoid a further backlog of reviews. Notifications made since June 2021 have been allocated for completion by CCG reviewers.
- 4.5** These issues are largely resolved and are not considered a current risk. However, the CCG Quality Team are aware of the delays, and NHS England/Improvement (NHSE/I) are maintaining an issues log to track any further glitches and their risk scores. All concerns regarding the changes to the web-based platform and processes have been shared regionally and escalated to the national NHS England team.
- 4.6** LeDeR in Sussex is now compliant in all key deliverables of the LeDeR policy, including being compliant with the new policy requirements.



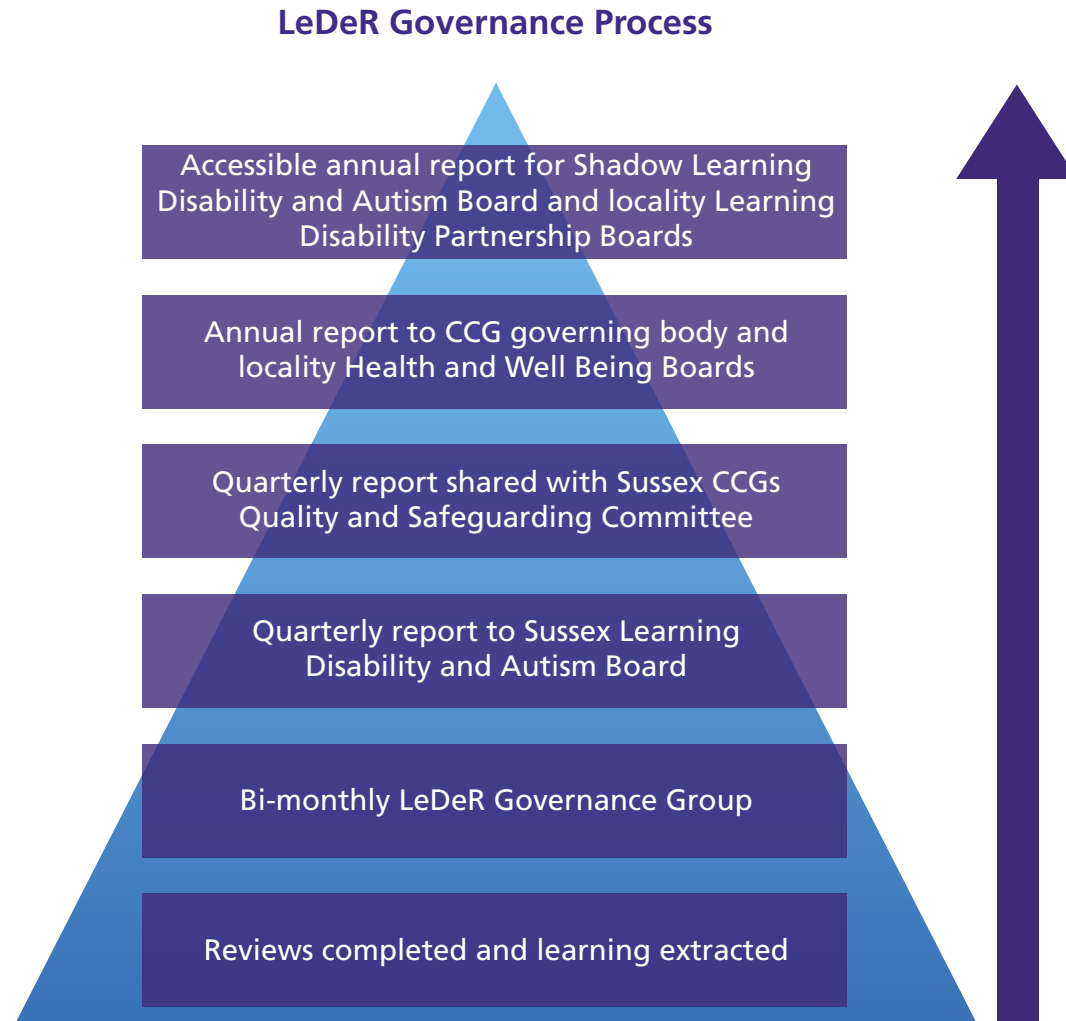
# 5 The inclusion of autistic people in LeDeR in Sussex

- 5.1** Local preparatory work has been completed to ensure that autistic people and their networks are familiar with the change to the LeDeR policy and understand the implications. This included briefings to Autism Partnership Boards, and the Sussex Experts by Experience Board.
- 5.2** The addition of autistic people's deaths in the programme has been considered when developing the new local standards for reviewing, including ensuring the new substantive LeDeR reviewers have knowledge of different barriers an autistic person may experience when accessing care and sufficient capacity within the reviewer team to undertake the reviews.
- 5.3** All notifications for autistic people will go to a 'focused review' until 2024. This differs from the learning disability notifications, which may be concluded after a less in-depth 'initial review', only going to a focused review if there are thought to be complexities or complications which necessitate further inquiry.
- 5.4** To date, there has been one notification for an autistic person, and they will receive a focused review.



# 6 Governance arrangements in the Sussex system

- 6.1** The Sussex LeDeR Governance Group was established in 2021, in line with policy requirements, and is responsible for the governance and local implementation of the LeDeR programme.
- 6.2** There is committed and consistent membership from the NHS Trusts in Sussex including: Southeast Coast Ambulance Trust, all three local authorities via their safeguarding teams, Sussex CCGs, the GP Clinical Lead for learning disabilities, the NHSE/I regional co-ordinator, Sussex Local Area Contacts (LACS), and a Sussex-wide provider of residential and supported living services for people with learning disabilities. Lay members have also been recruited and information governance is being worked through.
- 6.3** The chart opposite describes the governance framework:







- 6.4** The new LeDeR policy describes a tiered system of review. Initial reviews are completed for less complex or contentious cases and focused reviews are completed for those where there may be greater opportunity for learning.
- 6.5** Both types of review are shared with the Governance Group for sign-off. However, the focused reviews require the reviewer to deliver a brief presentation that includes a condensed pen portrait, presenting health and social care needs, events in the lead up to death as well as the identified issues and possible learning. The panel then agrees the actions required, which are fed-back to relevant organisations for action with progress tracked by the group.
- 6.6** A quarterly report is produced on behalf of the Governance Group and circulated to the membership of the Sussex Learning Disability and Autism Board and Sussex Expert by Experience Shadow Board to provide oversight, support and/or challenge on performance and outcomes.
- 6.7** In addition, reporting to the Quality and Safeguarding Committee occurs on a monthly basis and includes data with a brief narrative on themes and improvements underway. The full report is shared quality with this committee to provide assurance.
- 6.8** An annual report is produced, which is presented at executive board level in the CCG, and to joint committees across Sussex. The three Sussex Health and Wellbeing Boards and Safeguarding Adult Boards across Sussex also receive the report for discussion and an agreed version is then published on the CCGs' websites.
- 6.9** Additionally, an accessible version of this report is shared with the Sussex CCGs Shadow Learning Disability and Autism Board, which is made up of service users and people with lived experience, and the place-based Learning Disability Partnership Boards.

# 7 Performance

- 7.1** Sussex concluded 2020/21 having cleared a back-log of LeDeR reviews. This ensured that we went into this reporting period in a strong position to address any delays that might have occurred due to the establishment of the new platform and policy requirements.
- 7.2** In addition to this strong start, the 2021/22 reporting period has seen a reduction in notifications received. While this may be expected due to decreasing number of deaths attributed to COVID-19, we also plan to refresh LeDeR communications across Sussex to all partners and stakeholders to ensure the decreased numbers are not due to a lack of reporting.
- 7.3** Where possible, all Sussex reviews are now completed within six months of notification, which is the required standard. Those that breach this are due to holds being placed on the initiation of the review because they are subject to an alternative process that need to be concluded before the LeDeR review is started. Examples of these processes are: safeguarding enquiry, safeguarding adult review, serious incident investigation or inquest.

- 7.4** Sussex currently has nine reviews on hold due to statutory processes. These include three safeguarding adults' reviews, three safeguarding enquiries and three inquests.

## 7.5 Sussex reviewer arrangements

- 7.5.1** Sussex are proud to report that all of the substantive posts outlined in the new policy have now been recruited to.
- 7.5.2** The new LeDeR reviewers come from a variety of backgrounds; this includes general nurses, child nurses and other professionals such as social workers. This ensures a skill mix that is able to respond to both the inclusion of autistic deaths and also the complex health presentations seen in some notifications.
- 7.5.3** Reviewer's skills and knowledge are, wherever possible, matched to the reviews they are allocated, and support is provided via peer supervision and the LeDeR Case Manager or the LACs.

## 7.6 Bench marking

- 7.6.1** In May 2021, the South Central and West Commissioning Support Unit (SCW CSU) took over the data collection and preparation from the University of Bristol. This change has caused ongoing data quality issues that the national team have been trying to resolve. Unfortunately, this means that we have limited reliable data to draw on for bench marking purposes.
- 7.6.2** However, we do know the highest percentage of completed notifications at national level is 98%, placing the South East region in second with 97%. The lowest regional percentage reported is 95%.
- 7.6.3** Sussex ICS completed a total of 97% of the eligible notifications, which is in line with the South East total. The highest performing ICS regionally achieved 99% and the lowest 90%. Sussex ended this reporting period 2nd for LeDeR performance at a regional level.

# 8 Equality

## 8.1 Equality impact

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

## 8.2 Four domains of analysis

**8.2.1** 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, and level of learning disability. Level of learning disability is taken from the narrative of completed reviews only.
- The cause of death as recorded on the death certificate of completed reviews.
- Themes identified in the recommendations made in completed reviews.

**8.2.2** It must be considered that there have been long periods in this reporting cycle where the platform has had limited functionality and the ability to extract data is still limited. While this may have some impact on the validity of the reported information below, it is largely consistent with what we have seen in previous years and will therefore be reported with this caveat.





## 8.3 Age

**8.3.1** Seventy-three deaths were notified to LeDeR during the reporting period.

- The range of age of death was 5-87
- The mean average adult age of death was 54
- The median age of death was 61

**8.3.2** Thirty-five females with learning disabilities died during the reporting period.

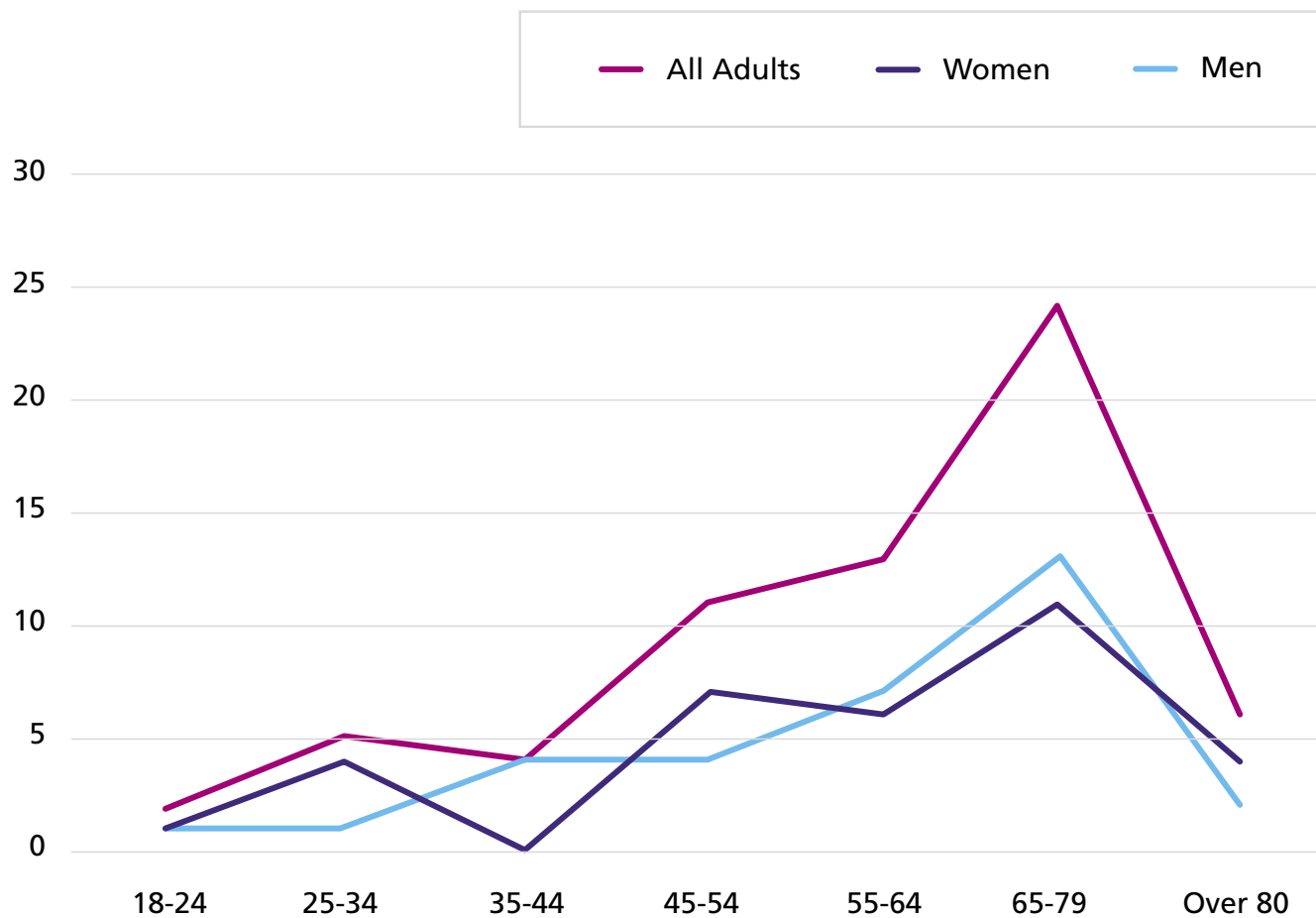
- The range of age was 5-87
- The mean average age of death was 54
- The median age was 61

**8.3.3** Thirty-eight males with learning disabilities died in the reporting period

- The range of age was 6-87
- The mean average age of death was 56.4
- The median age was 63

**8.3.4** The following graph shows a visual representation of the age ranges of the adults reported to LeDeR in the period

Deaths adults 21-22

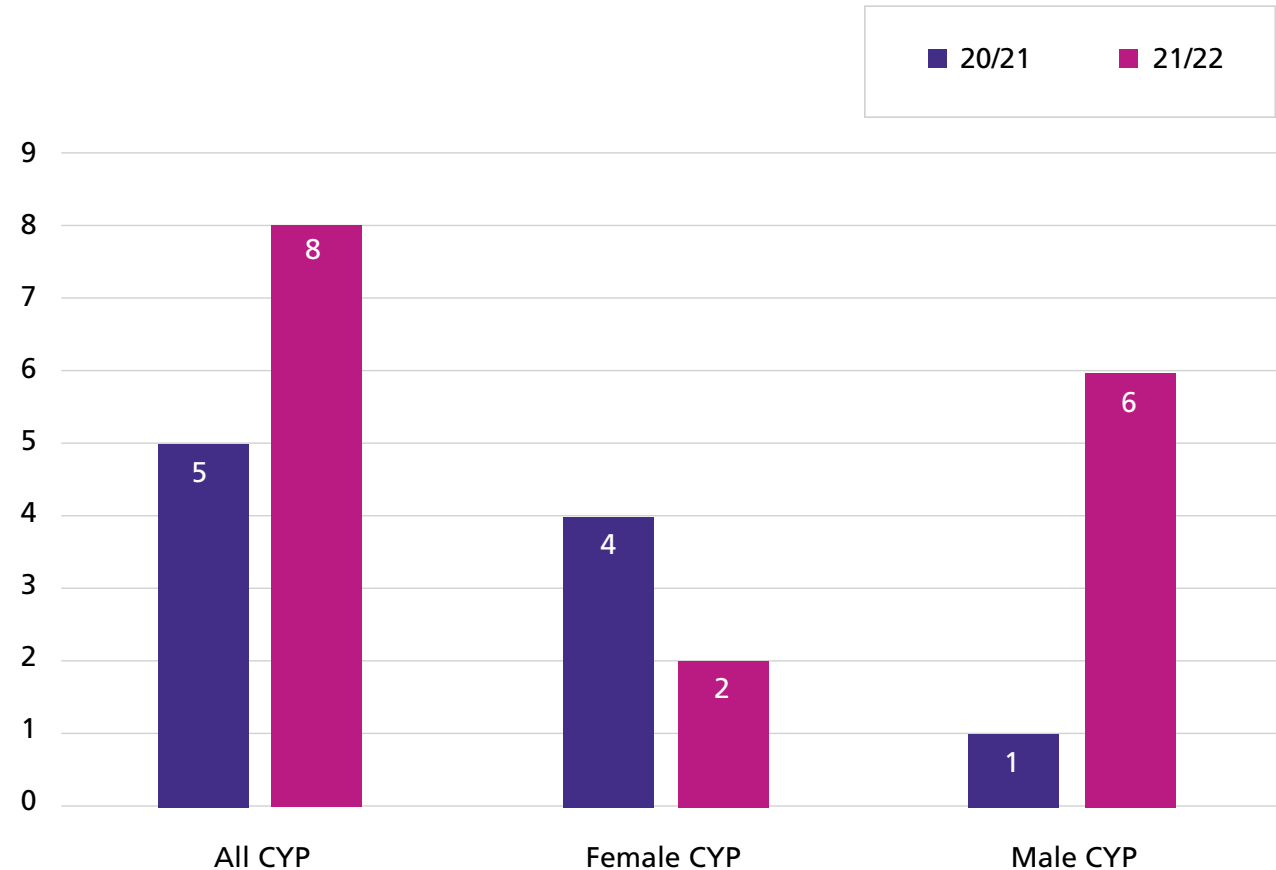


## 8.4 Age of children

**8.4.1** Eight child deaths (three more than the previous year) were reported to LeDeR during the reporting period. This increase will be compared with regional and national data when it becomes available. The Child Death Overview Panel (CDOP) has seen a comparable increase in notifications also.

- The range of age of death was 5-14
- The average age of death was 10.5
- The median age of death was 11.5

### Deaths of children and young people (CYP)



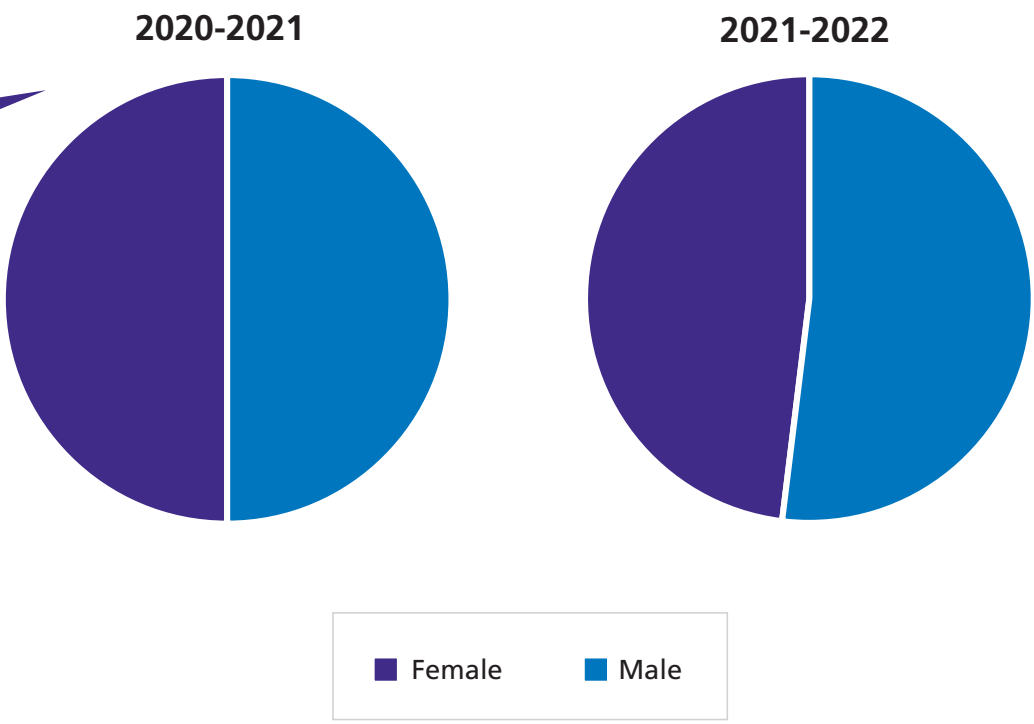
**8.4.2** CDOP is the lead process for the review of child death. Direct learning will be published and tracked by CDOP. However, there is LeDeR representation at all child death review meetings and on CDOP panels where there is a final sign off.

8.5 Gender

8.5.1 35 females died in the reporting period.

8.5.2 38 males died in the reporting period.

	2020-2021		2021- 2022	
	Male	Female	Male	Female
No.	61	61	38	35
%	50	50	52	48





## 8.6 Ethnicity

**8.6.1** Nationally, COVID-19 has disproportionately impacted people from minority ethnic backgrounds. This has also been reflected in local population data as those with learning disabilities, from minority ethnic groups, are consistently overrepresented in the notifications of deaths. All adult reviews of a person from a minority ethnic community will receive a focused review to further understand the impact and interaction between ethnicity and learning disability.

**8.6.2** The use of psychotropic medication is one theme that has been identified as particularly impacting this group. This learning has been raised in the 'Stopping the Over Medication of People with a Learning Disability (STOMP) Steering Group, which is chaired and attended by specialist pharmacy. Reviews have also highlighted the importance of interpreters being available at the earliest opportunity, this learning has also been shared through the Primary Care Networks and Health Inequalities Steering Groups.

**8.6.3** The table below provides further information on the ethnicity of those notified under the LeDeR programme in 2021/22:

Ethnicity	White				Mixed/multiple ethnicity groups				Asian or Asian British				Black or Black British			Other ethnic groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	48	0	0	1	1	0	0	0	1	1	0	0	0	0	0	0	0	0
% of all reported deaths	92	0	0	1.9	1.9	0	0	0	1.9	1.9	0	0	0	0	0	0	0	0
Ethnicity % of local populace	89	1	0.1	4	0.3	0.3	0.5	0.5	0.8	0.3	0.3	0.7	0.2	0.5	0.1	0.4	0.3	

## 8.7 A pen portrait to introduce some of the people who have died

**8.7.1** It is imperative that those reading this report are reminded that the learning comes from the lives and deaths of real people, who lived with their families or other support in our Sussex communities. This work could not happen without them and so we take time to remember some of them; Janet, Dan Adrian and Reg\* whose families we thank for their permissions to include in our report. *\*Names have been changed.*

**8.7.2** The following pen portraits provide a brief outline of the person and the circumstances of their life and death:

### Janet

Janet was one of 11 children. Whilst she was not in touch with most of her siblings, she was very close to two of her sisters. She grew up in a long stay hospital and until only a few years ago would bundle her belongings up at night as she had done in the hospital. Janet was the longest resident at her home, and she had lived there for 32 years. When younger she went to her sister's Doreen for weekends where she enjoyed playing with her nieces and nephews especially her favourite one, who she called fish face.

Janet had a passion for art, but she liked to keep hold of it. In a day centre she attended her work was on display, but she would ask if she could take it home regularly as it was hers.

Janet loved life and people. She was known for giving the best big hugs whilst saying "you old bugger". Janet lit up the room and is missed greatly.

### Reg

Reg had a mild learning disability and was proud of his role in looking after a brother with severe learning disabilities as a child. Reg loved to chat and liked to meet new people. He particularly liked cruises where he enjoyed the quiz shows and cabarets. Reg lived with six other people in a home he liked. He sometimes got irritated with other he lived with, but this was usually short lived. Reg was a night owl, but this meant that he often slept most of the day. He died in hospital and requested to be buried at sea as he loved all things naval.

Reg was diagnosed with a mental illness and was detained under the Mental Health Act. He was subsequently discharged without restrictions but continued to need skilled support to access the community. As Reg got older his ability to process information reduced. He was known to dislike law and governments, subjects that were generally avoided by those around him.

Reg had always been reluctant to attend health appointments but in later years he was diagnosed with an eye condition and asthma. He had declined all invites for bowel screening. Bowel screening was finally undertaken when Reg began to experience a significant change in his bowel habits, and by the time he was admitted to hospital he was very unwell. He continued to decline all tests and care, but minimal care was finally agreed as in his best interest under the mental capacity act.

## Adrian

Adrian was the oldest of three. His mum was told to put him into care but this was not an option for her. Adrian's mum was a primary school teacher and Adrian went to mainstream school, which was unusual at the time for a child with down's syndrome. Adrian loved a party and was confident and sociable. He would have planned Christmas from January if he could. As the oldest he was protective and supportive of his siblings and known for his calming effect. He loved clothes and fashion, won awards in art competitions and James Bond was his hero. He was also strong willed and loathed being patronised, something that occurred in some care settings.

Adrian was diagnosed with dementia. As his needs increased, he was well supported in his nursing home. His sister watched his world become smaller, but the pandemic was nothing more than tragic for Adrian and his mum. She had become frail, but the family and home worked hard to maintain connections. Adrian died peacefully in his home and was survived by his mum for only a week.

## Dan

Dan was born prematurely and was one of twins. They both had a very rare syndrome and his brother sadly died. Dan did not come out of special care until he was six months old, he was cared for jointly by foster carers and his family. His mum describes him as a gift. Dan had two younger brothers and enjoyed making mischief with them. Whilst his speech could be difficult to understand his brothers were expert at translating and advocating for him. Prior to the pandemic Dan would spend up to half of the year with his mum and their extensive and close family.

An avid royalist when Princess Diana died, he took to his sofa in a sleeping bag refusing to move, watching all the news and grieving. This lasted three days.

The pandemic frightened Dan and he became increasingly reluctant to come out of his room. Specialist support was sought as his behaviour changed. Dan had always been reluctant to visit hospitals and allow tests to be undertaken but staff at his home became very concerned when he lost weight and experienced falls. After several failed visits and with the support of the acute liaison nurses at the hospital Dan was diagnosed with cancer that had started in his bladder but had spread to multiple sites. He declined treatment, something he had the capacity to do. He was supported by his local hospice and then moved to be with his mum and aunt. All his family visited him in his last few months, and he died peacefully with his mum and aunt beside him. His mum described his death as joyful.



## 8.8 Level of learning disability

**8.8.1** For every review carried out the level of learning disability for that person is confirmed and recorded as either mild, moderate, severe, or profound/multiple.

- Based on previous data, a greater percentage of people with mild learning disabilities died this year.
- Sussex has a higher than national average number of care homes that are registered to look after people with severe learning disabilities.
- The information below shows a breakdown of the level of learning disability for all reviews completed in the reporting period:

Level of learning disability	No. 20/21	%	No. 21/22	%
Mild	23	29	9	32
Moderate	17	21	8	28
Severe	25	31	7	25
Profound and multiple	10	12	4	14
Unknown	5	5	0	0

## 8.9 Cause of death

**8.9.1** In 2020/2021 COVID-19 was the most common cause of death and pneumonia was second.

**8.9.2** There has been a marked shift in reported cause for this reporting period, with vascular conditions being the most common primary cause, accounting for 25% of deaths. Cardiovascular health will therefore be picked up as a priority workstream through the Health Inequalities Steering Group in 2022/23.

No.	Primary cause of death	No.	Secondary cause of death
1	Vascular conditions including heart attacks and stroke	1	Sepsis
2/3	Cancer	2	Frailty
3/2	Pneumonia	3	Alzheimer's dementia
4	COVID-19	4	Epilepsy
5	Frailty	5	Learning disability

**8.9.3** It's to be celebrated that in this reporting period, there has been a reduction in the incidence of death being attributed to a learning disability.

## 8.10 DNACPR – Do Not Attempt Cardio-Pulmonary Resuscitation

**8.10.1** During the first wave of the COVID-19 pandemic, concerns were raised about the potential for “blanket” decisions being made around resuscitation, particularly for more vulnerable populations.

**8.10.2** In response to the concerns about the practice around DNACPRs, this year Sussex has implemented the use of the ReSPECT tool across providers in Sussex. ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. Learning from LeDeR has been included in the Sussex ReSPECT projects.

**8.10.3** Completion of ReSPECT forms is now included in medical examiner scrutiny. Training has been provided to specialist learning disability teams in their benefit and use as well as initiating and supporting conversations to promote the understanding of the process, including the role of the Independent Mental Capacity Advocate.

**8.10.4** Learning from LeDeR continues to be shared with the Sussex palliative care and end of life project board and has been included in the Sussex-wide End of Life Strategy.

## 8.11 Recommendations made in completed reviews

**8.11.1** In the new format, initial reviews allow two learning recommendations to be made and two aspects of good practice to be shared.

**8.11.2** The table below shows the thematic analysis of recommendations made as a result of reviews in the period 2021-22. The top three themes remain the same as the previous year.

Theme	Number featured
Application of the Mental Capacity Act	6
A lack of advanced care planning	6
Prevention/identification of deterioration	2
STOMP/STAMP	4
Poor completion of ReSPECT forms	3
The importance of reasonable adjustments	4
Annual health checks (AHCs)	2
Poor co-ordination of care	4
Screening not undertaken	3
Access to health promotion	3
Diagnostic overshadowing causing delays	2

## 8.12 Positive practice themes

Theme	Number featured
Carers going the extra mile including meeting needs at a person's end of their life	3
Placements being maintained despite a person's needs increasing	2
Shared lives carers providing a high level of advocacy	2
Capacity assessment undertaken with specialist easy read resources	2
Regular and thorough reviews by primary care	2
Acute liaison nurses enabling coordinated care on discharge	2



# 9 Action from learning

## 9.1 What we have learned:

### Best practice and positive outcomes we have learned from reviews



Effective communication and liaison from and between the care home, CLDT and acute liaison nursing both in the community and when in hospital

Feedback to those involved in a person's care and support that the family have praised their approach

Excellent person-centred care from the care home in ensuring that a person was able to return home at the end of their life

Information used from a hospital passport ensuring that staff in A&E had Disney music playing when a lady was admitted at the end of her life

Application of Article 8 Human Rights Act (HRA) to enable a person to return to the family home to die

Application of reasonable adjustments including enabling visiting under COVID-19 restrictions

Specialist learning disability nursing in a hospice enabling the completion of ReSPECT

Good application of the Mental Capacity Act – supporting people to make their own decisions, which were respected.

Compassionate care in hospital when a transfer was delayed and discharge to home could not occur but the person's carer was able to be there and provide their personal care

Evidence of thorough and regular medication reviews by a pharmacist in primary care

A care provider supporting a lady's sister who also had a learning disability in their grief



## The areas for improvement that were identified in recommendations from reviews



People remaining on medications without regular review, specialist oversight and/or clear diagnosis indicating a clinical need for the medication

Documentation to reflect the application of Mental Capacity Act

Better understanding of the risks associated with constipation including long term laxative use.

Better care co-ordination to improve and ensure a consistent approach when a person with learning disabilities has multiple morbidities

The need to initiate advance care planning and ReSPECT when risks due to dysphagia remain

Better identification of frailty to inform advanced care planning

Access to good public health advice and reasonably adjusted social prescribing particularly to support weight loss and increased activity

Inclusion of learning disability care homes in the Enhanced health in care homes direct enhanced service

Application of the deprivation of liberty safeguards as required

Evidence of thorough and regular medication reviews by a pharmacist in primary care

A care provider supporting a lady's sister who also had a learning disability in their grief

## 9.2 Action from learning: what we have learned about deaths from COVID-19

**9.2.1** All except one death attributed to COVID-19 were of fully vaccinated people. The CCGs have worked hard to ensure that people receive their vaccines and boosters and that the pathway for application of MCA is clear.

**9.2.2** When vaccines are declined on behalf of a person with a learning disability who may not have capacity to make this decision, health facilitation teams assess what reasonable adjustments are required and whether a program of familiarisation should be developed. GPs are also supported to consider possible barriers and seek legal advice, including prompt application to the Court of Protection if appropriate.

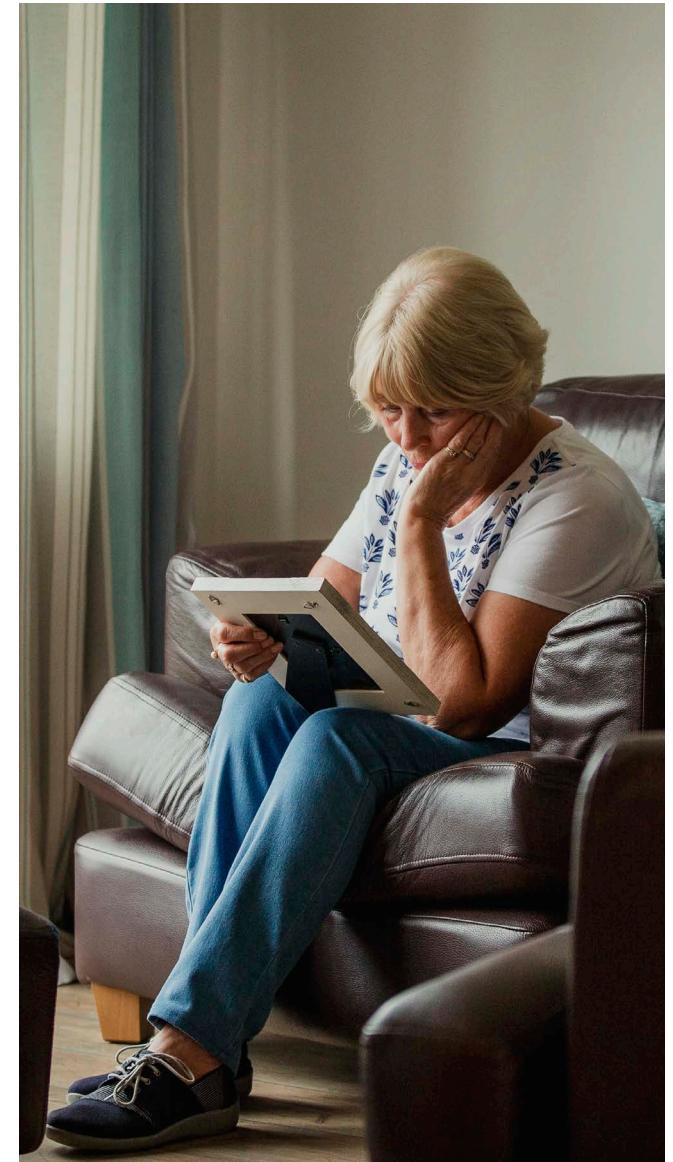
## 9.3 Impact

**9.3.1** Opposite is feedback received from Adrian's sister to a reviewer.

I just wanted to connect with you following your call today.

I am really pleased to be in touch with you and your team. It is a really important aim for me to improve lives for people with learning disabilities and I like to think I do this in Adrian's name. I miss him so much. You are a great advocate for your team, how can I explain it - I enjoyed talking to you about Adrian's life and you do that at such a difficult time in people's lives - it feels like he is still here. It is really good to be looking forward to doing more now that life has changed so much.

I look forward to keeping in touch – it is on my action list to share some information about Adrian and his life, and Mum of course who did such a great job in difficult circumstances. I am so proud of him and his achievements in life and hope to continue reaching out to others.



## 9.4 The Sussex CCGs LDA Health Inequalities Steering Group

**9.4.1** The Learning Disability and Autism Health Inequality Project Board was established to ensure that the health inequalities identified through LeDeR Programme and committed to in the Sussex LDA Strategy are addressed.

**9.4.2** The board includes representation of people with lived experience, families and carers and links to wider population health workstreams that are being picked up in the developing ICS.

**9.4.3** Clinical priorities for the group have been set in accordance with last year's LeDeR data. Due to this, respiratory is the top priority because it accounted for 25% of 2020/21 notifications.

**9.4.4** Based on local and national LeDeR priorities working groups for the LDA HI Steering Group are focused on the following clinical areas:

- Respiratory
- Immunisation and vaccinations
- Cardiovascular disease
- Hearing and sight checks in residential special schools
- Bowels/constipation
- Diabetes – flash glucose monitoring
- Epilepsy awareness
- Cancer and cancer screening

**9.4.5** Work is linked back into mainstream commissioning to ensure a wide impact.

**9.4.6** The Steering Group also oversee the implementation of the 'Dynamic Support Register' for physical health.

## 9.5 Dynamic support register – physical health

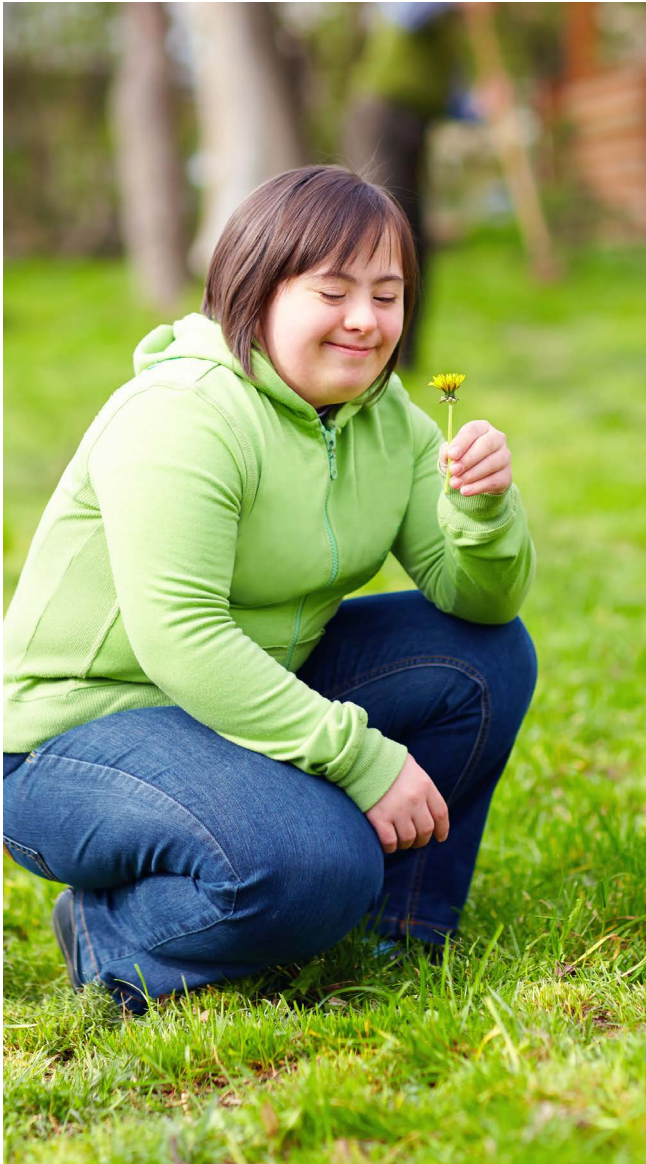
**9.5.1** Based on a tool developed by Cheshire and Wirral NHS Trust, a project worker has been employed to pilot the application of this tool across primary, community and specialist (community learning disability teams). Utilising an agreed GP learning disability register, the tool will be applied to all on the register in order that they can rate risks to health and premature mortality.

**9.5.2** The tool will support the identification of, and referral to, relevant care pathways including social prescribing, STOMP medication reviews and healthcare co-ordination and agencies.

## 9.6 Advance, anticipatory and end of life care planning

**9.6.1** Training has been provided to community learning disability and health facilitation teams across Sussex through the role-out of ReSPECT, on understanding frailty and how to plan for the person's last year of life.

**9.6.2** The learning from LeDeR has been included in the Sussex palliative care and end of life strategy and strengthens the commitment of inclusivity of people with a learning disability and autistic people in services such as hospices and single point of contact hubs.



## 9.7 Identifying a deteriorating patient – Restore 2, Restore 2 mini and Stop Look Care

**9.7.1** Working collaboratively with the Kent, Surrey and Sussex Academic Health Sciences Network (AHSN), Restore 2 mini ‘train the trainer’ sessions have been delivered across the Sussex footprint. A suite of three packages is being developed to include training for care providers, family carer and personal assistants and people with learning disabilities.

**9.7.2** Stop Look Care is a NICE recognised tool and handbook for care workers and carers, which is used to identify, prevent and respond to deterioration among older people in the health and care sector. However, little was known about its use in the variety of social care settings where people have a learning disability and/or autism.

**9.7.3** Based on local and national learning from LeDeR, members of the Sussex learning disability and autism, and Stop Look Care teams devised a training package adapted for this work force using LeDeR case studies. One focused on oral care and the prevention of chest infections among people with a learning disability and/or autism. The other used the principles of active support to consider the active health support required for a person with mild learning disabilities to prevent constipation.

**9.7.4** The team is now cascading this tool via partners, to anyone supporting people with a learning disability and/or autism. The team aims to create a new Learning Disability and autism version of the Stop Look Care booklet for the programme, which will include guidance on epilepsy care, postural and respiratory management, the prevention of chest infections, and STOMP.

## 9.8 Action from learning: the evidence base for local priorities 2021/2022 – based on the recommendations from completed reviews

### Applying the Mental Capacity Act

#### Recommendations raised issues with its application include:

- Assuming incapacity
- Lack of available assessment of capacity
- A lack of application of the self-neglect guidance when a person is considered to have capacity but remains at risk of death
- Applying the MCA for 16-17 year-olds
- Poor understanding of the role of the independent Mental Capacity Advocate when undertaking ReSPECT

#### Positive practice to share:

- Evidence of excellent application in maximising understanding to promote choice, rights and dignity in death
- Preparation for the roll out of the liberty protection safeguards

### A lack of advanced care planning

#### Recommendations include:

- Improving the skills in identifying that a person with dysphagia who is experiencing multiple chest infections, should have a plan recognising their views and wishes about their death
- The need for a lead clinician to develop advance care plans and initiate ReSPECT conversations
- The need for speech and language to develop contingency and/or advance care planning when delivering 'risk feeding' care plans.
- Better understanding of the application of frailty models for those with multiple morbidities
- Earlier referrals to hospice or end of life single point of contact hubs by acute liaison nurses and primary care
- People should not be discharged from hospital without hospice involvement if their prognosis is terminal

#### Practice to share:

- Learning disability liaison nurses working behind the scenes to enable good hospice support.
- The evaluation of a hospice health facilitation project



## Understanding the risks associated with constipation

### Recommendations include:

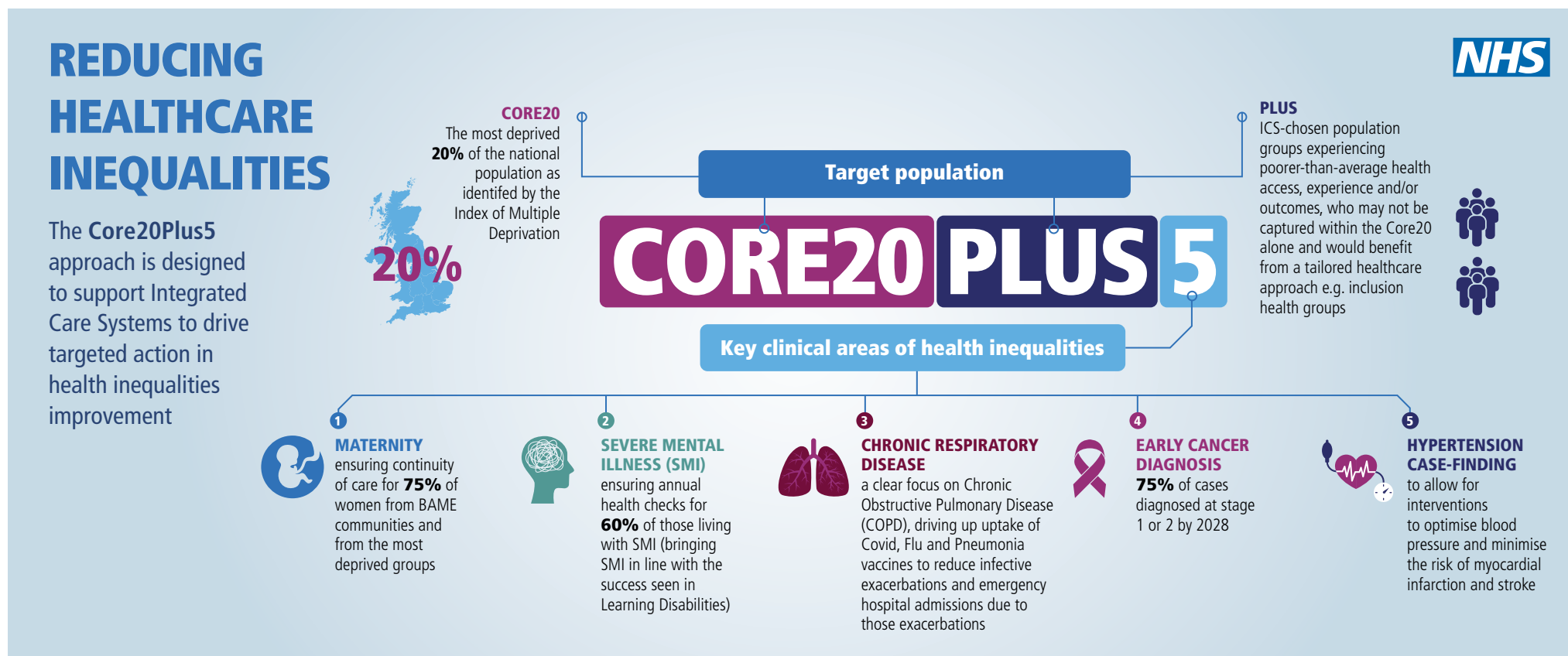
- Providing health promotion advice lifestyle factors
  - › Hydration
  - › Diet
  - › Exercise
- Ensuring good monitoring of bowel health when medication is provided
- Ensuring the availability of accessible resources and reasonably adjusted health promotion
- Promoting the importance of FIT
- Ensuring specialist involvement (bladder and bowel) when constipation remains problematic
- Increasing the understanding of good bowel health in preventing bowel cancer
- Ensuring that surveillance and management is clear when there may be a risk of volvulus



# 10 Learning into action: Population Health Management

**10.1** The NHS Long Term Plan (LTP) and Sussex's Vision 2025 require the Integrated Care System (ICS) to develop and increase the use of Population Health Management (PHM) as a tool to support the transformation of care and service provision.

**10.2** Core20PLUS5 is an NHS England and NHS Improvement approach to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort – the '**Core20PLUS**' – and identifies '**5**' clinical focus areas requiring accelerated improvement.





**10.2.1** Targeting the **core 20%** most deprived as identified by the national index of multiple deprivation.

**10.2.2 Plus**, considering the locally determined population groups experiencing poorer than average health experiences and outcomes and inclusive of multiple morbidities and protected characteristics.

**10.2.3 5**, the focus areas of maternity, severe mental illness, chronic respiratory disease, earlier cancer diagnosis and hypertensive case finding.

**10.2.4** PHM in Sussex has identified six priority areas of which mental health and learning disabilities is one. These priorities support Primary Care Networks (PCNs) to prevent ill-health and tackle neighbourhood health inequalities.

**10.2.5** Specific to those with a learning disability is the commitment to

- Develop better pathways of care tailored to the needs of people with a learning disability
- Increase access to social prescribing
- Improve the uptake of health checks

**10.2.6** A member of the Sussex Population Health Management, Prevention and Personalised Care team sits on the Sussex Learning Disabilities and Autism Health Inequalities Steering Group. This ensures alignment of workstreams in order that learning from LeDeR influences population health management workstreams and this also ensures that LeDeR national themes are addressed.



# 11 Learning into action

## 11.1 Addressing the national themes in the areas of respiratory care, cardiovascular care and care and increasing the focus on those from minority ethnic communities

**11.1.1** The Sussex Learning Disabilities Health Inequalities Steering Group has devised its workplan in accordance with national and local learning from LeDeR.

**11.1.2** LeDeR is embedded in the wider Sussex health inequalities work streams as well as a driver for the Sussex Learning Disabilities and Autism Health Inequalities Steering Group.

**11.1.3** LeDeR will work to develop relationships with ICS partners from minority ethnic communities in order that the needs of those with a learning disability and who may be autistic within their communities are better understood and addressed.

**11.1.4** The Sussex Population Health Management Strategy demonstrates a clear commitment those with a learning disability and their inclusion in all work streams.

## 11.2 Action from learning; Annual Health Checks

**11.2.1** Throughout 2021-22 Sussex has been working towards a target of at least 72% completed health checks for those eligible.

**11.2.2** Pressures on primary care have continued to increase and staffing has been significantly affected by the pandemic and specifically the Omicron variant. Health facilitation teams across Sussex have worked creatively to support primary care in the completion of annual health checks. Whilst the target has not been achieved to date, performance continues to improve.

*Annual Health Check performance data\* with previous year comparisons:*

CCG	2020-21			2021-22		
	Checks	Q4 register	AHC %	Checks	Q4 register	AHC %
Brighton and Hove	799	1,492	53.6%	788	1,546	50.8%
East Sussex	2,283	3,208	71.2%	1,722	3,299	52.2%
West Sussex	3,413	4,690	72.8%	2,509	4,818	52.1%
Sussex total	6,495	9,390	69.2%	5,016	9,663	51.9%

*\*Please note this data is taken from the Sussex Month 11 position. Data from the end of year is expected shortly and this section will be updated accordingly.*

**11.2.3** There are health facilitation teams across Sussex, with the East Sussex team operational from September 2021.

**11.2.4** In this reporting period, there has been an increased focus on the quality of the annual health checks. A quality audit has been completed as part of the Thumbs up work. Details of this are below.

**11.2.4** Our ambition remains to achieve and maintain 75% by 2023-2024 while concurrently increasing the number of people with a learning disability on GP registers. In addition, there will be a renewed focus on ensuring AHCs result in a Health Action Plan, with a 100% concordance rate set for 2022/23.

## 11.3 A positive practice example: The thumbs up audit 21/22

**11.3.1** During 2018 we developed the 'Thumbs Up' to Good Health Award in conjunction with Speak Out, an independent advocacy service. The award is a quality kite mark scheme.

**11.3.2** In 2021/22 the first audit was completed against the standards outlined below.

Criteria
1. Has a HAP been produced?
2. Has the HAP template been used?
3. Is a copy saved on the patient's record?
4. Is a copy given to the patient?
5. Is simple language used?
6. Are the actions on Health Action Plan clear?
7. Is it clear who is going to complete each action?
8. If any, is there evidence that actions allocated to GP have been actioned?
9. Are any referrals identified in the Annual Health Check recorded in the HAP?
10. Reasonable adjustments necessary for the delivery of the agreed follow-up actions are recorded and communicated to relevant personnel and agencies (e.g. in referral letters)
11. People have been given easy read information about any recommendations for healthy lifestyles / conditions / tests etc'



**11.3.3** The following results were collected from the audit:

Criteria	Total number of HAPs that criteria was applied to	Yes	%	No	%	N/A	%
1. Has a HAP been produced?	99	62	62.63	37	37.37	0	
2. Has the HAP template been used?	62	53	85.48	9	14.52	0	
3. Is a copy saved on the patient's record?	62	59	95.16	3	4.84	0	
4. Is a copy given to the patient?	62	45	72.58	17	27.42	0	
5. Is simple language used?	62	21	33.87	41	66.13	0	
6. Are the actions on Health Action Plan clear?	62	56	90.32	4	6.45	2	3.23
7. Is it clear who is going to complete each action?	62	28	45.16	32	51.61	2	3.23
8. If any, is there evidence that actions allocated to GP have been actioned?	62	38	61.29	4	6.45	20	32.26
9. Any needed referrals identified in the Annual Health Check are they recorded in the HAP?	62	30	48.39	2	3.23	30	48.3871
10. Reasonable adjustments necessary for the delivery of the agreed follow-up actions are recorded and communicated to relevant personnel and agencies (e.g. in referral letters)	62	32	51.61	11	17.74	19	30.65
11. People have been given easy read information about any recommendations for healthy lifestyles / conditions / tests etc.	62	24	38.71	16	25.81	22	35.48

**11.3.4** The most common actions taken as a result of an annual health check were:

- Further support regarding weight management identified and offered
- Medication review needed
- Blood tests needed
- Referral to podiatry

**11.3.5** The following areas of good practice were identified:

- Learning disability champions/ leads in all practices
- Follow up after discharge from hospital.
- Robust medication reviews systems
- Reasonably adjusted appointment times, locations, and lengths

**11.3.6** The following areas were identified for improvement or more support:

- The recording of reasonable adjustments
- More easy read information
- Better awareness of specialist teams
- Training in coding and templates
- Training on how to produce a good HAP
- Follow up when a person is not brought or does not respond to invites
- Ensuring feedback from people with a learning disability and their families and carers
- Including people with learning disabilities in patient reference groups

**11.3.7** This audit is the consolidation of a longer project and the data that it's produced will feed into quality improvements for the delivery of AHCs across Sussex.

## 11.4 Action from learning: the role of cancer screening

**11.4.1** During this reporting period there have been two deaths in Sussex from cancers where the person was eligible for screening but declined. These have been shared with the Sussex cancer screening interface manager to inform future work.

**11.4.2** An awareness campaign has been developed to promote the undertaking of faecal immunochemical test (FIT) and to increase awareness that bowel cancer affects comparatively younger people with learning disability.

**11.4.3** A film is being produced jointly with those with a learning disability to promote the importance of screening.

**11.4.4** Learning disability health facilitation teams are working with screening services to ensure the availability of reasonable adjustments and accessible information is promoted for all appointments. Teams are also ensuring flags are used appropriately to ensure people with a learning disability, autism or both receive the right support for appointments.



## 11.5 Action from learning: Local priorities for delivery in 2021/2022 based on the learning from reviews locally and nationally

**11.5.1** Sussex continues to increase the rates of annual health checks for people with learning disabilities, and the 'Thumb's Up' campaign supports the focus on quality reviews and subsequent health action plans.

**11.5.2** Working with wider Population health and Core 20 plus 5 systems to ensure system wide focus on the health inequalities experienced by people with a learning disability.

**11.5.3** Working with primary care medication optimisation teams on the principles of STOMP will be included in medication reviews and annual health checks.

**11.5.4** Continue the delivery of 'Stop Look Care' training to social care to ensure the tool becomes embedded; an evaluation will then follow. The booklet that accompanies the training will be revised to ensure learning from LeDeR is integrated, e.g. postural management and constipation.

**11.5.5** Evaluating the pilot for the dynamic support register for physical health and clear outcome pathways, including public health and social prescribing.

**11.5.6** Continued work with AHSN to embed RESTORE 2 mini, including in their 'deteriorating patient' safety work-stream including the development of training that is suitable for family, carers, PAs and those with a learning disability.

**11.5.7** Sussex will continue to look to develop innovative ways of delivering annual health checks for autistic people. Pilot health checks for autistic people and delivery through secondary care will be co-produced with autistic people.

**11.5.8** Sussex will continue to provide training and support to health and social care to ensure reasonable adjustments are understood and requested to improve access to universal services such as screening.

**11.5.9** Clear pathways will be developed across Sussex for people with learning disabilities who have respiratory needs requiring specialist care.

## 11.6 Action from learning: evaluating the impact

**11.6.1** Learning from LeDeR and subsequent action plans will be presented to the Sussex Learning Disabilities and Autism Board and LDA Health Inequalities Steering Group. This will ensure all parts of the system commit to understanding the needs of those with learning disabilities to improve access to good health care.

**11.6.2** The LeDeR Governance Group now routinely reports to the Sussex LDA Board and Shadow Board, which is a board made up of people with learning disabilities and autistic people. This group acts as the reference group for learning from LeDeR with biannual workshops to co-produce service improvements.

**11.6.3** The impact of Stop Look Care and Restore 2-mini will be evaluated jointly with partners in 2022/23 to be reported in the next annual report.

**11.6.4** People with a learning disability, autistic people, family carers and providers views will be sought to determine whether they have experienced improvement in the health care they received over the last two years.

# 12 Conclusion

**12.1** LeDeR in Sussex continues to play a pivotal role in both identifying and addressing the health inequalities experienced by people with a learning disability and through its expansion this year to include autistic people. This report highlights a range of good practice across Sussex. However, the continued reporting of premature deaths, shows the enduring need for the LeDeR Programme to support further development of good practice across Sussex as outlined within our LeDeR Health inequality strategy.

**12.2** We know that people with a learning disability and autistic people from minority ethnic communities face additional health inequalities. LeDeR in Sussex is committed to identifying and addressing these additional inequalities.

**12.3** It is pleasing to note the system-wide increased recognition and commitment to addressing the health inequalities experienced by people with learning disabilities and autistic people. This has enabled the development of strong links between the Learning Disability and Autism Health Inequalities Steering Group and Sussex population health and strategic health inequalities work.

**12.4** Meaningful involvement of people with learning disabilities, autistic people, and their families/ carers in service improvement continues to develop and strengthen, with strong links to the Sussex Learning Disability and Autism Shadow board, local self-advocacy groups and place-based Learning Disability Partnership boards and Autism Partnership boards.

**12.5** The national LeDeR policy has supported the change in focus from performance to sustained quality improvements with a number of deliverables achieved including the funding of a LeDeR review team and required updates to the governance processes.

**12.6** Despite the continued pressures experienced by individuals, families, services and systems by the Covid-19 pandemic, we are in a strong position entering the next reporting cycle, with a newly recruited LeDeR team and a co-produced plan for how best to support the changes to the programme, most notably with the inclusion of autistic people.

**12.7** Sussex also continues to be proud of, and indebted to, the participation of our families and experts by experience in the LeDeR programme