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22 January 2020

West Sussex Health and Wellbeing Board

A meeting of the committee will be held at **10.30 am** on **Thursday, 30 January 2020** at **Garden Room, Southwick Community Centre, 24 Southwick Street, BN42 4TE**.

Tony Kershaw
Director of Law and Assurance

Agenda

10.30 am 1. **Chairman's Welcome**

10.35 am 2. **Declaration of Interests**

Members and officers must declare any pecuniary or personal interest in any business on the agenda. They should also make declarations at any stage such an interest becomes apparent during the meeting. Consideration should be given to leaving the meeting if the nature of the interest warrants it; if in doubt contact Democratic Services before the meeting.

10.40 am 3. **Urgent Matters**

Items not on the agenda that the Chairman of the Board is of the opinion should be considered as a matter of urgency by reason of special circumstances.

10.45 am 4. **Minutes** (Pages 5 - 16)

The Board is asked to confirm the minutes of the meeting of the Health and Wellbeing Board held on 10 October 2019.

10.50 am 5. **Public Forum**

The Board invites questions and comments from the public observers present at the meeting. Those with more complex issues are asked to submit their question before the meeting (ideally several days) in order to allow a substantive answer to be given. Contact Erica Keegan on Telephone: 0330 222 6050 (a local call) or via email: erica.keegan@westsussex.gov.uk

11.05 am 6. **Health and Wellbeing in Adur and Worthing** (Pages 17 - 50)

A presentation will be given by Adur & Worthing Borough Council on the work this Council has been doing with respect to health issues relevant to the residents in Adur and Worthing.

The Health and Wellbeing Board is asked to:

1) hear and acknowledge the work that has been done, especially around Find it Out Plus; and
2) consider how this way of place-based working can be supported to grow and embedded across West Sussex to support Starting Well and a Children First approach.

STARTING WELL

11.50 am 7. **Children First Improvement - Review of Commissioner's Report and Service Update** (Pages 51 - 60)

This paper explains the response to the Ofsted 'Inadequate' judgement of West Sussex Children's Services in May 2019, and the subsequent appointment of a Commissioner to make recommendations as to whether the service should remain under the County Council's control.

The Health and Wellbeing Board is asked to:

1) note the Commissioner's recommendations (Section 1), and the actions already undertaken as part of a continuing improvement narrative (sections 2 & 3);
2) note the next steps in the improvement journey (Section 4); and
3) Continue to support the County Council through the partnership in enacting the necessary changes.

12.05 pm 8. **Child and Adolescent Mental Health Services (CAMHS)** (Pages 61 - 82)

This paper provides an update on Children's Emotional Wellbeing and Mental Health.

The Health and Wellbeing Board is asked to:

1) note the plans for presentation of the Sussex wide review of children's emotional wellbeing and mental health; and
2) note that the Local Transformation Plan for West Sussex has been assured by NHS England and the Making Progress summary as circulated.

12.20 pm 9. **Healthwatch Youth Pack** (Pages 83 - 94)

This presentation concerns overview of the new Youth Pack resource which will be made available to all stakeholders later in the Spring.

The Health and Wellbeing Board is asked to promote awareness and endorse use of the Youth Pack to facilitate engagement with young people in ways that are meaningful for them, to test new ideas and evaluation services at an early stage of planning.

LIVING AND WORKING WELL

1.00 pm 10. **Community Based Models of Access to Health Services** (Pages 95 - 100)

This paper concerns the award of Public Health England grant monies, to test community based models of access to health services.
In West Sussex, the grant will fund a twelve month project - the Hospital Admission Reduction Pathway (HARP). This will improve access to health services for adults with co-occurring substance misuse and mental health needs who are experiencing or at risk of returning to rough sleeping.

The Health and Wellbeing Board is asked to:

1) acknowledge background and work to date;
2) provide strategic leadership and governance of the twelve month project; and
3) receive regular updates through the life of the project and consider learning from its implementation and delivery.

AGEING WELL

1.15 pm 11. **West Sussex Joint Dementia Strategy 2020-2023** (Pages 101 - 186)

This paper concerns the refresh of the Dementia Framework 2014-19 and development of the new Joint Dementia Strategy 2020-23.

The Health and Wellbeing Board is asked to:

1) review the draft West Sussex Joint Dementia Strategy 2020-23 and support its launch in the spring;
2) provide ongoing oversight, of progress against the strategy; and
3) champion the new Dementia Strategy and the need for additional investment to maximise the preventative value of supporting those living with dementia to remain as independent as possible.

1.30 pm 12. **West Sussex Better Care Fund** (Pages 187 - 196)

This paper provides a summary of the funding sources and expenditure plan for the West Sussex Better Care Fund in 2019/20 along with the regular monitoring of performance against the 4 national metrics for Quarters 1 and 2, 2019/20.

The Health and Wellbeing Board is asked to:

1) note the West Sussex Better Care Fund funding sources and expenditure plan;
2) note the West Sussex performance against the national metrics at Q2 2019/20; and
3) note the 2019/20 schedule for quarterly returns.

1.35 pm 13. **Date of Next Meeting**

The next meeting of the Board will be held at 10.30am on 30 April 2020, at a venue to be confirmed.

To all members of the West Sussex Health and Wellbeing Board

West Sussex Health and Wellbeing Board

10 October 2019 – At a meeting of the West Sussex Health and Wellbeing Board held at 10.00 am at Horsham District Council, Goodwood Room, County Hall North, Parkside, Chart Way, Horsham, RH12 1XH.

Present: Mrs Jupp (Chairman)

Mr Marshall	Natalie Brahma-Pearl	Nik Demetriades
Kim Curry	Laura Hill	Mr Turner
Anna Raleigh	Katrina Broadhill	Annie Callanan
Alex Bailey	Pennie Ford	Chris Clark
Nigel Lynn	Helen Rice	Debra Balfour

Apologies were received from Gill Galliano

Part I

24. Chairman's Welcome

24.1 In welcoming Board Members, Officers, Members of the public and the Press to the meeting, the Chairman made the following announcements:

24.2 Committee Membership – The Board noted that Dominic wright, NHS Coastal West Sussex Clinical Commissioning Group, was leaving his role on 30 September and would, therefore, step down from the Board. The Chairman and Board Members passed on their thanks for his service, over many years and wished him success in his future endeavours.

Philippa Thompson, Sussex Oakleaf, was also reported as stepping down as Board Member. The Board thanked Philippa for her continued support representing the voluntary sector and wished her well for the future.

Frances Russell and Katrina Broadhill, Healthwatch, were stepping down as Healthwatch's representatives. The Chairman and the Board thanked them both for their contribution to the Health and Wellbeing Board particularly recognising their support in partnership working. It was announced that as of the next meeting of the Health and Wellbeing Board, Sally Dartnell**,** HealthWatch West Sussex, Chief Officer would join the Board.

The Board noted and welcomed newly appointed representatives from the Voluntary Sector, Helen Rice (Age UK) and Nik Demetriades (4Sight) who had sat on the board as a substitute member in the past. Pennie Ford, Sussex Health & Care Partnership, was also welcomed as a new Member of the Board representing West Sussex CCGs and Chris Clark was welcomed

as a Board Member due to his new role as West Sussex County Council's Joint Strategic Director of Commissioning.

24.3 The Chairman announced that following the Health and Wellbeing Board's Seminar held on 29 July the Voluntary Community Sector Consortium (VCS) and the Voluntary & Community Sector Infrastructure Services (VCSI) Alliance members would shortly receive a letter from Catherine Galvin, Head of Commissioning at West Sussex County Council, outlining proposals on a co-production approach to commissioning with the Voluntary Sector. This would initially focus on a 'learning by doing' basis with preventative social support.

24.4 The Chairman was pleased to highlight the successes of capital and revenue bids to Public Health England over the last four years to support substance misuse service priorities in West Sussex. In total and from 2015, this had secured just over £1.5m capital monies and £425k revenue.

24.5 In completing her welcome the Chairman took the opportunity to remind Board members that the Collaborative Working Agreement Conference would take place on Thursday, 24 October, in Horsham. This would be the official launch of the CWA between the four boards (West Sussex Health and Wellbeing Board, West Sussex Safeguarding Children Partnership, West Sussex Safeguarding Adults Board and Safer West Sussex Partnership). The Chairman encouraged all Board Members to attend.

25. Declaration of Interests

25.1 There were no Declarations of Interest.

26. Urgent Matters

26.1 There were no Urgent Matters to consider.

27. Minutes

27.1 Resolved that the minutes of the Health and Wellbeing Board held on 20 June 2019 were agreed and signed as a correct record by the Chairman.

28. Public Forum

28.1 There were no questions.

29. Health and Wellbeing in Horsham

29.1 A presentation on Health and Wellbeing in Horsham was given by Horsham District Council's Health & Wellbeing, Community Safety Manager and Head of Housing and Community Services. This provided an overview of the health and well-being issues and key priorities that were relevant to residents in Horsham. (Presentation tabled at the meeting and available on the website).

29.2 Board Members were informed that as part of Horsham District Council's Corporate Plan 2019-2023 a Strong, Safe and Healthy Community was cited as a key priority. The district's key demographic facts were provided and these included:

- there was a population of 141,100K (2017)
- the area had an ageing population 22% of residents are over 65 years of age, higher than the England and West Sussex average
- Life expectancy was noted as 84.6 (Women) and 82.1 years (Men)
- The area had one of the lowest teenage conception rates in England.
- There was a workforce of 67,300k (economically active)
- An entrepreneurial district – the second highest business start-up rate in the County with 72% of businesses rurally based.
- The prevalence of underweight, healthy weight and overweight and obese children in Horsham was noted as better than the rates in West Sussex, which was better than in England.
- Horsham District was noted as having the highest rate of unpaid carers who provided 50 hours or more care in West Sussex.
- In terms of family the district had one of the lowest rates of children living in relative poverty at 9.1%. The number of lone parents in the region was joint lowest in West Sussex at 4.6% of families against a West Sussex figure of 5.4%.
- The District had the lowest rate of mental health admissions for 0-16 year olds in West Sussex, in the last recorded year.
- It was pointed out that the majority of Horsham District had the least deprived area of England (10%) when looking at crime and deprivation, health deprivation and disability but the number of households accepted as homeless and in priority need was above the national average.

29.3 It was recognised that although Horsham District was a great place to live and work it also had key health challenges. These included; health inequalities; an Ageing population; loneliness and isolation and a high number of carers; alcohol related hospital admission remained a concern as did the numbers of smokers and 62% of adults were noted as obese or overweight. 7.6% of homes were classed as fuel poor.

29.4 A key health challenge highlighted was the amount of emergency hospital admissions for hip fractures amongst those aged 80 plus. In 2016/17 West Sussex had 946 emergency hospital admissions for hip fractures amongst those aged 80 plus. Horsham District Council had linked to the West Sussex Falls and Fracture Prevention Service which were noted as having a team based in Horsham.

29.5 In order to tackle some of the challenges and plan for the future, Board Members heard that Horsham District Council was expanding their falls prevention programmes, helping to deliver NHS Health Checks and Stop Smoking by working alongside GPs and Pharmacies and targeting areas of deprivation to improve contact rates.

29.6 Board Members were informed that Horsham District Council had, for the last 20 years, placed a strong emphasis on working in collaboration with other service providers but for the last two years there had been a

noticeable reduction in the interest and engagement from several key organisations. In terms of their future planning it had been recognised that there remains compelling evidence that partnership working is more critical now than ever, given reducing budgets. As a result, Horsham District Council was adopting a new Safe and Well Partnership This would aim to:

- Identify the current major issues and concerns that will benefit from collective intervention.
- Engage and empower partners and communities to take action through time limited task and finish groups.
- Evaluate and publicise outcomes to inform future responses to issues and concerns.
- Influence local environments through planning and provide quality, affordable housing
- Aid healthy ageing especially from mid-life
- Tackle inequalities in areas of pronounced deprivation, targeting vulnerable groups.

29.8 In receiving the presentation the Board:

- agreed that smarter ways of working together, producing creative responses involving a wider range of stakeholders and crucially doing a better job of evaluating outcomes to determine what works was key;
- highlighted that the provision of quality, affordable housing for a positive home environment can positively affect the wellbeing of the population;
- welcomed outreach work important to those vulnerable groups such as the elderly to combat social isolation and loneliness;
- praised the Horsham District Council's work around homelessness and identified that the Board could assist with partnership working between the CCGs and District and Boroughs and other partners on this issue. For example, providing access to a GP;
- discussed that trips and falls in the region could be more serious as rural communities had to sometimes wait longer for ambulance assistance. The Council was setting up a Community Link Service so that community volunteers could be a first responder to offer a speedy and vital 'pick up' service. The use of technology was also discussed as a way of assisting with trips and falls;
- Recognised that access to Mental Health Services was a key issue across West Sussex with increasing demand impacting on capacity. The Director of Public Health stated that the Board would be requested to provide input on a new Mental Health Trust Strategy, and this was welcomed;
- explained how the new West Sussex County Council role of, Joint Strategic Director of Commissioning would help to build strong partnerships with the local NHS and provide oversight on how health services are delivered within the County.

29.7 The Chairman thanked the Horsham District Council's Health & Wellbeing, Community Safety Manager and Head of Housing and Community Services for their informative presentation.

29.8 The Board then Resolved that;

1) the presentation be noted;
2) commented and asked questions on the information received; and
3) provided feedback on how the Board and Local Health and Wellbeing Partnerships could support the Health Priorities in Horsham.

30. Children First Strategy Development

30.1 In the absence of the Director of Children's Services the Assistant Director, Early Help, Children's Services presented the report on the Children First Strategy Development. The Children First Strategy was noted as a multi-agency Strategy sponsored by the Director of Public Health, the Director of Education and the Director of Children's Services. The report provided an update on the process of co-production and consultation to date.

30.2 Board Members were referred to Section 2.6 of the report and asked to provide a response to the questions listed as follows:

- What would be different if Children and Families came first in West Sussex across our organisations? Do you think they already come first?
- Where are the opportunities to work better together for children and families and their carers?
- What are the barriers and how can we overcome them?
- Why do you think previous strategies haven't worked in the ways we hoped?
- What can you/your organisation bring to this agenda? What can you commit?

30.3 In discussing the questions raised the Board recognised the importance of hearing the voice of children in order to provide a considered and appropriate strategic response to provide services that meet need. It was agreed that the Voices of Children had to be the central focus moving forward. The Board responded as follows:

- Joint ownership to put children first was agreed as the aspiration and intent.
- Healthwatch had been listening to the voice of the children and would be supplying a report that would be made available within the next two weeks. The Board agreed that the partner organisations had to get better at listening to children.
- Good placed based prevention activity was cited as key and Board Members were keen to use the local knowledge and influence of the District and Boroughs. Localised plans with the focus on actions and implementation were preferred to avoid a 'one size fits all' approach.
- Members were keen not to look at barriers but focus on an asset based approach, defining what 'good' should look like.
- It was recognised that all partners needed to change and adapt behaviours so Children First is seen as one piece of work across the County whilst still being place based. This was seen as both a financial (pooling resources) and strategic issue (ceasing duplication of work). It was agreed that younger people needed to be involved in the process and suggestions were

made on who the Partnership Steering Group could engage with. It was suggested that contact was made with the young/youth leaders such as Youth Mayor, Voice of Looked after Children Council, Youth Cabinet, Scout Association, Guiding Association Leaders.

- Members agreed that Housing, Environment and Education was vital to a child's security and development.
- It was recognised that in West Sussex it was easy to be drawn into needs around an Ageing Population but the Health and Wellbeing Board's Strategy also championed the Start Well agenda.

30.4 In summing up, the Board agreed that children needed to share the balance of power and ways of engaging the wider audience of children needed to be addressed. The Chairman noted that the Partnership Steering Group needed invites to the youth/young and perhaps other partners such as Headteachers from schools/colleges. The Chairman also asked that consideration be given to the timing of the meetings so children could attend if they wished to do so.

30.5 The Board Resolved that;

1) the strategic leads, to include those suggested by the Board, from each organisation to be involved in a monthly partner steering group between October and April at Appendix 1 be agreed; and
2) it had considered and responded to the questions for discussion in 2.6.

(Nigel Lynn, Natalie Brahma-Pearl and Alex Bailey left the meeting, with apologies, at 11.30am)

31. Re-invigorating a strategic approach to healthy weight for children in West Sussex

31.1 The Chairman introduced the West Sussex County Council Start Well Public Health Consultant who presented the report on, 'Reinvigorating a strategic approach to healthy weight for children in West Sussex', that set out proposals for the Health and Wellbeing Board to take an active role in supporting a new strategic, whole systems approach to tackling childhood overweight and obesity in West Sussex.

31.2 The Board was informed that the Public Health Board had recently endorsed a paper outlining a new, strategic approach to children's healthy weight in West Sussex, beginning with the launch of a Healthy Weight Steering Group in January 2020. Districts and boroughs were being asked to do the same through the Chief Executives' Group. The Health and Wellbeing Board, as a wider strategic grouping of the key partners involved in influencing this agenda, was noted as a key to the success of this new approach and was now being asked to do the same.

31.3 It was explained that West Sussex compares favourably with national averages for childhood obesity although there were notable variations within the County. It was noted that crucially, weight was closely linked to emotional health and wellbeing, a key priority of the 'Starting Well' section of the West Sussex Joint Health and Wellbeing Strategy 2019-24.

31.4 The Board noted the report and provided feedback on ways in which the Health and Wellbeing Board could support. In discussion the Board:

- noted that West Sussex had average statistics for childhood obesity but acknowledged the importance of tackling childhood obesity and the need to support the whole systems approach;
- stated that the whole systems approach should start with hearing the voice of the children;
- pointed out that it was important to involve Housing as deprivation/temporary accommodation could mean no access to cooking facilities for fresh food;
- suggested that public health teams build on their work with influencing organisations such as takeaways, supermarkets, hospitals, children & family centres and schools to make healthier options more accessible so that individuals were given opportunities to make healthier choices;
- welcomed the 'quick wins' with the use of existing schemes such as Park Run and the Daily Mile in schools to promote exercise;
- agreed that Community Based projects such as the Community Fridge Project (supplying fresh food to those in need) and Community Kitchen (teaching cookery skills) were good initiatives that could be utilised and expanded upon as an asset;
- pointed out that consideration should be given to pre-teens and teenagers as a group when tackling child obesity;
- felt that there was a need to expand upon the Family Wellbeing Programme so that it was offered across the County and not just in two areas;
- emphasised the need for systems leaders to challenge within their own organisations, for example healthy lunch options served during County Council meetings;
- focus on the benefits of a healthy weight and do not 'fat shame'.

31.5 In summing up, Board Members agreed that this topic should be revisited by the Health and Wellbeing Board to monitor and support progress.

31.6 The Health and Wellbeing Board resolved that;

1) the importance of this topic in West Sussex be acknowledged and the new strategic, whole systems approach being outlined be endorsed; and
2) feedback on ways in which the Health and Wellbeing Board will support this agenda to be provided, including identification of key leads to join the new Healthy Weight Steering Group and the place based subgroups to drive this agenda forward; agreement of governance arrangements; commitment to taking appropriate actions within members' own organisations to influence the wider environment in relation to access to healthy food and opportunities for physical activity and active travel.

32. Children and Young People's Emotional Wellbeing and Mental Health

32.1 The Board received a report and presentation on Children and Young People's Emotional Wellbeing and Mental Health (CAMHS) presented by the Principal Manager, Children and Families. The report provided an overview of the West Sussex Local Transformation Plan (LTP) for Children and Young People's Emotional Wellbeing and Mental Health Services Refresh and the Sussex Wide

Review of Emotional Health and Wellbeing Support for Children and Young People (CYP).

32.2 The following key points were outlined:

- Children and young people's emotional wellbeing and mental health was recognised as a key local and national priority. Data indicated that there are greater numbers of children and young people seeking support with their emotional wellbeing and mental health and there are many and varied drivers for this increase.
- The West Sussex LTP outlines an integrated, multi-agency system-wide approach which builds resilience, improves access to services and supports Children and Young People along pathways of care whatever their needs.
- Much had been achieved since 2015 – as described in the current LTP and Making Progress, Making a Difference (September 2019). It was noted that the refresh would focus on progress of the plan, and next steps with the deadline of 31 October 2019.
- Particular groups of children were identified as a risk for poor emotional wellbeing and mental health. Examples included children that lived in areas of deprivation/poverty, were in care or had parents who had alcohol or substance misuse problems.
- Board Members were informed that going forward, by 2023/24 an additional 345,000k children and young people 0-25 would access mental health support; The LTP would aim to; continue to achieve the access targets for eating disorder services; ensure children experiencing a mental health crisis receive the response they need through mental health liaison teams in acute hospitals and a 24/7 response via NHS 111 with a robust community follow up support; embedding mental health support in schools through the roll out of Trailblazers; adopting an integrated approach across health and care, education and the voluntary sector to develop a model of care for 0-25 year olds; and improve the response to Learning Disability and autism.

32.3 Board Members noted the information provided about the review. In commenting on the presentation, the Board:

- reported that although children may be seen quickly initially there was significant delay between the first appointment and access to care;
- stated that support in schools needed to be robust, enhancing provision whilst avoiding duplication of service;
- emphasised the need to have more support in Junior Schools to aim provision at an earlier life stage;
- agreed it was important to use a whole systems approach and avoid silo working and look at how services interact to ensure effective access to relevant support.

32.4 The Health and Wellbeing Board Resolved that the Local Transformation Plan Refresh as of October 2019, be agreed.

33. West Sussex Age Healthy Communications Campaign

33.1 The West Sussex Acting Consultant in Public Health (Ageing Well) presented the report on the West Sussex Age Healthy Communications Campaign. Ageing Well was noted as one of the three components of the West Sussex Joint Health and Wellbeing Strategy 2019-24. It was stated that overall, older people in the county were relatively healthy, contributing to the life of their communities and find West Sussex a great place to live. However, with age there was an increased likelihood of living with one or more long term health conditions and / or sensory impairment. It was reported that older people have increased risk of dementia, and large numbers of older people suffer from depression. It was also noted that older people had an increased risk of falls and were vulnerable to social isolation and/or loneliness. All of these could result in a reduced quality of life and increased use of health and care services.

33.3 It was reported that at the launch of the West Sussex Joint Health and Wellbeing Strategy 2019-24, delivery of a healthy ageing campaign was agreed as a priority action for 2019/20. Board Members were informed that the West Sussex Public Health team, working with partners, had led on developing a six month campaign which was launched on 1 October 2019. The campaign adopted a different theme each month: October – introduction; November – the home and neighbourhood environment; December – social connections; January – finance; February – mental health; March – physical health. Campaign activity included a survey on older people's views on ageing in West Sussex, a dedicated campaign page, monthly newsletter, and social marketing campaign.

33.4 Board Members were shown the dedicated West Sussex County Council webpage that focused on the Age Healthy Campaign providing signposting, resources, prevention support and case studies. In viewing this page, the Chairman requested that photo content accurately reflect positive ageing with images detailing activities such as dancing and climbing. Board Members agreed that the language used also needed to be positive and not use words such as 'frail'.

33.5 Key partnership working opportunities were identified and it was noted that the Ageing Well theme was included in the NHS Long Term Plan. It was noted that Age UK could support this work with their FALLS hazard free toolkit, loneliness research and corporate sponsorship opportunities. This campaign could also align with the work of 4Sight.

33.6 The Health and Wellbeing Board resolved that;

1) the delivery of a 6 month Healthy Age campaign commencing on 1st October 2019 be noted; and
2) the delivery of the campaign via the Health and Wellbeing Board member organisations be supported.

34. West Sussex Health Protection Annual Report 2018/2019

34.1 The Health and Wellbeing Board was invited to consider the West Sussex Health Protection Annual Report 2018-2019 and the subsequent recommendations made, providing any comment to the Director of Public Health (DPH) prior to its publication.

34.2 It was outlined that West Sussex County Council holds key statutory health protection responsibilities. To ensure robust delivery of these statutory responsibilities, the Director of Public Health chaired a multi-agency West Sussex Health Protection Committee bringing together organisations across the county that contribute to protecting the health of the West Sussex population. The group produces an Annual Report to provide assurance that all parts of the system are working together effectively towards various targets and outcomes.

34.3 It was reported that the West Sussex Health Protection Annual Report 2018/2019, detailed the West Sussex data, and activities carried out by the Council and partner organisations during the period 1 April 2018 to 31 March 2019.

34.4 In receiving the report the Board noted the key priorities and challenges. Challenges included flu prevention, TB, immunisations including MMR, national rise in Scarlet Fever. It was suggested that flu vaccination should be taken into Care Homes and residential settings to increase immunisation rates.

34.5 The Health and Wellbeing Board Resolved that the West Sussex Health Protection Annual Report 2018-2019 be agreed.

35. Healthwatch West Sussex Annual Report 2018-19 and Work Plan for 2019-20

35.1 The Healthwatch Service Manager presented the local Healthwatch Annual Report 2018/19 and the Work Plan going forward 2019/20, based on this year's agreed priorities, to the Board. The Board was asked to note these documents and have awareness of the focus that Healthwatch West Sussex would have over the remainder of this financial year.

35.2 It was explained that the insight given by local people to Healthwatch West Sussex, should be viewed as complementary to other evidence. The Board and other stakeholders could consider the insight as indicators of how and where things might be done differently. The insight provided through the Work Plan offered a positive opportunity to hear, understand and respond to the public voice.

35.3 In receiving the Annual Report and Work Plan the Board commended Healthwatch's valued and constructive challenge and looked forward to continuing partnership work with Healthwatch West Sussex.

36. ICS/STP Place Based Plan

36.1 The Board received the West Sussex Response to the NHS Long-Term Plan, delivering the Joint Health and Wellbeing Vision for the County's Population. In receiving this report, the Board noted that Sustainability and Transformation Partnerships (STPs)/Integrated Care Systems (ICSs) were required to create their five-year strategic plans by November 2019 covering the period 2019/20 to 2023/24. In West Sussex, partners had agreed to co-produce a joint response plan between West Sussex County Council and Coastal West Sussex, Horsham and mid-Sussex and Crawley CCGs.

36.2 It was reported that the West Sussex plan is being developed following an extensive period of public and stakeholder engagement and would be the agreed delivery plan to achieve the Joint 2019-2030 Health and Wellbeing Vision for the County, as well as delivering a local response to the STP clinical priorities and the objectives of the NHS Long-Term Plan. In particular, the West Sussex plan would seek to address the health inequalities identified within the local population.

36.3 Attention was drawn to the joint approach across West Sussex with work in progress. It was recognised that more work would be required. Medical Directors, Public Health Directors and Clinical leads were ensuring local plans were being co-designed and co-supported.

36.4 It was agreed that the Health and Wellbeing Board would have an important role in overseeing this plan and its implementation. As such the Chairman announced that a Health and Wellbeing Board Seminar would be held on the subject during November 2019.

36.5 The Board Resolved that the importance of this plan for West Sussex be acknowledged and endorsed the new strategic whole systems approach.

37. Winter Planning to support the health and care system

37.1 The Board was provided with an update regarding the plans across West Sussex to manage demand in health and social care over the winter period.

37.2 It was reported that each year the health and social care systems across West Sussex undertake reviews of winter to understand lessons learnt to enhance future planning. These lessons had been incorporated into the plans for winter 2019/20 as follows:

- Support from other local health and social care systems in response to pressure in the local system.
- Maintenance of patient safety in A&E during periods of sustained demand pressure.
- Ability of system partners to rapidly support additional capacity in response to system pressure.
- Single winter communications plan across West Sussex and East Surrey aligned to the national NHS campaign.

- Development of discharge to assess pathways across health and social care to ensure people do not wait in acute hospitals when they can be supported at home.
- More live feeds are required into the real time data system Single Health Resilience Warning Database (SHREWD) including mental health and 136 capacity. The database provides up to date information about demand allowing the system to react in a timelier manner to surges in demand.
- Renewed focus on stranded/ super stranded patients to manage patient flow.
- There are high levels of minors attending A&E. System wide collaboration was noted as underway to deliver Integrated Urgent Care model (IUC) including Urgent Treatment Centres (UTC) roll out from December 2019.
- West Sussex wide system capacity and demand planning for this winter has built further upon the successful planning model that use for last winter ensuring that mitigation actions are in place for forecast surges in demand over winter.

37.3 The Health and Wellbeing Board Resolved that the plans in place for the health and social care systems across West Sussex, be noted.

38. Date of next Meeting

38.1 The next meeting of the Board will be held on 30 January 2020 in Adur.

(The meeting closed at 1.35PM)

Chairman

Date of meeting:	30th January 2020
Item Title:	Starting Well and Children First in Adur and Worthing: Young people, wellbeing and mental health
Executive Summary:	This report sets out some of the background work that has been carried out in Adur and Worthing by leaders in the system around the Starting Well and the Children First agenda. It sets out some connected issues around a 'thrive' agenda in relation to wellbeing and mental health and is premised around the need for a place-based approach, in order to bring about the change needed for young people.
Recommendations for the Board:	To hear and acknowledge the work that has been done, especially around Find it Out Plus. Consider how this way of place-based working can be supported to grow and embedded across West Sussex to support Starting Well and a Children First approach.
Relevance to Joint Health and Wellbeing Strategy:	Starting Well, young people. Mental health and emotional wellbeing Children First Approach.
Financial implications (if any):	Finances to support this work are in place for the pilot period There will be financial implications to ensure the continuation of this service but the HWB is not being asked to consider these at this point
Consultation (undertaken or planned):	Consultation has been carried out with approximately 1,200 young people, as set out in the presentation and further work is planned. Young people's boards are being established alongside the Find it Out Plus work.
Item author and contact details:	Tina Favier Head of Wellbeing Adur and Worthing Councils

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Starting Well and Children First: Young people, wellbeing and mental health

West Sussex Health and Wellbeing Board

Tina Favier, Dr Rick Fraser, Aaron Gain

Adur and Worthing
30th January 2020

What we know

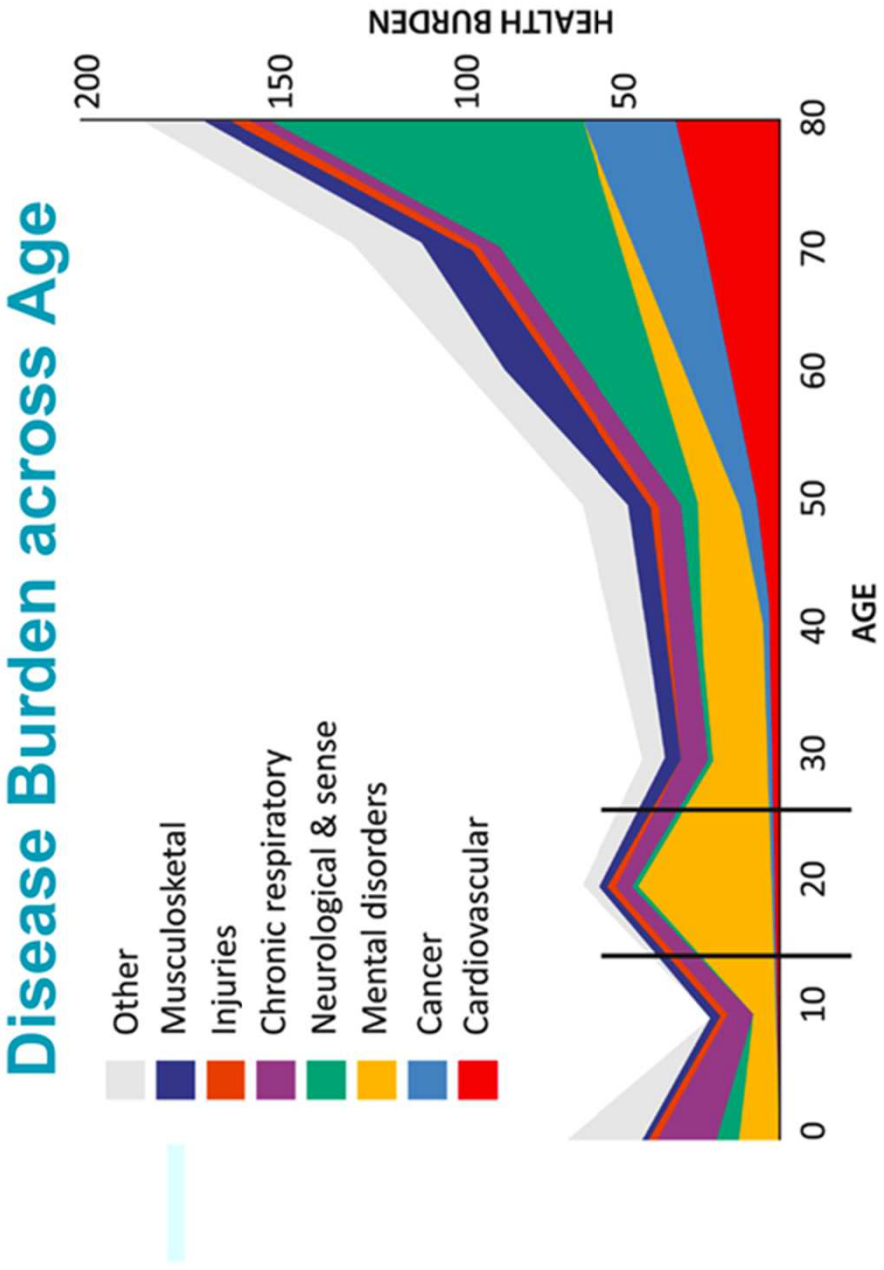
1 in 4 young people between 15-24 will experience a mental disorder in any 12 month period

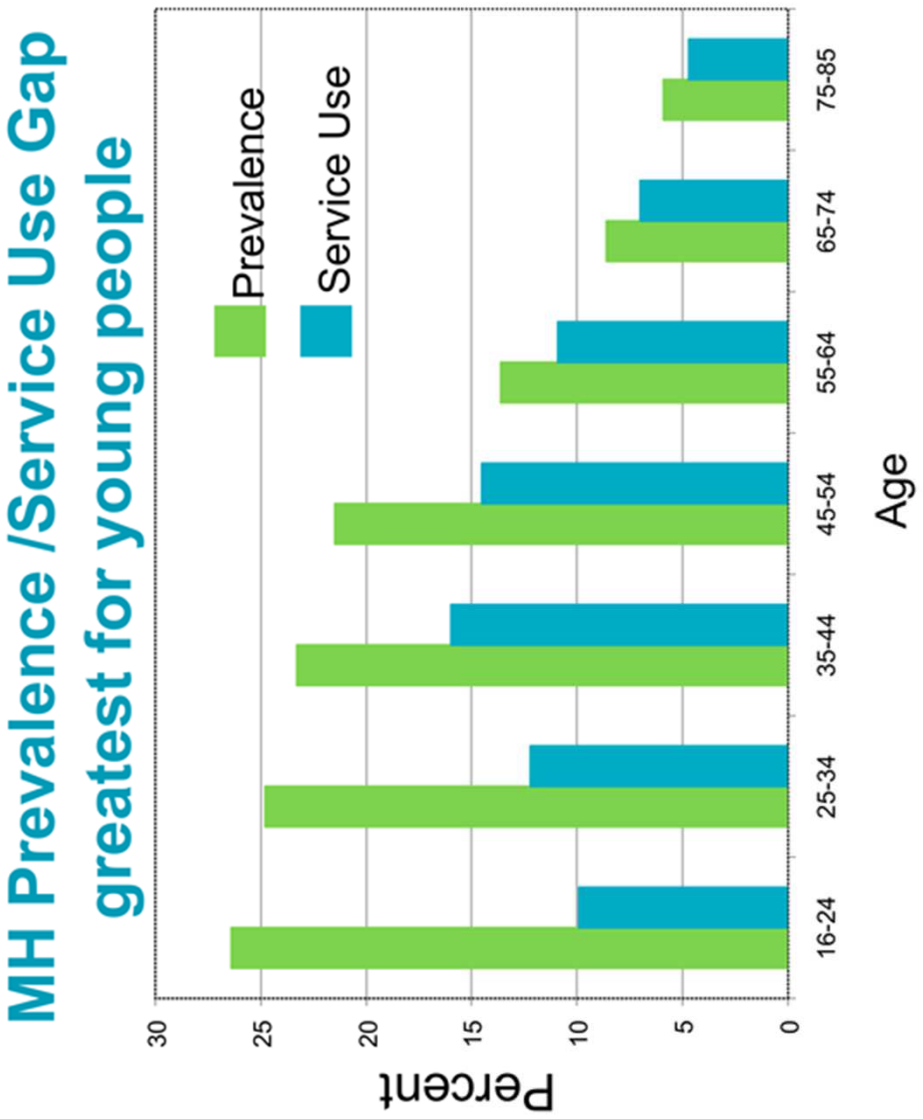
15 - 24 years old is the peak period for the onset of mental disorders (75%)

Pathways for young people to access health resources are limited as use of standard GPs is under-represented in this age group

Negative impact on longer term vocational pathways and economic participation

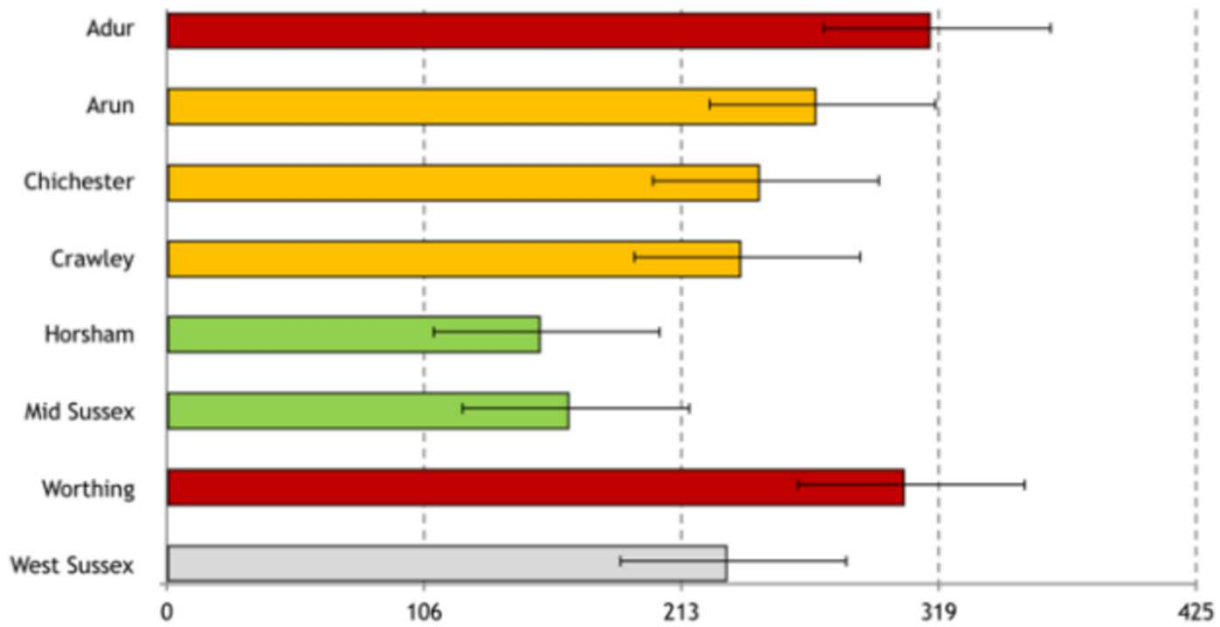
(Birchwood, Singh & McGorry, 2013) stem4


Disease Burden across Age
Other
Musculosketal
Injuries
Chronic respiratory
Neurological & sense
Mental disorders
Cancer
Cardiovascular
HEALTH BURDEN
200
150
100
50
0
10
20
30
40
50
60
70
80
AGE


MH Prevalence /Service Use Gap greatest for young people
Prevalence
Service Use
Percent
30
25
20
15
10
5
0
16-24
25-34
35-44
45-54
55-64
65-74
75-85
Age

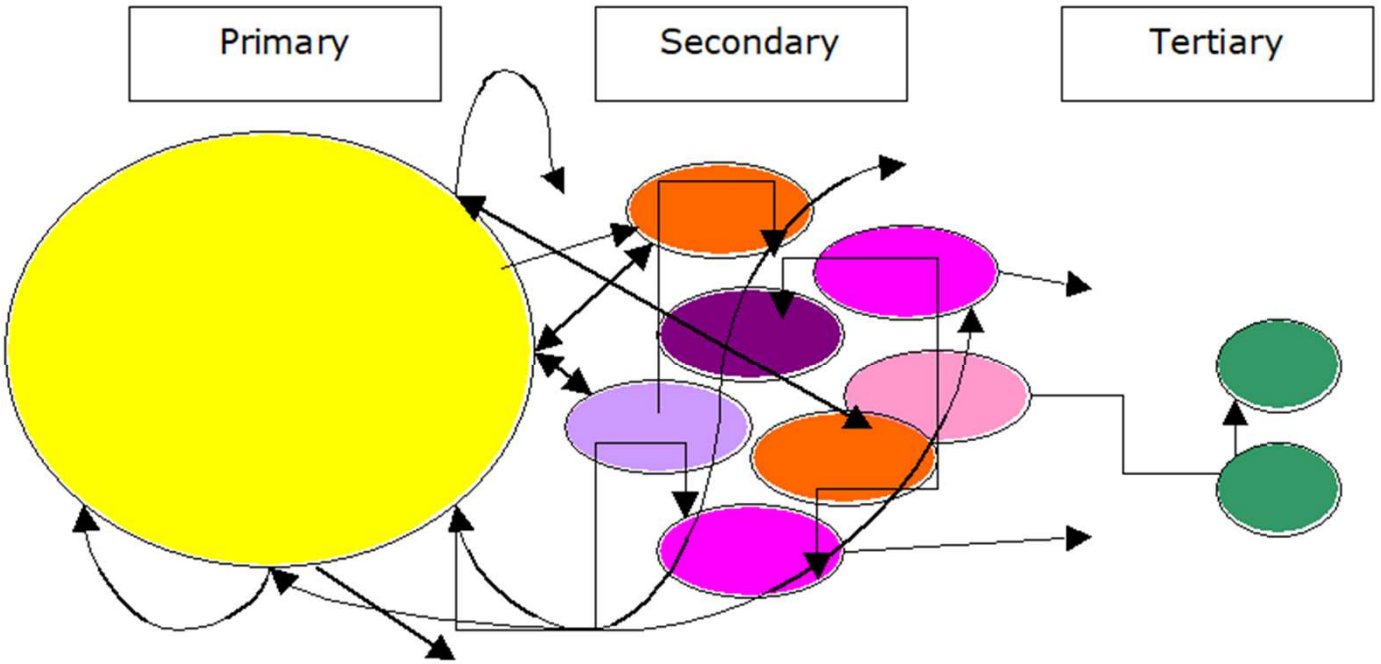
Self harm data

Figure 1: Emergency hospital admissions (First FCEs) for self-harm in 2014/15: directly age standardised rate (per 100,000 population



Source: PHOF 2014/15. Colours relate to comparisons with West Sussex. Red = significantly higher, amber = no difference, green = significantly lower.

Current MH system for YP




Exploring community-based approaches to good mental health for Young People
Adur and Worthing Local Community Networks

Current context

ACTIVITY

Hearing about the current context from different perspectives. Panel sharing their points of view about: How does it feel right now for CYP and promoting good MH? What is the biggest challenge? What is the biggest opportunity?

Challenges

The main challenges identified are:

- not enough support for YP
- difficult to access support
- not joined up working
- not enough support for YP during transitions

Opportunities

The main opportunities identified are:

- equip friends and family to support YP
- improve access to support
- joined up working
- meaningful partnerships to explore issues and ideas
- timely interventions

Current context - Shoreham Academy

Challenges

Some young people are slipping through the net. A young boy in YR8, who was fine before, has been known to be 'groomed', involved in drugs,... a difficult situation for him and his family. Vulnerable YP coming into the school should be able to access support. We know what the issues are, we need to talk more about them, share them and then decide what we can do. YP are not having enough experiences.

Opportunities

What if...

- we join things up to find solutions to complex situations (including families)?
- we work with families?
- we focus in early identification to allow early intervention?
- every YP (especially vulnerable)can access support coming into school?
- YP had access to more experiences?

Current context - GP

Challenges

There's a tendency to overmedicalise and often YP are in crisis once present at GP. When refferring to services, we are aware of delays, and the anxiety and isolation that comes with it is an issue.

YP may not be 'severe' enough to access CAMHS but they still need help. There is a gap in service because they 'don't fit' into current services.

Lack of time in consultations and lack of joined up triage.

Opportunities

What if...

- families get the support they need
- we look at wider determinants of health
- to overcome the challenge of GPs lack of time in consultation, know who to contact who has skills to support YP and family
- there is a joined up triage

Shared ambition - Design Principles

ACTIVITY

Exploring our shared ambition and principles

- **Our shared ambition** - Success is (e.g. reducing the stigma around mental health)
- **Our shared principles** - Enable young people to (e.g. feel confident to talk about their experiences)

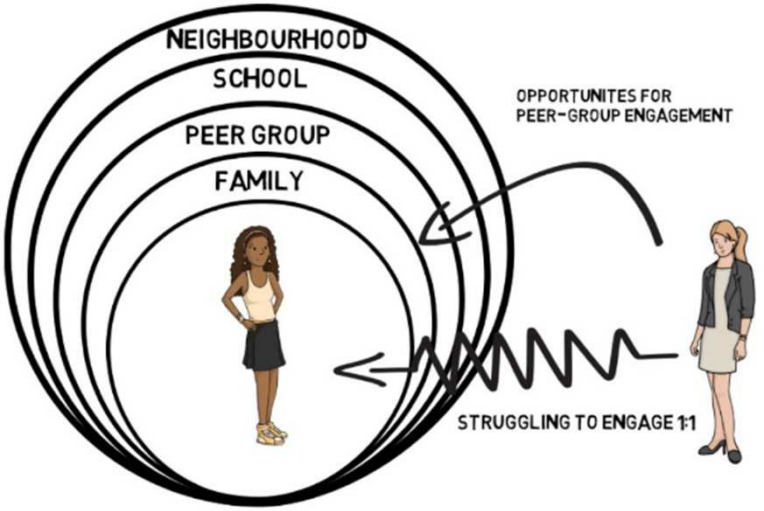
- **EARLY INTERVENTION:** Early help and timely - looking at the whole life and involve families
- **A CLEAR SYSTEM FOR EVERYONE:** Clarity for non-health professionals about the 'system' so referral is appropriate and measured.
- **CULTURE CHANGE:** Create a culture of 'doing with' (families, young people) not 'doing to'
- **INTEGRATED WORKING:** Integrated working across the whole system
- **LEADERSHIP** that promotes the right service, at the right time, in the right place
- **GOOD RELATIONSHIPS:** Every child has a significant adult / somebody to talk to
- **PERSONALISATION:** Person centred approach
- **POSITIVE LANGUAGE:** emotional wellbeing less scary for CYP than mental health.
- **BUILDING RESILIENCE IN CYP**

In the BBCs Loneliness experiment
involving 55.000 people
1
16-24 year olds are reported to be the most lonely in the cohort.

Contextual safeguarding issues

Young people's experiences of significant harm are driven by different relationships formed in neighbourhoods, schools and online.

Parents and carers have little influence over these contexts



Contextual safeguarding issues

Operation Signal

A&W Peer Group Conference

- 100+ young people across Adur and Worthing?
- As young as 11 and 12 years old
- Several key locations - fluid
- Education?
- Parenting/families
- Violence/risk

Thrive connects this

WHAT DO YOUNG PEOPLE NEED TO THRIVE?

DESIGN PRINCIPLES

The ingredients of what young people need to thrive have emerged from the ethnographic research carried out by Local Vision partners.

THRIVING YOUTH

WHAT DO YOUNG PEOPLE NEED TO THRIVE IN WORTHING?

The ingredients of what young people need to thrive have emerged from the ethnographic research carried out by Local Vision partners and two synthesis sessions in December 2016 and January 2017.

Our collective focus and action

Skills for parents

- A programme to develop the skills and resilience of parents so they can more effectively support their children around mental health and well-being
- Free/very low-cost open workshops and events linked to schools across West Sussex open to any and all parents and carers – Also free e-learning
- Funded by CCG/WSCC following successful pilots
- 2 aspects - General programme around emotional well-being and mental health and more specialized programme focusing on autism and ADHD
- Lived experience perspective – Parents and young people
- 18-19 first full year – Over 60 events supporting nearly 700 parents
- Continuing and developing in 19-20

West Sussex | mind
for better mental health

Knowledge or strategies gained:

"understanding the struggle and behaviour of my teenagers"
"talking to my husband and daughters about what I had heard"
"a lot of my fears were normalised, and I felt better able to talk about things"
"tried strategies discussed and still ongoing trial and error"
"adapted our whole parenting style and adopted specific strategies to deal with challenging behaviour. We have also purchased additional recommended resources."

General programme includes	Autism/ADHD programme includes
• Anxiety, Low Mood and Resilience in Young People • Anxiety and low mood in primary age children • Coping with Exam stress for families • Helping Young People Cope with Life • Living with Self Harm • Managing Transitions • Dealing with behaviour of concern	• Making sense of autism/ADHD • Handling Stress and building your resilience • ASC and ADHD Strategies • Making sense of anxiety • Understanding emotional regulation • Making sense of challenging behaviour • Understanding School SEND Support, Statutory Assessment and EHCPs

The system: Primary Care and Schools

Initial LCN work provided the impetus to:

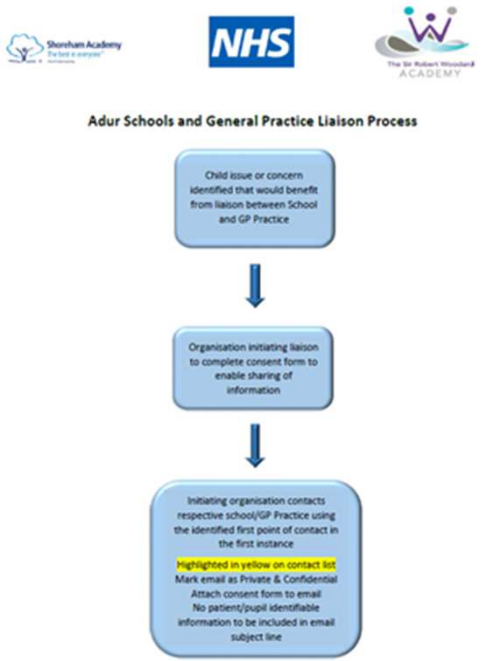
- Prioritise time to come together
- Develop relationships and trust
- Develop a deeper understanding of shared issues and potential new ways of working

To date this has enabled:

- Real time communication between schools and Primary Care
- integrated support approach
- Opportunities to intervene earlier

Plans Going forwards:

- Ongoing opportunities to come together; potential for wider inclusion
- Case study work to share learning
- Workstreams focusing on: Children who over medicate, Asthma Management & Supporting Return to School After Self Harm



Find it Out Plus - an approach

A front door for young people's **emotional wellbeing and mental health**

A place where young people (and parents) can find and access existing **support and help** in relation to their **emotional wellbeing and mental health,** easily and early.

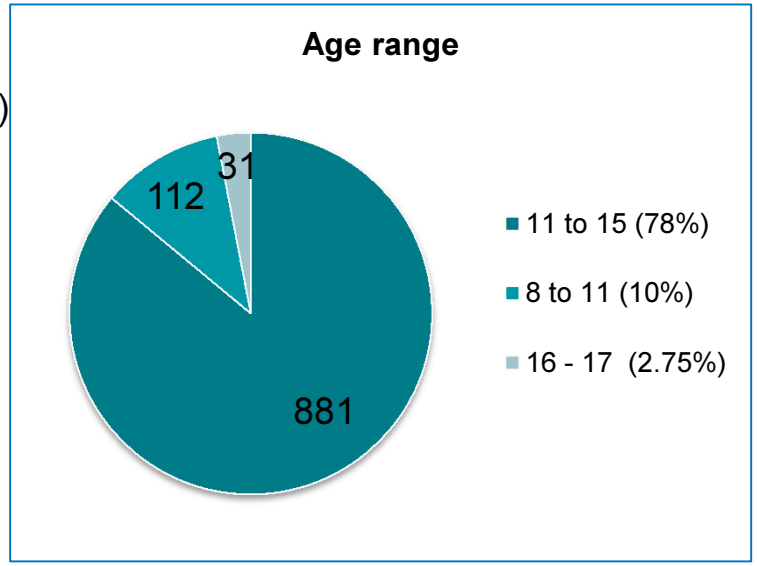
A **welcoming** space, starting with a conversation - **no need for a referral**.

An early approach, to explore what a young person needs/wants to **support their connection and transition** into the right type of service or activity that is helpful to them.

Listening to **a** young person's **story** **<u>once</u>**

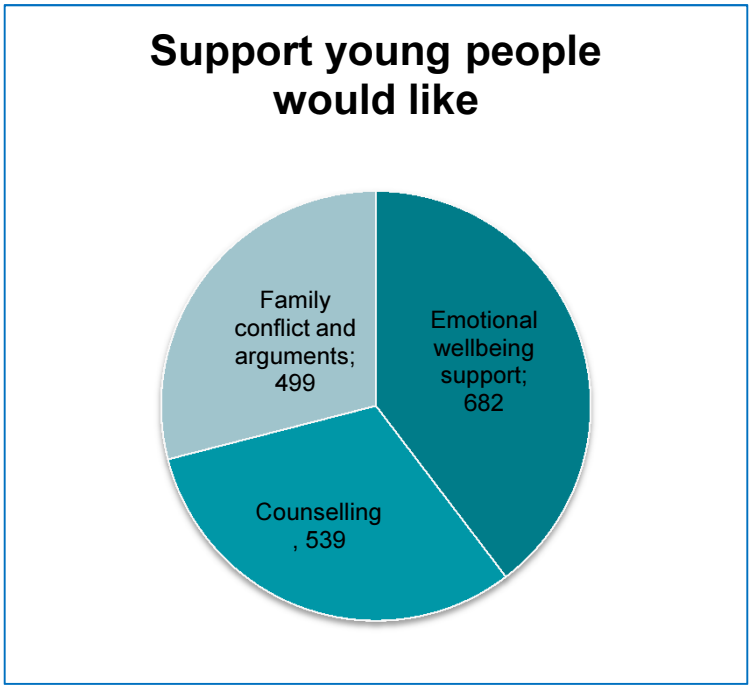
Early indications of need

- The Survey had 1124 Respondents.
- Majority school age (reflects the main routes for the survey)
- 84.04% White British in line with Census data.
- 80.94% female, 16.13% male.
- 64% (first) wanted to see a mental health professional face to face.
- 32% (second) would like to access groups.
- 30% (third) wanted to see a youth worker face to face.
- Most young people (43.7%) agreed they would feel comfortable coming in to a youth hub. 35% neither agreed nor disagreed.



Early indications of need

- Highest type of support sought is emotional wellbeing (including friendships, bullying and anxiety), followed by counselling and support with family conflict - see chart.
- Majority want 11 – 7 opening hours service with a weekend option.
- Majority want to be able to book an appointment, but there were a large number who wanted a drop in service, or both.
- The location, overcrowding and waiting lists are perceived as barriers to the service.
- Majority want to get in contact by phone / email / text at first or by drop in.



Early indications of need - Next Steps

ADUR & WORTHING COUNCILS

Next steps

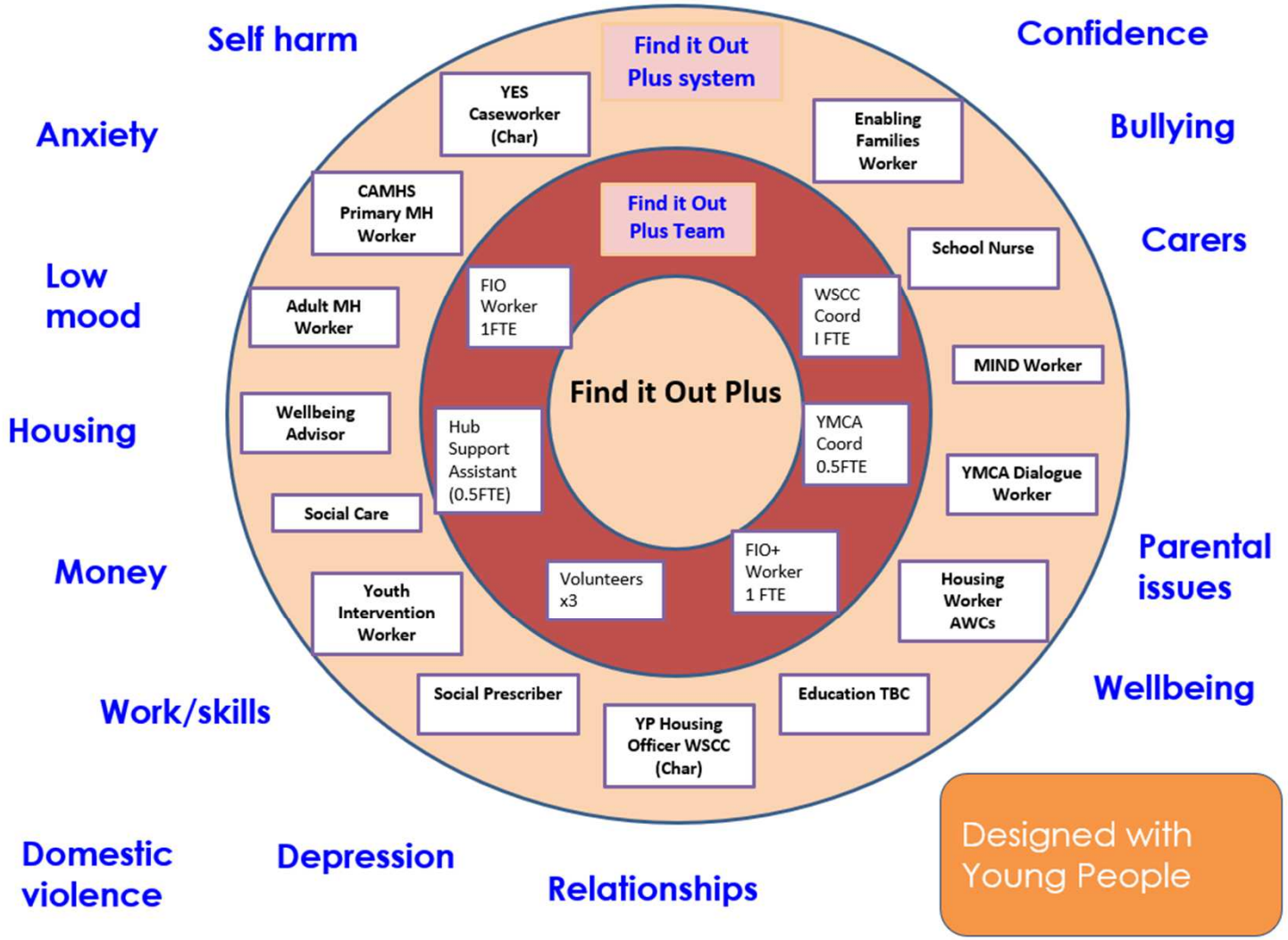
- 86 Respondents to the survey wanted to be involved in shaping the development of the FIO service.
- Create and develop a young persons board
- Further consultation targeted at more responses from a male audience.
- Further consultation needs to be done with 16 and 17 age range.
- Further consultation needs to be done with 18 – 25 age range.
- Further exploration needs to be done for 8 – 11 age range including consent and parent / carer attending appointments.

Find it Out Plus - how it will work

ADUR & WORTHING COUNCILS

- A building which is **accessible on the day**
- Skilled front of house people to meet and greet - no need for a referral;
- A **holistic approach** focused on what **individuals need/want**;
- **Integrating the workforce** behind the scenes, around children and young people in a place;
- Working through age boundaries (11 (?) – 25 YOs);
- Valuing clinical and social support, equally;
- Prioritising **early intervention and prevention;**
- Networking provision for young people;
- Developing the **capacity of the wider system;**
- Designed with young people.

CO-DESIGNED WITH YP



ADUR & WORTHING COUNCILS

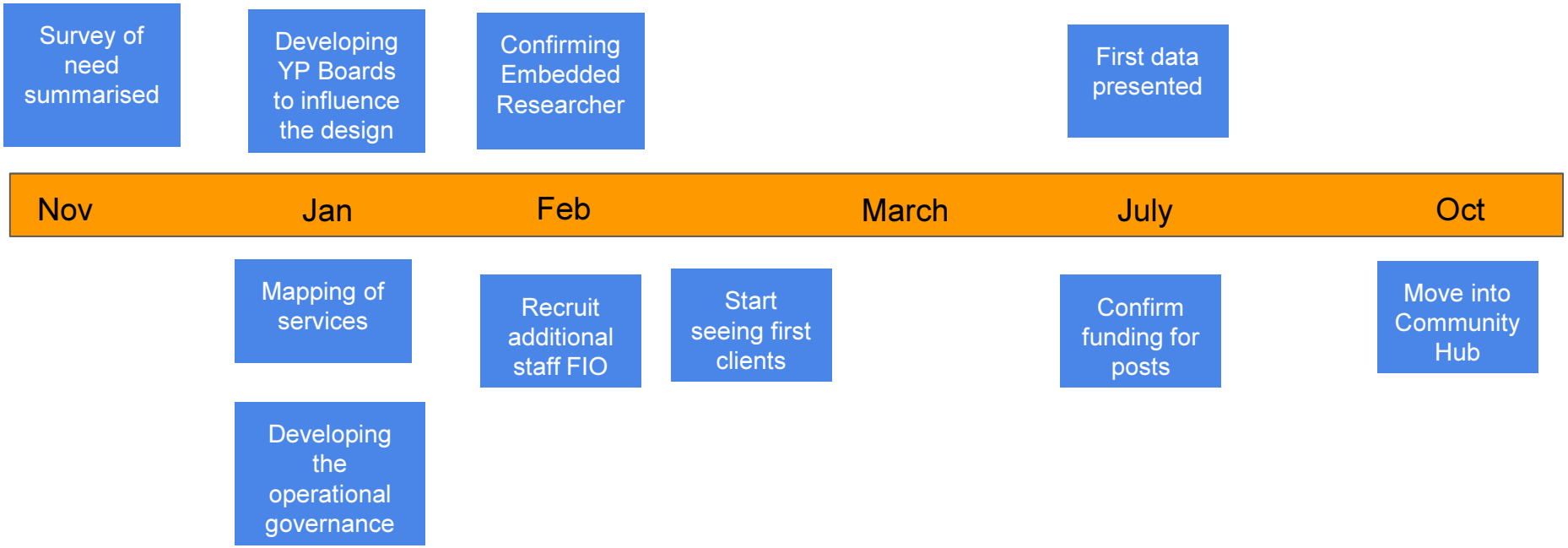
Evidencing impact

ADUR & WORTHING COUNCILS

Indicative Outcomes?

- Reduction in A&E mental health presentations
- Reduction in duplication of triage and assessments.
- Reduction in touchpoints and delay.
- CYP accessing services when they would otherwise not
- Retention/engagement in education and employment
- More effective use of low intensity and/or third sector provision/ self-help
- Greater choice
- No DNA's & improved engagement.
- Timely intervention
- Greater satisfaction
- Immediate reduction in reported distress

FIO+ Timeline 2020



MH in Schools – Pilot Trailblazer & Rolling-out

What are they?

1. Delivering evidence based interventions for mild to moderate MH issues.
2. Supporting Ed. MH health lead to introduce whole school approach.
3. Giving timely advice to school and college staff.

Collectively West Sussex stakeholders successfully bid for trailblazer status in 2019 – beginning in Crawley and Bognor Regis.

National Plans to roll-out by the end of 2022-23

We are currently preparing a bid to expand into other areas of West Sussex - and will therefore integrate further with our joint Worthing plans.


thank you

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Date of meeting:	**30 January 2020**
Item Title:	**Children First Improvement – Review of Commissioner's Report and Service Update**
Executive Summary:	This report summarises developments in West Sussex County Council's Children's Services during the second half of 2019. It discusses the recently published report of the Children's Services Commissioner, and the future direction of the service; it also provides a summary of the journey of improvement to date under the Children First programme.
Recommendations for the Board:	To note the position as set out in the Commissioner's report, the County Council's response, and the intended journey of service improvement over the next 12 months. To continue to support the County Council through the partnership in enacting the necessary changes.
Relevance to Joint Health and Wellbeing Strategy:	Key relevance, especially to 'Starting Well' and addressing inequalities in health and social care.
Financial implications (if any):	None
Consultation (undertaken or planned):	Not applicable – report for information
Item author and contact details:	Garath Symonds, Senior Improvement Lead 03302 222511

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Children First Improvement – Review of Commissioner's Report and Service Update

30 January 2020

Report by: Executive Director of Children, Young People and Learning

Executive Summary

This paper explains the response to the Ofsted 'Inadequate' judgement of West Sussex Children's Services in May 2019, and the subsequent appointment of a Commissioner to make recommendations as to whether the service should remain under the County Council's control. The Commissioner's report has now been published; it recommends that Children's Services be transferred to a Children's Trust for the time being. Notwithstanding the serious criticism contained in the report, the Commissioner has found evidence of recent service improvement, and this view has been endorsed by an Ofsted Monitoring Visit in December 2019. This paper goes on to summarise the improvements that have taken place, and explain the next steps in the improvement journey during 2020.

The Health and Wellbeing Board is asked to:

1) Note the Commissioner's recommendations (Section 1), and the actions already undertaken as part of a continuing improvement narrative (sections 2 & 3);
2) Note the next steps in the improvement journey (Section 4);
3) Continue to support the County Council through the partnership in enacting the necessary changes.

1. Background

1.1 On 20 June 2019 the Health and Wellbeing Board received a report explaining the initial response to the 'Inadequate' Ofsted judgement of Children's Services (**Ofsted report** May 2019), and the County Council's creation of a Practice Improvement Plan to address the 10 key recommendations for service improvement that Ofsted had made. That June 2019 report went on to explain that the Department for Education (DfE) on behalf of the Secretary of State for Education, had appointed a Children's Services Commissioner, John Coughlan, to judge the County Council's capability and capacity to return the service to a satisfactory level. The Commissioner's report was published on 17 December

2019, and this current report now summarises the Commissioner's findings and explains how his recommendations are being addressed. It also provides a broad summary of all the service improvements and developments that have been in progress during the second half of 2019 and looks towards further improvement planned in 2020.

The Commissioner's Report

1.2 The **Commissioner's report** was published on 17 December 2019. Its main conclusion was that the prospects for service improvement were not sufficiently strong, and accordingly the service should be transferred from the County Council to an Alternative Delivery Model (ADM). This section gives a necessarily summarised account of the content of the Commissioner's report, and focuses on its key recommendations.

1.3 In reaching his conclusions the Commissioner has undertaken detailed research and analysis, based on interviews with a comprehensive range of stakeholders. This investigation considered not only the delivery of Children's Services, but also the corporate context in which the service operated. Among the key corporate themes identified were:

- dysfunctionality in relationships between members and officers;
- an opaque and inefficient style of decision-making, coupled with excessive bureaucracy;
- an unwillingness at senior level to entertain alternative viewpoints;
- senior management 'churn' – i.e. frequent changes in service leadership personnel – leading to lack of strategic direction.

1.4 In terms of Children's Services, the following broad themes were identified:

- weaknesses and non-compliance in important areas of governance;
- ineffective scrutiny and challenge;
- insufficient attention to safeguarding of children;
- lack of understanding of quality and performance management;
- lack of focus on children as individuals with needs and wishes;
- complex and inefficient processes;
- dysfunctionality in interactions between the leadership, service managers and staff, giving rise to an impoverished culture.

1.5 Despite these very serious findings, the Commissioner has acknowledged that recent service improvements provide some encouragement that a return to sound operational practice in Children's Services is feasible. These are summarised against his recommendations below. Notwithstanding these, the Commissioner has determined that, due to the problems he has identified within the broader corporate context, placing the service with an Alternative Delivery Model for the time being is essential to its recovery.

1.6 The new Leader of the Council has apologised on behalf of the Authority for the deficiencies in its services to children and young people, and for the underlying defects of leadership, governance and culture which the Commissioner has identified.

Implementing the Commissioner's Recommendations

1.7 The Commissioner made 10 specific recommendations: these and the progress to date in implementing them, are summarised below.

1. **The Alternative Delivery Model (ADM)**: This is the key recommendation, and under John Coughlan's guidance immediate steps will be taken to commence the setting up of a Children's Trust. Its formation will take some months to accomplish, and the appointment of an Improvement Partner (Recommendation 3) is intended to guarantee and support continuing service development in the interim.

2. **Appointment of a Commissioner**: John Coughlan has been reappointed by the Secretary of State for a further 12 months; he will provide strategic direction through his chairmanship of the reconstituted Children First Improvement Board, and continue to report to the DfE on the progress being achieved.

3. **Improvement Partner**: Hampshire County Council has been appointed our Partner in Practice in order to provide service development support in the period before an ADM can be formally created. Steve Crocker, the Hampshire Director of Children's Services and his team will work closely with WSCC Children's Services.

4. **Role and status of Director of Children's Services**: Within the County Council's Constitution, the legal role of Director of Children's Services (DCS) is now formally established as 'Executive Director of Children, Young People and Learning' and reports directly to the Chief Executive. The Executive Director now has formal responsibility both for social care and education functions, as best practice dictates.

5. **Status of Improvement Board**: the Board has been reconstituted to reflect Ofsted priorities, Under the Commissioner's chairmanship, and is no longer 'voluntary'.

6. **Management Training Programme**: the Commissioner requires that management and staff have a common and robust understanding of quality and performance, in addressing 'what good looks like' throughout the service: arrangements are in hand to give this effect.

7. **Staff Engagement**: Arrangements are in hand to enact a process of continuous service-wide engagement, to ensure that all members of the service are culturally attuned to the expectations of the improvement journey, and professional decisions are informed by these expectations. One round of leadership team engagement occurred in November 2019, and a further round is planned for February 2020.

8. **Improving dialogue with partners & MPs**: The Commissioner stresses that building confidence in the Council's overall leadership within a broad partnership is essential to corporate health. This is fully acknowledged, and an initial response is the development, with partners, of the Children First Strategic Approach.

9. **Corporate Parenting Panel**: The Panel has been reconstituted, and will now be chaired by the Cabinet Member for Children & Young People. In common with the Children and Young People's Services Select Committee,

the expectation of exercising a more rigorous scrutiny function and engaging closely with frontline service delivery and the experiences of children and young people, is being put into effect.

10. **Corporate review of leadership, governance and culture**: The new Leader of the County Council has given strong personal and organisational commitment to conducting a full review of these, and this approach was endorsed at County Council on 17 December 2019. An early example of cultural change is the introduction of Cabinet meetings in public; the Commissioner's Report itself was debated at a Cabinet meeting in public on 14 January 2020.

Ofsted Monitoring Visit, December 2019

1.8 As part of the journey of improvement, Ofsted is undertaking short, focused monitoring visits on a 3-4 month basis, which will culminate in a full service re-inspection in 2021. The first Ofsted Monitoring Visit took place on 3-4 December 2019. The monitoring visit was helpful in assessing the progress being made and the challenges still faced in ensuring quality and consistency across the service. The inspectors gave feedback broadly as follows:

- The children's services workforce is now more stable and caseloads are becoming manageable;
- Staff are highly committed to delivering good outcomes for children, and staff morale has improved;
- Staff know their children well and have a clear sense of direction for their work;
- Some progress has been made in the quality of social work practice, particularly around visits, direct work with children and the use of tools to capture children's views;
- There is a need to ensure that the arrangements to oversee children who are privately fostered meet best practice standards, and are effectively joined up between teams;
- There is more work to do to ensure the consistent application of thresholds, and the quality of assessments and plans;
- The service understands itself well, and knows what more still needs to be done.

2. The Children First Improvement Programme

Leadership and Management in Children's Services

2.1 During the second half of 2019, a new management team was formed under the Executive Director for Children, Young People and Learning, and Director of Children's Services, John Readman, with the capability and experience to lead the service on the improvement journey. John Readman will be moving to another authority at the end of January 2020. He is taking part in the current process of appointing a successor.

2.2 The importance of a strong and supportive culture as part of the service improvement has been recognised. Regular sequences of staff engagement sessions are now in place, encouraging staff at all levels to contribute to positive

organisational change, and to enter into a constructive dialogue about how management can best support and value the workforce.

Workforce Development

2.3 Having a stable, fully-staffed social care workforce, possessing the necessary skills and resources is a key ingredient of an effective service. During 2019 significant steps have been taken to turn around high levels of vacancies, an uncompetitive recruitment offer, and unsustainably high caseloads for staff in post. Although staff had remained committed and hardworking, high vacancy levels had contributed significantly to the poor performance identified by Ofsted. The following narrative summarises the improvements made in this area.

2.4 **Social Worker Vacancy gap:** The service currently comprises approximately 511 FTE (full-time equivalent) social worker posts. The Vacancy Gap which in February 2019 stood at 18.5% is now (December 2019) at 2.2%. The vacancy gap has been closed in part through the engagement of additional agency workers (approximately 80 at December 2019): in the short-to-medium term, agency workers will be retained in response to specific demand; however it is intended to place greater reliance on a stable, permanent workforce in the longer term.

2.5 **Recruitment and Retention:** A retention package is in place for social workers who commit to stay with WSCC for at least 18 months. To date around 93% of those eligible have taken up this offer. West Sussex now has terms and conditions as competitive as any of its neighbours. A new recruitment programme has commenced under the headline 'Be My Voice'. The Council's social work academy has also been successful in training aspiring social workers through to newly-qualified status.

2.6 **Caseloads:** Under-staffing, combined with rising demand for social care had led to unsustainable levels of caseloads for individual staff members. This inevitably reduced the timeliness and quality of interventions and hampered continuing professional development. Maximum case-holding targets have been set, and will vary between different staff cohorts: experienced social workers have a target of up to 18 cases, while newly qualified social workers (NQSWs) have a reduced target of around 15 cases; lower levels will apply where cases are very complex and intense. At the current time, caseloads are being progressively reduced in line with the thresholds set.

2.7 **Summary:** Broadly speaking, the current staffing situation is acceptable in the context of a journey of improvement, and remains under close management review. It is important to continue to monitor the key measures over a longer time sequence, in order to progressively increase the proportion of permanent staff and establish that full control over caseloads has been achieved. Measures to support staff through such provisions as training, management oversight and improving IT equipment are included in the digest of other service improvements that follows.

3. Other Service Improvements during 2019

3.1 Additionally to the governance improvements referred to at 1.7 and the workforce development initiatives in Section 2 above, a very wide range of

changes is being made in line with the objectives of the Practice Improvement Plan. Key examples are as follows:

- A programme has been put in place to address **wider transformation**, including service re-design, better use of technology and workforce development;
- **Signs of Safety** has been adopted as the practice framework, so that staff know what is expected of them;
- **An updated Scheme of Delegation** and **Supervision Policy** are in place to improve management oversight and accountability, so that staff are well-supported to deliver high-quality practice;
- **A new Learning and Development Pathway** is being developed, so that staff are provided with appropriate and relevant training;
- **A new Policy and Practice Group** is in place to ensure that Social Workers know 'what good looks like' and children and families receive a consistent and professional service;
- **Improvements to information systems** (Mosaic) and recording protocols used by social workers;
- **Improvements in social work practice** in Children Looked After and Assessment and Intervention teams; children being visited more often; assessments are more timely - all these being supported by improvement in management oversight.

4. Further service improvement planned for 2020

4.1 The following are examples of the main improvement measures now being planned for the coming year:

- **Working closely with Hampshire CC** as Partner in Practice in specific work streams, starting in January 2020;
- **Children with Disabilities**: an area of focus with support from Hampshire as Partner in Practice;
- **Neglect and Domestic Abuse**: a revised Neglect Strategy and toolkit will be completed in early 2020;
- Intensive support and coaching in **Family Support and Protection Teams**;
- Reviewing practice in **High Risk Complex Adolescents Team** and multi-agency arrangements for contextual safeguarding;
- Reviewing practice in commissioning of **external placements** for Children Looked After;
- Continuing to embed improvement work already underway in **Assessment and Intervention Teams, the MASH, and Early Help** to streamline processes and improve the timeliness of decision-making; more consistency in the application of thresholds and the quality of social work practice;
- Evaluating and further establishing **quality assurance audit process** to improve compliance across the service;
- **Adoption**: membership of Adoption South East from April 2020, to improve experiences and outcomes for children being considered for adoption;
- **Life Story Work**: training for foster carers and staff being launched;
- **Fostering**: secure base training to be introduced, so that carers can respond to children more skilfully;
- Creation of specific **Family and Friends Team** and tighter support to be offered to Special Guardians;

- Transfer of **Care Leavers Service** from Early Help to Children Looked After Service;
- Continue to address actions in **Practice Improvement Plan**, including Private Fostering, Permanence Planning, and Corporate Parenting Panel.

5. Summary: Support from the Board and the wider Partnership

5.1 This report has summarised a great body of very diverse improvement work in progress or planned within Children's Services. However, the County Council fully understands that its strategic aim of giving every child the best start in life depends equally on the support of the wider partnership – Health, Schools, District Councils, MPs and others – working on the broad Start of Life agenda. The Council is also mindful of the Commissioner's recommendation (No.8 at para 1.7 above) that attention should be paid to redefining external working relationships prior to the full introduction of an Alternative Delivery Model.

Children First Strategic Approach

5.2 It is in this context that, in collaboration with partners across West Sussex, the County Council is developing a West Sussex Children First Strategic Approach. The Health and Wellbeing Board has been closely involved in the initial consultation and preparation, and received a report on this subject at its last meeting on 10 October 2019. The Strategic Approach is now expected to be adopted in March 2020. The continued support and engagement of all partners is requested to give vitality to this initiative, so that children in West Sussex can in future be assured of services that truly promote the best start in life.

John Readman
Executive Director of Children, Young People and Learning

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Date of meeting:	**30th January 2020**
Item Title:	**Children's emotional wellbeing and mental health**
Executive Summary:	Partners across Sussex commissioned an independent review of children's emotional wellbeing and mental health. The review engaged an Independent chairperson and there has been an Oversight group and review panel in place. The review has concluded its engagement and research phase and recommendations are being prepared for a final report. NHSE requires local areas to produce a Local Transformation Plan for investment in children and young people's emotional wellbeing and mental health. The proposals for this plan have been presented to the HWB and the plan has now been assured by NHSE and is being implemented. The commissioning team have produced a Making Progress summary which sets out developments and performance to date.
Recommendations for the Board:	To accept the recommendation that the review report is presented to HWB in March 2020 To note the LTP plan refresh and Making Progress summary
Relevance to Joint Health and Wellbeing Strategy:	Specifically supports the Starting Well outcome that: Children, young people and families have good emotional wellbeing and mental health
Financial implications (if any):	None
Consultation (undertaken or planned):	Significant consultation with stakeholders and service users has been undertaken to support the Sussex wide review of services. The LTP refresh was reviewed by stakeholders via the CYP Emotional Wellbeing and Mental Health partnership board acting as LTP steering group. The priorities within the plan remain the same and are built on earlier engagement at the inception of the plan.
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Report Title Children's emotional wellbeing and mental health

Date 23rd December 2019

Report by Alison Nuttall
Commissioning Lead: All Age Services West Sussex County Council and CCG

Executive Summary
This paper concerns Children's Emotional Wellbeing and mental health.

The Health and Wellbeing Board is asked to:
1) Note the plans for presentation of the Sussex wide review of children's emotional wellbeing and mental health
2) Note that the Local Transformation Plan for West sussex has been assured by NHSE and the Making Progress summary as circulated

1. Background

Partners across Sussex commissioned an independent review of children's emotional wellbeing and mental health . The review engaged an Independent chair person and there has been an Oversight group and review panel in place. The review has concluded its engagement and research phase and recommendations are being prepared for a final report.

NHSE requires local areas to produce a Local Transformation Plan for investment in children and young people's emotional wellbeing and mental health. The proposals for this plan have been presented to the HWB and the plan has now been assured by NHSE and is being implemented. The commissioning team have produced a Making Progress summary which sets out developments and performance to date.

2. Proposals

That the outcomes of the review are presented to the HWB in March 2020

That the HWB note that the Local Transformation Plan is now in place and assured by NHSE and note the Making Progress summary

3. Next Steps

The Independent Review report and recommendations to be brought to the HWB in March 2020

Anna Raleigh
Director for Public Health

Appendices:

1. **LTP refresh 2019/20**
2. **Making Progress Sept 2019**

Our ambition is for children and young people (CYP) in West Sussex to have access to the information and support they need to stay well, and effective treatments to enable them to achieve the best possible mental health.

Local context

In West Sussex we have a joint commissioning team for CYP emotional wellbeing and mental health services, bringing together the three clinical commissioning groups and local authority to work as one.

We have made great progress in recent years with significant investment increasing access, choice and integration, particularly for early support. However, we are clear about where we have more to do and this includes better supporting our most vulnerable CYP. In addition, population growth and changes in the profile of need means demand for services is projected to increase between 5%-15%.

What matters to our CYP

Our CYP, families and stakeholders have told us what matters to them:

- Being seen quickly, with continuity of care
- Early identification and provision when help is needed
- More capacity and choice for early support
- Easy access and simple pathways
- Recognising the complexity of individual lives
- A quality experience as well as quality care
- Greater coordination between all agencies and with adult services.

Since our first LTP in 2015 we have:

- **Improved integration with council services** – early intervention and support is provided through the Youth Emotional Support (YES) Service.
- **Increased capacity and choice** – leading to significantly improved access to services.
- **Introduced new services** – including the eating disorder service and community mental health liaison service.
- **Developed strong partnerships** – with trusts, independent providers and stakeholders.
- **Developed schools and colleges strategy** – working closely to improve outcomes.
- **Developed the workforce** – knowledge and skills training for all staff working with CYP and an outline workforce strategy.
- **Established an outcomes framework** – designed in partnership with CYP and their families, to ensure rigorous monitoring and evaluation of all our services.
- **Involved CYP** – and their families through co-production in all that we do.

In particular, over the last year we have:

- **Further improved access** – exceeding the NHS England target of 32%.
- **Further increased choice** – launching a new face-to-face and online counselling service with YMCA Dialogue.
- **Become a trailblazer** – successful application to begin implementing two Mental Health Support Teams in schools.
- **Focussed on our youth support offer** – developing a strategy and implementation plan for youth access pathways which will bring existing services together

EXECUTIVE SUMMARY

Our Local Transformation Plan describes how we will invest in services and improve outcomes. This year's refresh reaffirms our clear priorities. It updates our plans for 2020/21 - building on progress to date - and our financial commitments in line with NHS England's Long Term Plan.

Priorities for 2019-21

Our specific priorities for investment are set out below. There are a number of themes that underpin all of our work. Key is managing the projected increases in demand for services. We are also improving the clarity of pathways, integrating services and streamlining referral processes for CYP and professionals alike.

We are supporting improved communication between all agencies, including primary care and schools. We are also developing the workforce, not just ensuring we have the right specialist staff, but building the knowledge, skills and confidence of everyone who works with CYP to make timely and appropriate interventions.

Eating disorders

Continuing to ensure improved access to the service, and improve outcomes for CYP and their families.

Workforce transformation

Planning the future workforce and developing knowledge, skills and networks for all professionals working with CYP.

Early intervention

Further developing our successful early intervention services for on-going sustainability. This includes early support and targeted services and Mental Health Support Teams in schools.

Vulnerable CYP

Ensuring we have specific mental health support in place for our most vulnerable and at-risk CYP.

Crisis care and urgent help

Strengthening local community services and increasing the number of CYP able to access effective interventions when they need it, and close to home.

Neurodevelopmental pathway

Re-designing the pathway and service model to enhance timely access and support for CYP and their families.

Health and Justice

Continued development of services and better support for CYP who are in secure estate (or at risk of entering), or held on a mental health section in hospital accommodation.

Transfer to adult services

Developing the youth access pathways for 16-25 year olds building on current services and ensuring effective transfer between specialist CAMHS and Adult MH services.

CYPIAPT

Continuing to embed the principles for consistent partnership working across all services to improve quality and access.

Community specialist CAMHS

Supporting the development of specialist services to manage projected increase in demand.

Making progress, making a difference

Commissioning for children and young people's mental health and emotional wellbeing in West Sussex

September 2019

Introduction

The Children and Young People's Mental Health and Emotional Wellbeing Commissioners work jointly on behalf of West Sussex County Council and the NHS clinical commissioning groups (CCGs) for Coastal West Sussex, Crawley, and Horsham and Mid Sussex.

We plan, agree and quality-assure mental health and emotional wellbeing services for local children and young people (CYP). The types of service we commission are described in the diagram below.

This is our third annual *Making progress, making a difference* report, highlighting the progress and achievements since the introduction of our five-year local transformation plan (LTP) in 2015. The LTP was backed by significant and much-needed additional investment. The plan aimed to ensure the new funds not only enabled service expansion to meet demand, but also transformed the way we go about supporting CYP to enjoy the best possible mental health and emotional wellbeing.

Our ambition is to develop services so that CYP have access to information and support to stay well and – should they need it – access to the most appropriate treatment to achieve the best mental health.

We have made great strides and many more CYP then ever before are receiving the support they need. In particular, we have developed and expanded early intervention and targeted services, providing a range of accessible support to address problems early.

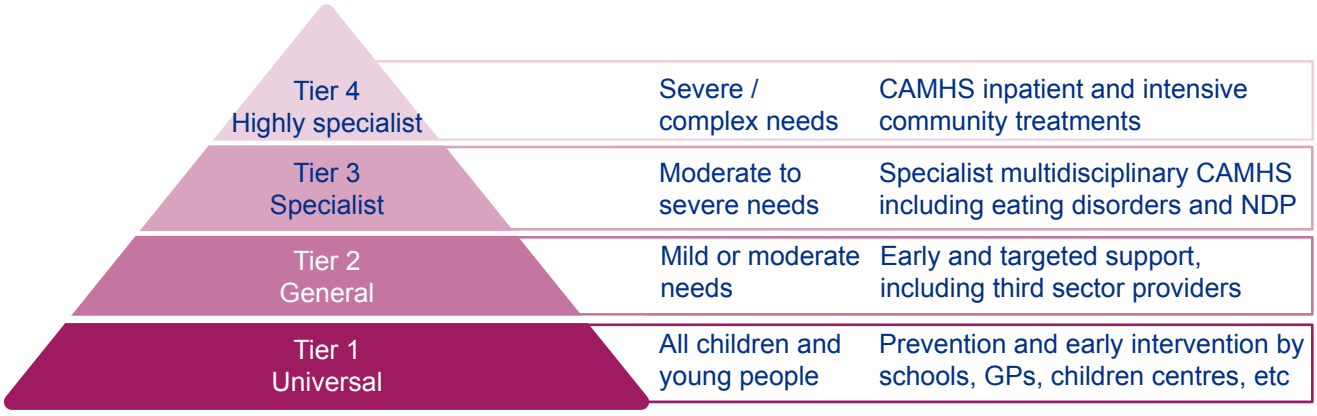
An important element of our approach is to help CYP develop personal resilience and coping strategies for life's inevitable stresses. This can be vital in preventing difficulties developing into conditions that require a medicalised mental health response now or in later life. Central to our vision is enhancing the skills, knowledge and confidence of everyone who works with CYP to identify problems early and know how best to address them.

We continually listen to feedback from CYP and their families, schools, GPs and service providers. While more CYP than ever are able to access

West Sussex Local Transformation Plan

An integrated, multi-agency, system-wide approach to build resilience, improve access to services and support CYP along pathways of care whatever their needs. By 2021, in collaboration with partners, we will have:

- accessible, timely services in the community
- a suite of intervention and targeted services to catch problems early
- more capacity and greater choice along the continuum of need
- a focus on outcomes, particularly for the most vulnerable
- fewer gaps between services and improved transition to adult services
- a workforce with the skills to deliver the services CYP want and need.

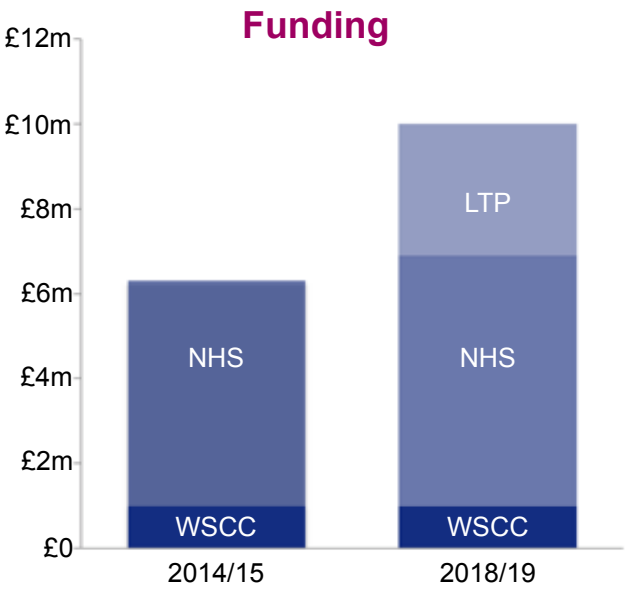


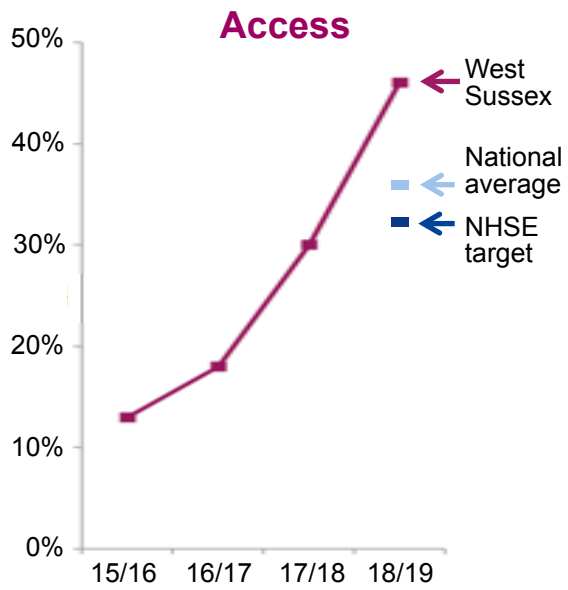
support - and feedback from services users is very good - we know it can sometimes be difficult for CYP, families and professionals to navigate the system and access the right service in a timely way. Sometimes there can be long waits or people can become stuck in gaps between services.

An important focus for the LTP now is on facilitating and developing the professional relationships and knowledge that will enable the whole system around CYP to work more effectively. Through information, networks, training and consultation, we are developing the knowledge and skills for professionals working with CYP to better understand and address mental health and emotional wellbeing issues. We are empowering support CYP and families directly, build resilience and to signpost and refer to other services as appropriate.

This report illustrates how we work and highlights just some of the many valuable services provided by the organisations we commission. We are proud of the achievements made together with our partners. However, we know there is more to do. We thank our partners for their support as we continue delivering our shared plan for better mental health and emotional wellbeing for CYP.

Increased funding and access





Funding is the total annual investment made available to commissioners from West Sussex County Council, from the NHS CCGs, and from NHSE in relation to the LTP.

Access is assessed using the NHSE target measure of the number of CYP with a diagnosable mental health condition accessing commissioned services at least twice during the year.

Our commissioned services have submitted their high level activity data and this shows that 6,585 CYP accessed these services in 2018/19. In addition, most CYP receiving services are seen well in excess of twice in a year.

Figures before 2018/19 are estimated on the best available data as not all services have reported in a consistent way until now.

Early support

YES – youth emotional support

Youth Emotional Support (YES) provides intensive 1-2-1 emotional wellbeing support and access to counselling, group programmes and support from other agencies. During the year, YES supported 2,152 young people aged 11-18 with a wide range of emotional wellbeing issues, helping them to make positive choices and build resilience. Many others were supported to access other more appropriate services.

Operating from the eight FindItOut centres across the county, YES accepts self-referrals and referrals from GPs, child and adolescent mental health services (CAMHS) and school nurses. YES works closely with the Integrated Prevention and Earliest Help (IPEH) service to ensure integration with other services and wider family support where appropriate. It also works closely with CAMHS to carry out joint assessments and ensure timely and appropriate escalations. On average, less than 2% of people receiving support from YES go on to require a referral to CAMHS.

This year, YES has introduced a range of emotional wellbeing workshops to provide coping strategies, practical tools and tactics to help young people manage their wellbeing in a more proactive and positive way.

"Without your support, and coming with me on a long journey, I wouldn't have been able to achieve what I have so far this last year… None of this would have been possible without going to YES."

Service users play an important role in the recruitment of YES staff. Ten current and former service users have been involved in recruitment panels over the year, helping to design interview questions and scoring candidates. Supported by a YES worker, their feedback plays a large part in the final outcome, reflecting the importance of engagement to the service.

YMCA Dialogue counselling

YMCA Dialogue offers face-to-face counselling in various locations for 11-18 year olds with mild to moderate mental health difficulties. The service re-launched in November 2018 to include an integrated online counselling offer.

The service received 1,201 referrals last year, an increase of nearly 10% from 2017/18. Outcomes for young people include coping better, feeling better in themselves or feeling less anxious. Nearly three quarters rated the service 8/10 or more for helpfulness.

Dialogue's e-wellbeing online service offers eight sessions of counselling and is particularly suited to those who prefer to write down their feelings or find it difficult travelling to one of Dialogue's centres.

The service has begun offering low-intensity CBT in Worthing and Horsham and plans to soon expand this to Crawley. This evidence-based therapy is

Young people were involved in the design of Dialogue's newly refurbished space in Crawley. Through questionnaires, group sessions and individual interviews, over 30 CYP helped shape the services on offer, opening times, furnishings and décor and they contributed to inspirational quotes on the walls. Named Crawley YAC (youth advice centre), feedback on the new space has been very positive.

Crawley YAC

particularly suited to anxiety, low mood and phobias. Dialogue is also running a programme of group activities from summer 2019.

"I found I learnt a lot about myself and things to take away that will help me in the future."

"It has really helped me control and accept my anxiety."

"It helped me become more self-confident and has helped me find out who I am."

Community Mental Health Liaison Service

The Community Mental Health Liaison Service (CMHLS) offers advice and support for professionals working with CYP - such GPs, teachers, school nurses and social workers - who are concerned about a young person's mental health and wellbeing. It has a particular focus on children under 12 and the vulnerable.

CMHLS supports early intervention and prevention, develops the capacity and capability of professionals in other services and contributes to a multi-agency approach. The service offers consultation and direct therapeutic interventions such as group work with CYP and their families. The team is co-located in the council's six community-based IPEH Hubs and the service lead provides clinical supervision to the YES service.

The service provided nearly 1,000 consultations to professional clients over the last year, most of whom wanted advice on the best course of action or help with appropriate strategies and interventions. Following consultation, around 40% of clients were supported to work with the young carers. Another 20% resulted in referrals, with the remaining 10% referred to CAMHS.

The service is highly effective. Evaluation feedback found that 95% of professional clients reported progress after a consultation and 92% were satisfied with the outcome (with the remaining 8% reporting the consultation as beneficial but dissatisfied with the outcome because of CAMHS referral thresholds). In addition, 77% of clients reported a greater knowledge and understanding of the mental health needs of CYP following the consultation.

"An invaluable service for both reflecting on individual cases and identifying ways to improve the mental health of students across the school."

"Great service. Helps increase my knowledge, get quicker outcomes for families, and also gave me strategies to talk about with a family to help them."

Targeted services for specific issues

Recovering from domestic abuse

Over the year, 20 CYP and their families have received intensive therapeutic support to recover from domestic abuse. My Sisters' House women's centre in Bognor Regis provides the ten-week, NSPCC-approved Domestic Abuse Recovery Together (DART) programme.

DART supports CYP to communicate about their experiences and rebuild relationships. Afterwards, CYP report greater self-esteem, improved school attendance, fewer emotional and behavioural problems and better peer relationships. In addition, mothers have greater self-esteem, feel more affectionate and more effective as a parent.

"We are a family again and I know I can talk to my mum about anything. I feel safe and I feel better about my life."

Support for children affected by substance misuse

Change Grow Live provide counselling for CYP aged 5-18 years who have been affected by a parent, carer or sibling's substance misuse. Run as a pilot in Worthing, Adur and Crawley in 2018/19, the therapeutic service received 108 referrals. From April 2019 it has been commissioned county-wide and, as an innovative project, has also attracted additional funding from Public Health England relating to alcohol misuse and dependency.

"When I thought I wouldn't get over my hardest times, you helped me to overcome them by listening and understanding."

"She loves the sessions and feels valued and supported. It has had a direct impact on her ability to manage friendships and to challenge behaviour she doesn't like."

Whole-family bereavement support

In 2018, 170 CYP (from 88 families) who experienced the death of a parent or sibling received specialist bereavement support. The death of close family members has a profound impact on every area of a child's life.

Charity Winston's Wish deliver whole-family support, providing therapeutic support not only for the child but also building resilience throughout the family. Nearly nine out of ten parents and carers rated the service 9/10 or higher for helpfulness and understanding of the family's needs.

In addition to the commissioned counselling, this year Winston's Wish also ran a weekend away for bereaved teenagers, days out, drop in sessions and an after school club. A special Christmas event was also held, recognising how difficult the time of year can be for bereaved children.

"For making connections and friendships where grief and loss are understood, the teen weekend has been a great success with a positive impact."

Winston's Wish provide therapeutic support for CYP who have experienced bereavement

Suicide and self harm prevention

The Mind the Gap project, run by YMCA Downslink, helps young people aged 16-25 living in supported accommodation to better manage their emotional wellbeing to reduce the risk of suicide and self-harm. Based in a supported accommodation centre in Crawley, the key worker offeres a range of interventions including counselling, drop in sessions, healthy cookery sessions, arts and crafts and 'walk-and-talk' with a dog.

Over the last year, the service supported 134 young people. It has been credited with a reduction in self-harm and suicidal ideation and positive feedback from service users demonstrates the impact of the project on their emotional health and wellbeing.

Reducing self-harm

Recognising and reducing the risk of self-harm has been a focus for all commissioned services over the last year, from early intervention to specialist care. Self-harm is one of the key measures in our outcomes framework and we are working to better monitor this across all of our services to demonstrate their impact on this important issue.

"I talk about emotional things that I don't talk to anyone else about. Checking in with her reminds me to look after myself, and that people do care."

Supporting the transition to adulthood

Last year Coastal West Sussex Mind and Sussex Oakleaf worked in partnership to provide the Be OK service for 382 young people aged16-25. Over half were aged 16-18.

Be OK managing anxiety workshop

The service works with young people concerned about their mental health to promote resilience and independence. It supports people to move into work or education and can address the specific challenges associated with the transition to adult mental health services. Be OK offers 1-2-1 sessions, learning activities and informal social opportunities such as badminton, photography, dog-walking and guest speakers.

"Be OK has allowed me to grow as a person and helped me to overcome my vices."

"Be OK has helped me to meet new people going through the same emotional difficulties as me. They have helped me to feel less alone."

LGBTU support

Allsorts supports young people aged 11-19 who are lesbian, gay, bisexual, trans or unsure (LGBTU) of their sexual orientation or gender identity. Many LGBTU young people experience isolation and the service enables them to be themselves, talk about their feelings and make friends in a safe and fun environment.

The service expanded rapidly in 2018/19, with over 100 individuals attending regular groups in Horsham, Chichester and now also Worthing. In addition, more than 150 individuals from across the county accessed 1-2-1 sessions. In the most recent Allsorts survey, 88% of respondents said they had experienced mental health issues and 88% also said that Allsorts had improved their wellbeing.

In addition to the commissioned sessions, workshops and age-appropriate activities, Allsorts also provide specialist LGBTU youth support and education in schools and colleges, reaching over 2,000 young people and staff over the last year.

"Allsorts is my home where I don't have to worry about how I look or how I act. I don't know where I'd be without Allsorts."

"We are hugely grateful for the unique and invaluable support offered by Allsorts in helping our child to navigate their teenage journey. It's a godsend."

Allsorts placards for Pride parade

Therapeutic support for sexual abuse

A therapeutic support service for CYP affected by sexual abuse received over 194 referrals in 2018. Provided by Lifecentre, the service offers pre-trial therapy, face-to-face counselling for CYP and their families and play therapy for younger children, supported by telephone and text helplines. It has supported CYP from ages 2-18 and has demonstrated significant improvements in self-confidence, emotional coping and relationships.

"I like playing in my house and in my garden now. I don't hide in my room anymore."

"When I first came to Lifecentre, I felt depressed and stuck in the mind of my past. Now, a week away from 18, I'm able to realise that I'm no longer that 14 year old and don't have to wear her like a second, flinching skin."

Targeted services for vulnerable people

Youth Offending Service

The council's Youth Offending Service (YOS) is supported by a Sussex Partnership NHS Foundation Trust (SPFT) psychologist and CAMHS practitioners. Co-located with the YOS, they offer advice to the team to enhance their support for young people at risk of offending, carry out mental health assessments and work therapeutically with children and families.

Over the last year, the SPFT team have supported 64 young people referred for a range of reasons, including low mood, anxiety, self-harm and poor emotional regulation. The service carried out 37 mental health assessments and provided direct interventions in 31 cases. The team are part of SPFT's therapeutic and family intervention team and work collaboratively to address the needs of children and families.

The team also provide consultancy to YOS staff to help them work effectively with individual children. This reduces the number of professionals involved in a child's life – whilst ensuring they receive appropriate intervention and support – and enhances the skills, knowledge and confidence of the YOS team.

Looked after children

The CAMHS Looked After and Special Guardianship Team work with CYP in the care of social services or under a special guardianship order. They are trained to deal with issues that arise for CYP who have experienced abuse, neglect or traumatic loss and are now in alternative care. In addition to providing direct therapeutic interventions, the team support those with day-to-day responsibility for the individual and the wider systems around them.

Over the last year, the team has worked with more than 100 CYP, providing direct therapeutic interventions to just over half and providing support to carers and other professionals for the other 45%.

Currently seconded from SPFT, the team will become part of the new Child and Adolescent Multidisciplinary Psychological Service from October 2019.

YES health and justice workers

YES has two dedicated caseworkers funded by NHS England to support vulnerable young people who are in - or at risk of being taken in - to detention, secure accommodation or inpatient care. Many of these young people have experienced sexual or criminal exploitation. The caseworkers develop a relationship with the young person before providing interventions to improve their social and emotional resilience and promote stability.

Over the last year, the service supported 28 young people. Assessments of stability, risk and missing episodes have shown that the interventions help young people on a journey from chaos to stability and structure. There was a 25% reduction in the number of children assessed at high risk of exploitation, a 50% reduction in missing episodes and a 50% reduction in crime and disorder.

Following a recent national evaluation, our West Sussex service and model have been identified as an example of best practice and recognised for the impact they haver had on CYP and the wider system.

"I really like the way my caseworker works with me. She does not judge and I feel comfortable with her."

Unaccompanied asylum seeking children

Over 80 vulnerable young people were helped by the mental health assessment and treatment service for unaccompanied asylum seeking children.

SPFT provides the service for children who are looked after by the council. The practitioner sees children with various trauma related and behavioural issues including anxiety, self-harm and difficulties with sleeping, often working with interpreters and liaising with other services. Activities this year included art groups, allotment projects and 'staying safe' workshops.

Many of the children have seen and experienced unimaginable distress. They benefit from a distinct service because of the complexities of their needs and common barriers around language. The aim is to offer therapy as far as possible and on-going support to prevent further mental health problems from developing.

"Our sessions have helped me a lot. I appreciate everything. I've tried to make better use of my time."

"I liked the gardening the most, the painting and just having some conversation. Thank you."

Addressing harmful sexual behaviour

The Assessment and Treatment Service (ATS) provided by SPFT offers psychological support to CYP who engage in harmful sexual behaviour. It provides consultation to other agencies and carries out assessments and therapeutic interventions with CYP and families.

Last year ATS accepted 44 new referrals for CYP aged 4-17. In addition, the service delivers well-received training through the local safeguarding children's board to equip professionals with a better understanding of harmful sexual behaviour and how to identify and address it.

ATS has also worked closely with the Safeguarding in Education team over the last year to develop and implement a tool to help schools respond quickly and effectively to harmful sexual behaviour and to ensure robust safeguarding plans are in place.

CHAMPS: New Child and Adolescent Multidisciplinary Psychological Service

From October 2019 all these targeted services for vulnerable CYP, with the exception of the Youth Offending Service, will become part of the new Child and Adolescent Multidisciplinary Psychological Service. The service name – and CHAMPS acronym – was decided by CYP themselves.

Specialist CAMHS

Specialist tier three CAMHS are provided by SPFT. They receive an average of 340 referrals a month and go on to treat around half, signposting the remaining 50% to other services such as YES. All referrals are triaged by professionals and a decision made about how best to meet the needs of the CYP

Community teams

The majority of specialist tier three CAMHS services are provided through the four community teams based in Mid Sussex; Northern West Sussex; Worthing; and Chichester. Specialist multi-disciplinary teams offer assessment and treatment to CYP with emotional, behavioural or mental health problems.

They work with CYP with moderate, acute or severe mental health problems that are causing significant impairment to their day-to-day life. These include:

- depression, anxiety, PTSD and behavioural problems
- hyperkinetic and obsessive compulsive disorders and tics
- significant self-harm or suicidal thoughts
- attention deficit hyperactivity disorder, autism spectrum and neuropsychiatric conditions.

The demand for specialist CAMHS services is increasing year on year. All referrals are triaged by a professional panel to ensure the CYP receives the most appropriate support. This may mean the referral (for example if it is related to bullying, bereavement or substance misuse) is redirected to another service.

Community teams do not provide a crisis service. Any referrals marked as urgent are reviewed within four hours and, if a crisis response is required, will be passed to the urgent help team. Urgent CAMHS referrals are seen within seven days if the referral meets the criteria.

Urgent help service

This specialist crisis resolution and home treatment team offers assessment and intervention for young people in crisis whose needs cannot be safely met by other services because they are at significant risk of harm to themselves or others. The service aims to provide the least restrictive options to hospital admission, trying to help CYP at home with their family or carers wherever possible.

Urgent and emergency care has been identified as a priority for investment across Sussex. Additional funding will be used to increase intensive home treatments and strengthen liaison services. A business case is being developed which is looking at patient flows to ensure the maximum impact for the additional investment. Commissioners hope the new enhanced service will be in place by April 2020.

Children and family eating disorder service

Commissioners across Sussex have joined forces to commission a Sussex-wide eating disorder service for CYP. Provided by SPFT, the service focuses on supporting the whole family, not just the young person. The team receives an average of 16 new West Sussex referrals every month.

The service offers intensive home treatment to CYP and their families, including psychological interventions, family therapy, psychiatry and nursing support.

A&E liaison

The CAMHS A&E Liaison Service, based at Worthing Hospital and St Richards Hospital in Chichester, provides mental health assessments, care planning and advice for CYP presenting at A&E. It supports CYP following a suicide attempt, self-harm, suicidal thoughts or psychosis.

It improves the quality of care for CYP experiencing mental health problems while in hospital and aims to prevent admission to inpatient mental health services where possible. The team also works with hospital staff, empowering them to better support patients with mental health needs. The service arranges onward referrals as appropriate and provides a follow up appointment for young people not known to CAMHS to aid with assessment, transition, signposting and any referrals.

There is an equivalent in-reach service to support West Sussex CYP who present at East Surrey hospital in Redhill.

Other SPFT services

SPFT also provides the Community Mental Health Liaison Service (see page 6); Assessment and Treatment Service for addressing harmful sexual behaviour (see page 11); support for the Youth Offending Service (see page 10); support for the Looked After and Special Guardianship Team (see page 10); support for unaccompanied asylum seeking children (see page 11) and is one of the providers of neurodevelopmental services (see page 13).

Neurodevelopmental pathway redesign

Commissioners have brought together SPFT, Sussex Community NHS Foundation Trust and Western Sussex Hospitals NHS Foundation Trust to transform pathways of care for CYP with attention deficit hyperactivity disorder (ADHD) and autism spectrum conditions (ASC).

A neurodevelopmental pathway (NDP) steering group has been established involving commissioners, the providers, West Sussex Parent Carers Forum, the CCGs, third sector providers and the local authority to develop a new service model for April 2020.

Families often report long waiting times for diagnosis and care; confusion about the roles of professionals on the pathway; and a need for more information and individual support before, during and after a diagnosis. The new service model aims to address all these issues and is backed by additional funding which will enable an expansion in the NDP workforce over the coming months.

In addition to senior clinical commitment to the NDP steering group and service redesign from the three main service providers, achievements this year include:

- The introduction of a multi-disciplinary team clinic to see CYP with possible dual diagnosis, reducing the need for additional appointments to see other specialists.
- The introduction of collaborative waiting list initiatives.
- Increased staff resource working specifically on the neurodevelopmental pathway.
- The introduction of a standard referral pack for ASC and ADHD to streamline and simplify the process for schools, GPs and families.
- Work with GPs to raise awareness and understanding of the condition and the most appropriate referral routes.

Building relationships and skills

Central to delivering our vision for better emotional wellbeing is enhancing the skills, knowledge and confidence of everyone who works with CYP to identify problems early and know how best to address them.

This year we have continued our successful training programme for the wider workforce. We have also made great progress in developing relationships across the whole system, with a particular focus on schools and GPs.

Working with schools

Over the year we have continued to strengthen our partnership with schools and colleges. Our aim is to support school staff to help children and families directly with appropriate advice, signposting and referrals and to help build a network for schools to work more closely and effectively with health services, particularly GPs.

We successfully applied to become a trailb;azer site to develop and implement Mental Health Support Teams (MHSTs) in Crawley and Bognor. The pilot is funded by NHS England for two years and will enable us to enhance the support available to schools and colleges.

MHSTs are an important strand of the Government's 2017 Green Paper 'Transforming Children and Young People's Mental Health Provision'. They will deliver evidence-based interventions for mild to moderate mental health issues and support the development of a whole school/college approach in each institution. They will also give timely advice to school and college staff and liaise with other services to help CYP get the right support and stay in education. Each MHST will include mental health and emotional wellbeing practitioners, senior therapist and educational psychologist and will work directly with around 500 CYP.

MHSTs are being introduced in a number of schools and colleges during the 2019/20 academic year, with the new staff undergoing placements and training with the University of Sussex. The MHSTs will start full operation from September 2020, with on-going rollout if they prove successful.

Children's wellbeing practitioners for schools and colleges

Two children's wellbeing practitioners have been recruited to work specifically with schools and colleges to enhance access and referral routes for CYP with low to moderate mental health needs. The new roles sit within the YES service, extending the reach of these crucial early support services and strengthening the integration with schools, colleges and other partners.

Working with GPs

We have been working with groups of GPs in Crawley and Worthing to explore their experiences of specialist CAMHS and emotional wellbeing services. The focus is on understanding how we can better engage GPs in the CYP mental health pathway and strengthen relationships between general practice and SPFT. We will be continuing this work, aiming to engage with all GP practices, to listen to their their feedback and develop a shared understanding of the most effective pathways for CYP with mental health and emotional wellbeing needs.

Training for professionals, parents and carers

Since May 2016 Coastal West Sussex Mind, in partnership with other subject experts, has been providing training to professionals and volunteers working with CYP such as GPs, social workers, teachers and police officers. This year, nearly 500 more have received training to increase their skills and confidence to identify and support CYP

experiencing mental health and emotional wellbeing issues, taking the total trained to over 2,000.

The service continues to offer in-house courses for schools, with topics including anxiety, low mood, attachment and trauma, and emotional resilience.

Training has also been extended this year to parents and careers, with over 150 attending courses covering a diverse range of issues from tics and Tourette's to exam stress and the adolescent brain. In addition, a number of e-learning courses for parents and careers are now being offered.

"I have a better understanding of the young person's world, how to engage them in dialogue, and the impact on their life."

Further information and resources

Resources available

Leaflets for parents and young people on self-harm and emotional wellbeing, containing useful tips and links to national and local services, have been developed in collaboration with young people.

Copies are available from:
publications@westsussex.gov.uk

Useful websites

Your space
West Sussex site offering information, resources and access to services for young people:
www.westsussex.gov.uk/education-children- and-families/your-space/

Contact the commissioning team

To get in touch with the team, please contact Aaron Gain, Children and Young People's Comissioning Team: aaron.gain@westsussex.gov.uk

Youth Emotional Support (YES)
Find out more about the YES service and how to access it: www.bit.ly/wsxyes

Sussex CAMHS website
Information about CAMHS for CYP, families, carers and professionals from SPFT:
www.sussexcamhs.nhs.uk

Free Your Mind
Find out more about the award-winning West Sussex young people's mental health campaign group: www.westsussex.gov.uk/education-children-and-families/your-space/participate/free-your-mind-mental-health-campaign-group/

Local transformation plan
Download the latest version of the LTP:
www.bit.ly/ltpoct18

Delivering With, Delivering Well
Information and newsletters from the West Sussex CYP IAPT (Improving Access to Psychological Therapies) programme and community of practice:
https://cypiapt.com/sussex-delivering-with-delivering-well-newsletter/

Healthwatch Youth Pack

January 30, 2020

Report by Healthwatch West Sussex

Executive Summary
This presentation concerns an overview of the new Youth Pack resource which will be made available to all stakeholders later in the Spring.

The Health and Wellbeing Board is asked to:
Promote awareness and endorse use of the Youth Pack to facilitate engagement with young people in ways that are meaningful for them, to test new ideas and evaluation services at an early stage of planning

1. **Background –** From engaging with Young People in 2019 we have found it is clear that Young People actively want to be part of developing solutions for their own mental and emotional health. We have coproduced this pack in response to identifying a gap in current engagement activities.

   We see this as highly relevant to the Children First Agenda as it in asset to achieving some of the aspirations.

2. **Proposals –** The Draft pack has already been further tested with schools, colleges and Youth Groups.

3. **Next Steps –** Healthwatch Plan to make the pack available, as a free resource,to all relevant stakeholder and community partners.

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A Focus on Children and Young People

Supporting co-production and good engagement

Young people have co-designed with Healthwatch West Sussex, a range of activities and information to promote productive health and care conversations.

These conversations are important to:

- know how to support young peoples' physical and mental wellbeing
- test out new ideas and assumptions
- promote health and care as a positive career opportunity
- empower young people to have their voices heard and to be active partners in making positive changes to our health and care system.

Contact us for our FREE Youth Pack

Healthwatch West Sussex - facilitating young people to become partners in the future of healthcare.

0800 012 0122 www.healthwatchwestsussex.co.uk
helpdesk@healthwatchwestsussex.co.uk

Youth Activity Resource Pack

How was the pack developed?

The Healthwatch Youth Pack is the result of our Board decision to invest some of our Community Interest Company social enterprise revenue.

Our Community and Engagement team had identified a need as a result of our Mental Health priority work with young people. As a result, our focus expanded to **wellbeing discussions, prevention, intelligence gathering and feedback on service design, development and evaluation.**

We engaged with young people throughout 2019 (including Colleges, National Citizens Scheme and SEN groups) and together we have **co-produced a range of activities.**

What is it?

- A *pick and mix* of 30+ **meaningful** resources and activities that encourage young people to share their experiences **and look at how experiences can be improved**

- Includes short activities for mentor groups

- Flexible and can grow according to the needs, motivations and interests of young people

- Free - we plan to make it available from Spring 2020 (digitally and in a physical re-useable pack – subject to sponsorship)

What does it offer?

In a climate where we're all stretched, this offers an effective way of starting conversations, transferring knowledge and developing partnerships to find solutions.

- **explicitly invites** service providers to discuss plans with young people
- enables commissioners and providers to **embrace** the principles of **Children First** and supports the behaviour changes that may be needed

What's in the Youth Activity Resource Pack

- Hey – Tips to Help You
- Taking Care of Me
- Coping Mechanisms
- Holistic Health
- Developing Communications
- Listen to ME
- Just Tell – Your Voice Matters
- Posters
- Games & Activity Resources
- We Listened, We Acted, Things Changed
- Self Esteem
- Support List for Health, Advice & Wellbeing
- Shaping New Services
- What Would We Do
- How Services Can Change
- Volunteering Activities – Citizens Service and DofE
- All About You – Wellbeing
- Fortune Teller
- Evaluation Forms
- Impact Measurement

What have we found?

Our conversations with young people highlighted a deficit in knowledge about **where** and **how** they can get support, and a **belief** that help is only available if you're in a crisis. The Pack aims to address this with activities :

- focussed on **prevention** and conversations of wellbeing and support (includes materials produced by young people working with us)
- develops communication skills and how to get the best from appointments and conversations with health care providers and each other – making sure **their** voices are heard in **their** care.

What are the benefits?

- Enables all stakeholders to gain intelligence directly from young people, and **shape services effectively to their needs**
- Empowers young people to understand that they can facilitate change, so becoming **powerful voices** in their own wellbeing
- Supports people when faced with change, such as transitioning to adulthood.

Working with young people in this way has shown their appetite for creating materials and solutions to support their peers where they see a need.

What else does it offer?

The County Council are issuing a PSHE strategy (with guidance) – the pack could support the core themes of **health and wellbeing, relationships** and **being active citizens.**

Schools have commented that this would work well for them and have input feedback to ensure it is fit for purpose.

Youth Groups including Scouts, Guides, Drama and Youth Clubs have already used the pack


Support List for Health, Advice and Wellbeing

healthwatch West Sussex

Introduction

Need some help? We've put together a list of services to help you find support. It doesn't cover everything available but it is a good starting point.

We will review this info quarterly, but information can go out of date quickly. Please, let us know if any of the service information is wrong. Please also be aware that some of the services detailed will have waiting lists and a criteria for accessing the service.

Remember to talk! It may sound silly, but talking can help. Your friends or family may be able to make a difference. Or talk to someone at school or college. Schools will have pastoral and/or support staff who will be able to offer some guidance and possibly some 1-2-1 time. Or visit your GP and explain how you're feeling. They can also help you find support.

It's worth talking things through with someone you trust. They might be able to help.

Please contact the Healthwatch Helpdesk for information and guidance if you can't find it here. 0300 012 0122 or helpdesk@healthwatchwestsussex.co.uk

Self Help

West Sussex Your Space (https://www.westsussex.gov.uk/education-children-and-families/your-space/) have a list of phone and tablet apps to try that you may find useful. Search for them on your app store by name:

- Bellybio - Breathing techniques to help calm you down (available on Apple)
- Headspace - Guided meditations (this app has some free meditations, but also offers a subscription)
- Mindshift - Anxiety coping tools
- Moodspace - Short, daily workouts to put your mood in a better space
- Rise Up: Eating Disorder Help - If you are struggling with food, dieting, exercise and body image
- SAM Anxiety Management - Tracker to see how your anxiety changes
- Sleepio - Support for those with sleeping difficulties. Found on iPhone, Try Sleepo, baby sleep sounds, in the Play store.
- Smiling Mind - Designed to assist people in dealing with the pressure, stress and challenges of daily life
- Stay Alive - Information for those who feel suicidal
- stem4 - Provides mental health support for anxiety, depression, self-harm, eating disorders and addiction.
- Virtual Hope Box - Distraction, inspiration, relaxation and coping tools.

Find, Get, Give - A national website that [illegible] carers and professionals. Access to [illegible] service directory of national [illegible]

[illegible]ople, parents and [illegible] guides, blogs and a

© Healthwatch West Sussex

How to get in touch and be involved

For information and advice, or to share your story call 0300 012 0122
or email us at helpdesk@healthwatchwestsussex.co.uk

@Healthwatchwestsussex

@Healthwatchws

Date of meeting:	30 January 2020
Item Title:	Testing Community Based Models of Access to Health Services: HARP Project, West Sussex
Executive Summary:	This paper concerns the award of Public Health England grant monies, to test community based models of access to health services. In West Sussex, the grant will fund a twelve month project - the Hospital Admission Reduction Pathway (HARP). This will improve access to health services for adults with co-occuring substance misuse and mental health needs who are experiencing or at risk of returning to rough sleeping.
Recommendations for the Board:	The Board is asked to • Note the context and work to date. • Provide strategic leadership and governance of the twelve month project. • Receive regular updates through the life of the project and consider learning from its implementation and delivery.
Relevance to Joint Health and Wellbeing Strategy:	Provision of effective high quality drug and alcohol recovery services make clear contributions to West Sussex goals of improving the health and wellbeing of residents of all ages, and to supporting strong and safer communities. Activity will support efforts to reduce risks of drug related deaths and reduce the numbers of drug deaths in treatment (an area of focus, working with Public Health England)
Financial implications (if any):	None. The 12 month revenue funding of £345 529 has no match funding expectations. However, all funding may be immediately repayable to Public Health England if any of the grant conditions, contained in the grant agreement between WSCC and PHE are not met.
Consultation (undertaken or planned):	Planned Service Launch in April, date and details tbc
Item author and contact details:	Anna Raleigh, Director Public Health Contact: Philippa Gibson, Senior Commissioning Manager Philippa.gibson@westsussex.gov.uk

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Report Title
Testing Community Based Models of Access to Health Services: HARP Project, West Sussex

Date
30 January 2020

Report by
Anna Raleigh, Director of Public Health

Executive Summary
This paper concerns the award of Public Health England grant monies, to test community based models of access to health services.
In West Sussex, the grant will fund a twelve month project - the Hospital Admission Reduction Pathway (HARP). This will improve access to health services for adults with co-occuring substance misuse and mental health needs who are experiencing or at risk of returning to rough sleeping.

The Health and Wellbeing Board is asked to:
1) Acknowledge background and work to date.
2) Provide strategic leadership and governance of the twelve month project.
3) Receive regular updates through the life of the project and consider learning from its implementation and delivery.

1. Background

1.1 In May 2019, Public Health England (PHE) announced availability of £1.9million revenue funding to be awarded in 2019/20 and sought expressions of interest from partnerships between local authorities and clinical commissioning groups.

1.2 The aim of the funding is to test community based models that will improve access to health services for adults with co-occuring substance misuse and mental health needs who are experiencing or at risk of returning to rough sleeping.

1.3 The West Sussex Expression of Interest (EOI) was a partnership bid, drawn up with input from: Turning Tides; Stonepillow; CGL; Emerging Futures; Crawley Open House; A+E Consultant at Worthing Hospital; Primary Care; NHS Coastal West Sussex Clinical Commissioning Group and West Sussex County Council.

1.4 In the EOI, West Sussex Health and Wellbeing Board was identified as the local body to provide strategic leadership and governance.

1.5 Following shortlisting and interview, PHE has awarded funding to six projects, of which West Sussex is the only non-unitary. The other selected areas are: Lambeth, Leeds, Newcastle, Portsmouth and Westminster.

1.6 PHE will be funding an external evaluation.

1.7 West Sussex bid has been awarded £345 529 revenue, non-recurring.

1.8 The project in West Sussex is HARP (Hospital Admission Reduction Pathway). The model is made up of i)three nursing posts co-located in homeless services who will provide street triage and support high risk individuals; ii) three non- clinical posts located in hospitals, who will co-ordinate integrated treatment and support health colleagues; iii) qualified coaching support from people with lived experience.

1.9 HARP will assume the Systems Leadership approach now embedded through West Sussex in the sector, and will provide training from the Leadership Centre.

1.10 The model aims to engender a better understanding of pressure points in the current system, and how impact can be maximised by this one year intervention that supports individuals with multiple needs, often at times of crisis.

2. Proposals

2.1 Funding from PHE is made available to the local authority via a Section 31 Agreement under the Local Government Act 2001. There are no match funding requirements.

2.2 A Grant Agreement is drawn up between the County Council and the prime contractor, Change Grow Live (CGL).

2.3 The programme will run for twelve months from February 2020. Project timelines are drawn up, with February start in Worthing, followed by April start in Chichester/Bognor and Crawley.

2.4 Contract review meetings will be held between WSCC and prime contractor CGL a minimum of quarterly.

2.5 The HARP Steering Group will have collective oversight of the project and receive regular updates on progress and learning, but this will not cross over into performance management duties.

2.6 West Sussex Health and Wellbeing Board will provide strategic leadership and governance.

2.7 CGL will sub contract with relevant parties (Turning Tides; Stonepillow; Open House Crawley; St Johns Ambulance and Emerging Futures).

2.8 The Chief Executive of Turning Tides will lead on the Systems Leadership element of the HARP programme, and has secured the National Director for Systems Leadership at the Leadership Centre to run master classes.

3. Next Steps

3.1 Mobilisation group (chaired by Substance Misuse Commissioner, WSCC) and Steering Group (chaired by Chief Executive, Stonepillow) are established and will continue to meet regularly.

3.2 A launch event is scheduled for April 2020 in Worthing.

3.3 The grant will be monitored by PHE in accordance with Cabinet Office minimum standards. The Council will be required to submit regular financial and performance returns. All funding may be immediately repayable to PHE if any of the grant conditions, contained in the grant agreement, are not met.

3.4 The HARP partnership will co-operate in the learning process with all other successful areas, and will co-operate and share anonymised data with PHE and external evaluators.

3.5 Regular updates will be brought to West Sussex Health and Wellbeing Board with the purpose of:

- Identifying what is effective in improving access to services for adults with substance misuse and mental health needs who are experiencing or at risk of returning to rough sleeping.
- Informing priorities and policy making in this area.
- Informing local commissioning for people who rough sleep.

Anna Raleigh
Director for Public Health

Appendices: None
Contact: Philippa Gibson, Senior Commissioning Manager Substance Misuse.
Philippa.gibson@westsussex.gov.uk

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Report Title: West Sussex Joint Dementia Strategy 2020-23

Date: January 2020

Report by: Irene Loft, Senior Commissioning Officer, Adults & Health and Tracey Wooldridge, Commissioning Manager Mental Health and Dementia
Horsham and Mid Sussex CCG and Crawley CCG, Coastal West Sussex CCG

Executive Summary
This paper concerns the refresh of the Dementia Framework 2014-19 and development of the new Joint Dementia Strategy 2020-23.

It sets out the work that has been done to review the progress that has been made to date and identify gaps in the pathway. The paper also summarises what has been done to ensure the new strategy has been developed collaboratively with statutory and voluntary sector partners, with family and friend carers and individuals living with dementia.

The Health and Wellbeing Board is asked to:

1) Review the draft West Sussex Joint Dementia Strategy 2020-23 and support its launch in the spring.
2) Provide ongoing oversight, of progress against the strategy.
3) Champion the new Dementia Strategy and the need for additional investment to maximise the preventative value of supporting those living with dementia to remain as independent as possible.

1. Background

1.1 In 2014, West Sussex County Council in partnership with all three Clinical Commissioning Groups (CCGs); Crawley, Horsham and Mid Sussex and Coastal West Sussex, launched its first joint strategy for dementia; the Dementia Framework West Sussex 2014-19.

1.2 On the 5 February 2018, a HASC Business Planning Group was briefed that a full review of Framework led by WSCC and all 3 CCGs would be undertaken.

1.3 A robust review of the Framework took place during 2018. The review was based on health and social care performance data and on findings from an extensive stakeholder engagement exercise.

1.4 It was a county-wide engagement that comprised focus groups, interviews and on-line surveys. In total, 366 family carers, people living with dementia and health and social care staff took part.

1.5 It was found that there had been some progress since the launch of the Dementia Framework in 2014. For example, the diagnosis rate has increased from 46% in 2014 to 66.1% in November 2019, there has been an improved offer of post-diagnostic support for the individual and their family carers from Dementia Advisers and Dementia Support Workers and dementia friendly communities have grown and extended their reach and there is now 9 Local Dementia Action Alliances in the county. There is still more to do to improve the experience of people affected by dementia. Findings from the review have been used to refresh the Dementia Framework and set priorities for the Dementia Strategy 2020-23.

1.6 A task & finish group comprising representatives from health and social care statutory and voluntary and community sector providers have met regularly to drive through the development of the strategy. Alongside this, 4 focus groups comprising people living with dementia and/or family and friend carers from Worthing, Crawley, Horsham and Chichester have met to provide feedback to the task & finish group.

1.7 The task & finish group agreed a number of gaps in the pathway for someone with dementia and there have been a number of sub groups meeting to look at these gaps in more detail. Objectives of the sub groups have been to:

- explore and agree a plan for ensuring there is a joined up approach to how people with complex and challenging behaviour receive good quality care and support;
- agree a plan for how we work collaboratively to support Dementia Friendly Communities to become sustainable and for them to extend their reach and spread;
- clarify the current pathway of diagnosis and post-diagnostic support for people with Alcohol Related Dementia and to agree a map or pathway to support;
- explore how we raise awareness of dementia amongst Black and Minority Ethnic groups and how we ensure people from minority groups receive good quality post-diagnostic support;
- identify gaps and agree a plan for how family and friend carers access information and advice and support throughout their journey
- identify gaps and agree a plan for how people with dementia have access to meaningful person-centred daytime activities;
- explore the current process for care planning and agree a plan for ensuring people living with dementia have a care plan in place that is holistic and empowers the person living with dementia to live well with dementia;
- identify a pathway to diagnosis and support for people with learning disabilities and agree training required for support staff.

There is currently no additional funding identified for the implementation of the new Dementia Strategy and all of the above sub groups have therefore looked at what can be achieved in the current financial climate and what can be achieved if there is a little or a lot more funding available in the future. These

aspirations have been included alongside the delivery plan together with some estimated costings to be used as a basis for any future business case.

2. Proposals

For the Health & Wellbeing Board to:

1) Review the draft West Sussex Joint Dementia Strategy 2020-23 and support its launch in the spring.
2) Provide ongoing oversight, of progress against the strategy.
3) Champion the new Dementia Strategy and the need for additional investment to maximise the preventative value of supporting those living with dementia to remain as independent as possible.

3. Next Steps

The draft Dementia Strategy will go to HASC in March for sign-off. Following this, there will be a public launch in Spring 2020.

Anna Raleigh
Director for Public Health

Appendices:
Draft West Sussex Dementia Strategy 2020-23

Contact: Irene Loft, Senior Commissioning Officer, Adults & Health Directorate, tel: 022 23793, email: irene.loft@westsussex.gov.uk

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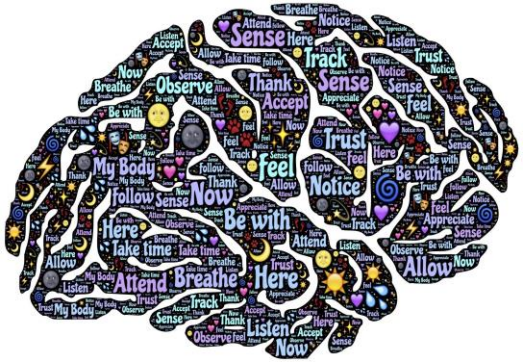


WEST SUSSEX
JOINT DEMENTIA STRATEGY
2020 TO 2023

Developed in partnership with
West Sussex County Council and
NHS Clinical Commissioning Group

CONTENTS

ACKNOWLEDGMENTS

We are very grateful to the residents of West Sussex, our partners, staff and other stakeholders who were instrumental in the successful development of this strategy through their participation and feedback.

Particular thanks go to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains and Worthing Town Cryer's. Age UK West Sussex's K2 Club members, Sangam Women's Group and Carers Support West Sussex East Grinstead carers group.

FOREWARD

With the ageing population of the county expected to rise exponentially in the next 10 years, a timely diagnosis for those with dementia is vital not only for them, but also for their family and friends. A timely diagnosis enables them to maximise control over their lives by planning ahead and accessing support to ensure that they can enjoy an active and independent life for as long as possible.

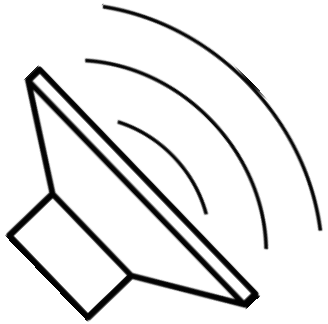
The County Council and the Clinical Commissioning Group are resolved to make West Sussex the best place to live well with dementia. This strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to delivery of services, we must ensure that there is adequate and meaningful provision to help and support those with dementia, as well as their family and friends.

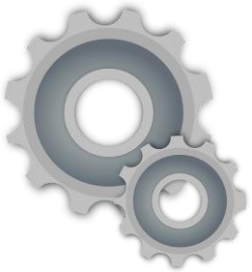
Promoting self-care and self-empowerment is often a primary requirement for those who want to stay in their own homes. Family and friend carers are influential in supporting those living with dementia and it is therefore key that we support them in their caring role. Carers tell us that their wellbeing is as much about their experience of the health and social care system as it is about services for them. We need the system not only to recognise carers, but to listen to them and involve them as appropriate.

I hope you will find this strategy informative and of interest. I believe that the more we engage and plan together with those who need our support, the better quality of life will be achieved for them which for me is of paramount importance.

Amanda Jupp

Chair – West Sussex Health and Wellbeing Board Cabinet Member for Adults and Health West Sussex County Council





INTRODUCTION

This is West Sussex's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out our commitments, the strategy provides a framework for further action to ensure the realisation of our shared vision for dementia in West Sussex.

This strategy has been developed in partnership with Health, Social Care, Councils and Community and Voluntary providers. It is based on the findings of the 2018 review of the Dementia Framework West Sussex 2014-19 and includes direct input from people with dementia and their families and carers. The Strategy sits within the context of national and local policies, guidance and legislation.

What is dementia?

The term dementia describes a set of symptoms including memory loss, mood changes, and problems with communications and reasoning. It is caused by diseases of the brain, the most common being Alzheimer's.

Dementia is not a natural part of growing old and, although dementia is more common in people over the age of 65, the condition can also be found in younger people.

Audience for the strategy

The primary audience for the West Sussex Joint Dementia Strategy 2020-23 is the Health & Wellbeing Board, local leaders, officers, commissioners and providers responsible for its delivery. However, care has been taken to make the strategy as accessible as possible for residents, staff and partners in understanding priorities and how all partners can contribute to them.

Findings from the review of the Dementia Framework

Findings from a review of the current Dementia Strategy, the Dementia Framework 2014-19 in 2018, showed there had been improvements in diagnosis rates and the care and support people with dementia and their family and friend carers receive during their journey. It was noted though that there is still more that can be done to improve their experience. This strategy sets out what we plan to do about this.

The strategy builds on the work of the 2014-19 Dementia Framework and the progress we have made. It refreshes our goals so that they better reflect the current financial climate, the changing needs of the population together with new local and national plans, policies and legislation. The strategy aims to set out the plan for action over the next three years by the County Council and the Clinical Commissioning Group (CCG) in order to inform the planning, commissioning and provision of services.

This Strategy is not a stand-alone document but sets the direction of travel and complements the many strategies and plans we already have, under one clear vision and purpose.

How we will get there

It is essential that a collaborative approach is taken across health, social care, community, voluntary and private providers, together with local people to achieve our objectives. Meeting the challenges faced needs a commitment and willingness to innovation and learning and there needs to be a focus on community led support, prevention and a strengths-based approach to Adult Services i.e. for an individual to be enabled to see the value they bring and resources around them rather than focusing on any negative characteristics.

The strategy will be supported by a delivery plan with clear measures and points of review to ensure that the intended aims are being achieved. The delivery plan includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved in commissioned services within the current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available in the future.

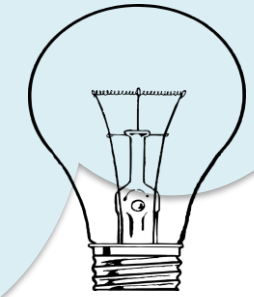
UNDERSTANDING THE CHALLENGE

There are three main challenges we must address over the course of this strategy.

1. An ageing population. With the rise in the number of people developing dementia over the next ten years set to rise, often with other significant and life-limiting chronic conditions. This means we should continue to look at how we can redesign and transform services and deliver more care and support in our local communities.

2. A timely diagnosis and consistent offer of person-centred, coordinated and flexible support for people living with dementia and their family and friend carers at every stage in their journey. This is key to ensuring people can live well with dementia.

3. Challenges within the care market around recruiting and retaining health and social care staff skilled in delivering good quality dementia care and reductions in the number of care home beds registered to support people with dementia.



STRATEGY DEVELOPMENT PROCESS

Review of the Dementia Framework West Sussex 2014-19 including engagement with wider stakeholders.

- Identification of key issues and emerging themes
- Multi-agency task & finish group to drive strategy
- Engagement with people with lived experience
- Themed sub groups
- Equality Impact Assessment
- Draft strategy consultation with stakeholders
- Strategy update and sign-off

OUR VISION

To improve the health and wellbeing of local people, and for those people who develop dementia to be supported to maintain their independence for as long as possible.

People with dementia and their families and carers receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice.

People with dementia and family and friend carers have access to timely, skilled and well-coordinated support throughout their journey.

People with dementia and their family and friend carers receive care and support that focuses on an individual's strengths and looks to promote their wellbeing.

People with dementia, along with their families and carers are central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

For supportive communities, where people feel able to participate in community life without stigma.

WHERE WE ARE NOW

In 2018, a full review of the Dementia Framework West Sussex 2014-19 took place. It was led by the County Council and all three Clinical Commissioning Groups and included a public engagement with around 400 different people and organisations. These are just a few of the achievements that were identified as part of the review:

West Sussex Dementia Learning & Development Framework. An on-line resource to signpost people to free learning resources.

All hospital staff trained in dementia awareness, care and support. John's Campaign and open visiting hours are just a few of the initiatives taking place in all our hospitals to improve patient outcomes.

Dementia Zone on the Council's Connect To Support website providing information about dementia and links to support.

Learning and training for family and friend carers through Alzheimer's Society and Carers Support West Sussex.

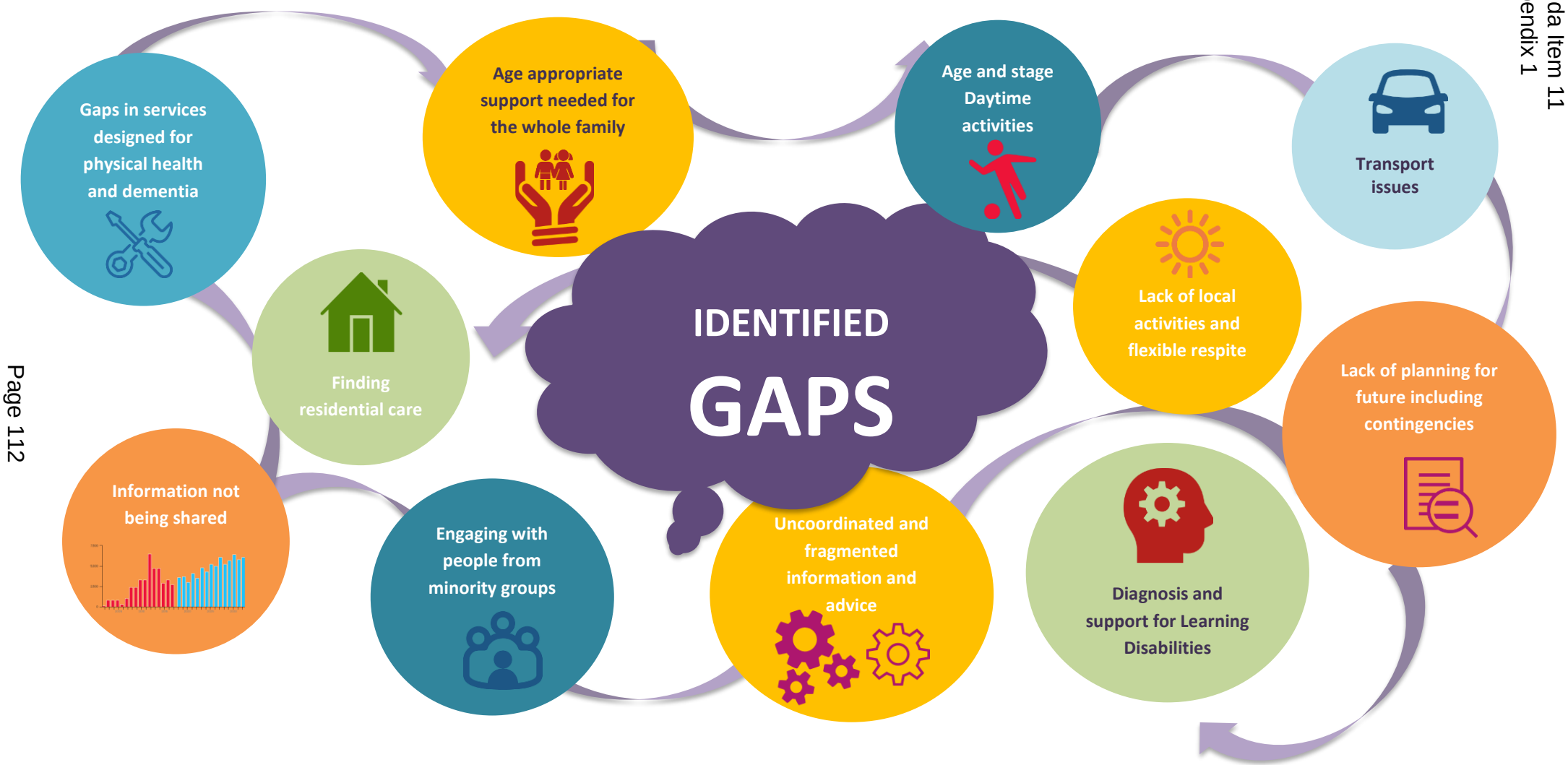
More people receiving a diagnosis and follow-up support. Around 20% more people are now receiving a diagnosis of dementia and the number of people registered with GP's has increased by 28%.

A more dementia-friendly West Sussex. 10 Local Dementia Action Alliances in West Sussex and around 300 members.

Libraries running Memory Management Ticket; Reminiscence Collections, dementia awareness drop-ins and Reading Well Books on Prescription for dementia.

Weekend away short breaks for younger people living with dementia run twice a year.

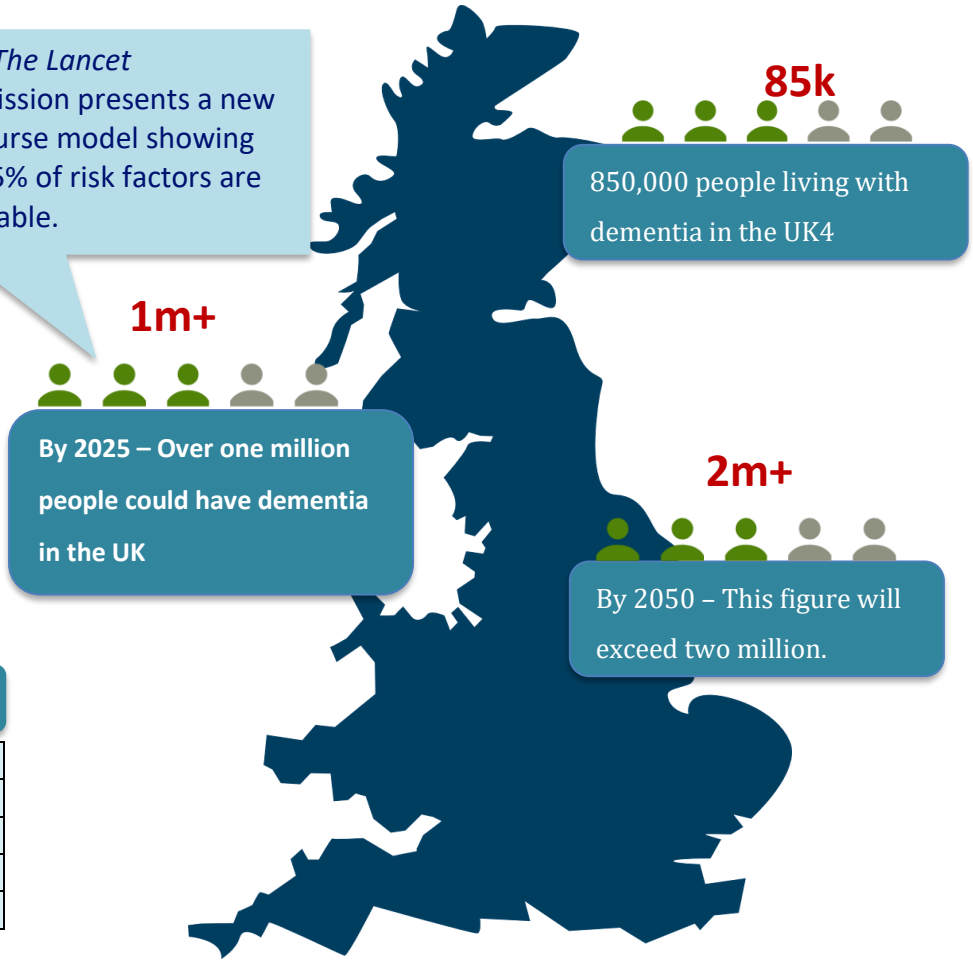
However, there is a significant number of people living in West Sussex with undiagnosed dementia and many people who feel unsupported following diagnosis. This document sets out what we plan to do about this.


IDENTIFIED
GAPS
Gaps in services designed for physical health and dementia
Age appropriate support needed for the whole family
Age and stage Daytime activities
Transport issues
Finding residential care
Lack of local activities and flexible respite
Lack of planning for future including contingencies
Information not being shared
Engaging with people from minority groups
Uncoordinated and fragmented information and advice
Diagnosis and support for Learning Disabilities

THE NATIONAL PICTURE

Most people associate dementia with older people but there are more than **40,000 people in the UK under the age of 65** years who are affected by this condition.

Note: The Lancet Commission presents a new life-course model showing that 35% of risk factors are modifiable.



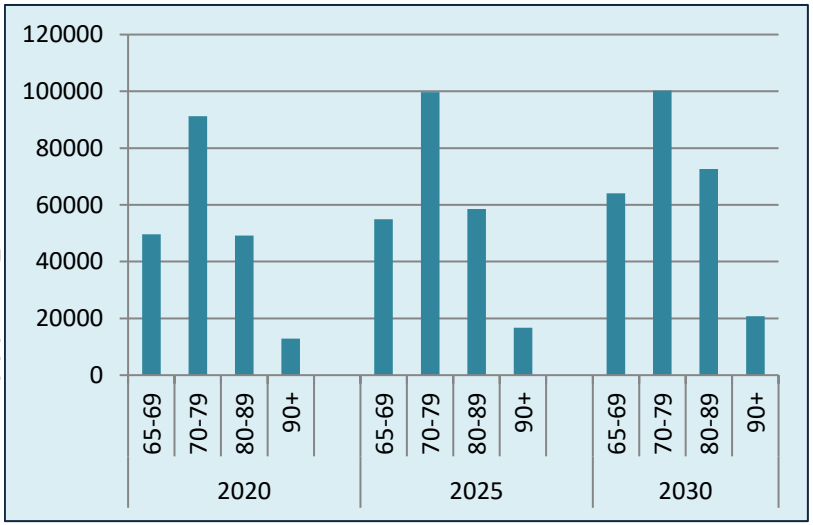
Projected number of older people living with dementia 2019-2040 England

	2019	2020	2025	2030	2040	%change
Mild dementia	107,100	108,300	118,900	136,100	166,700	56%
Moderate dementia	206,300	198,900	210,100	235,600	276,100	34%
Severe dementia	434,600	461,900	569,400	674,400	909,600	109%
Total	748,000	769,200	898,500	1,046,100	1,352,400	81%

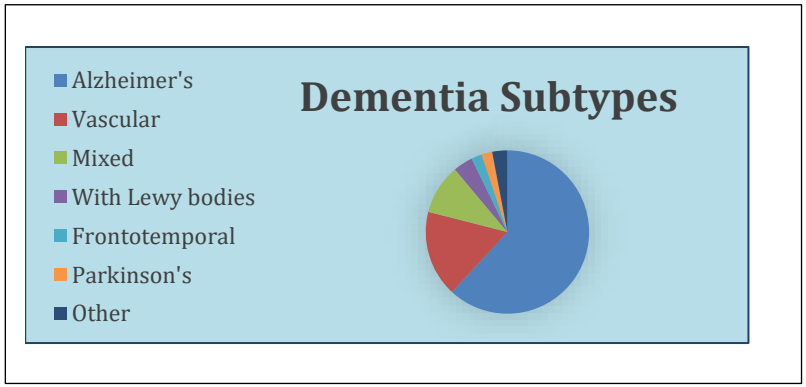
There are 850,000 people in the UK living with dementia, 42,000 of whom are under the age of 65. Many people with dementia also live with one or more other health conditions. Studies have shown that: 41 per cent have high blood pressure • 32 per cent have depression • 27 per cent have heart disease • 18 per cent have had a stroke or transient ischemic attack (mini stroke) • 13 per cent have diabetes (Barnett et al, 2012).[11]

THE LOCAL PICTURE

The population of people over age 65 is set to rise in the next 10 years



Highest increase is in people aged over 80



See Appendix C for a cartogram showing estimated population over age 65 with dementia at ward level

How dementia might look in next 10 years

	2020	2025	2030
Early onset (under 65)	500	550	600
Late onset	15,700	18,250	21,300
Total dementia	**16,650**	**19,350**	**22,450**

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800
TOTALS	**16,650**	**19,350**	**22,450**

People with mild symptoms will be able to remain independent in their own home. For some people in the 'Moderate' and those in the 'Severe' categories, more support and perhaps long-term care may likely be needed.

No. People with Down's Syndrome in West Sussex likely to have dementia

Age in Years	2009	2015	2020	2025	2030
45 -54	9	10	10	10	8
55-64	18	18	18	21	21
Sub-Total: 35 - 64	**27**	**28**	**28**	**31**	**29**
65 and over	1	2	2	2	2
TOTAL	**28**	**30**	**30**	**33**	**31**

Source: www.pansi.org.uk/index and www.poppi.org.uk/index

This strategy is based on the following relevant national and local policy, guidance and legislation:

NATIONAL CONTEXT

The **NHS Five Year Forward View** and the Department of Health **Prime Minister's challenge on Dementia 2020** set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers.

Ageing well and caring for people with dementia are both key priorities in the **NHS Long Term Plan**. The Plan focuses on the need for people to be helped to stay well and to manage their own health guided by digital tools. It also calls for a transformed workforce with a more varied and richer skill mix.

Care Act 2014 created a new legislative framework for Adult Social Care. Local Authorities have new functions to ensure people who live in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs and to have a range of provision of high quality, appropriate services to choose from. The Care Act also gave carers a legal right to assessment and support.

Five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life. (See Appendix A)

LOCAL CONTEXT

West Sussex Plan – Priorities around Independence for Later Life.

Sussex Health and Care Partnership Strategic Delivery Plan – **Appendix -** West Sussex Place Based Response to the Long-Term Plan October 2019

Joint Commitment to carers 2015-20 – states the main priority areas for family and friend carers for health and social care. This document will be refreshed during the course of this Strategy.

West Sussex Joint Health & Wellbeing Strategy 2019-24 sets out the Health and Wellbeing Board's vision, goals and ways in which it will work to improve the health and wellbeing for all residents in West Sussex.

Adult Social Care in West Sussex – Our vision and strategy 2019-21 - sets out how we will continue to work together to build on the good progress we have made to implement a strength-based community-led approach, focusing on prevention and reablement, supporting family and friend carers, and working towards the integration of services. It is anticipated this document will be refreshed during the course of this Strategy.

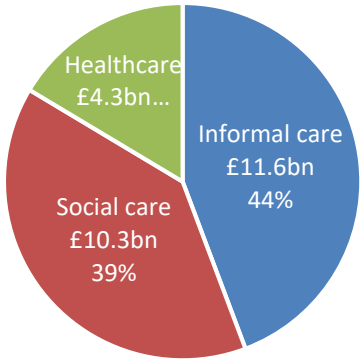
Sussex Community NHS Foundation Trust Dementia Strategy.

Western Sussex Hospitals NHS Trust Dementia Strategy

THE ECONOMIC COST

There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn[10].

Social care is projected to account for a slightly larger proportion of the total costs, and unpaid care a slightly lower proportion, in 2030 than in 2019. The proportion of older people living with dementia who have severe dementia is projected to rise in the next decade (see 'Local Picture' section). The likelihood of living in a care home increases with severity of dementia, which means that this rise will impact on the cost of social care over time.



West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)[9]					
	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

The total costs here include all those associated with supporting older people living with dementia rather than the extra costs attributable specifically to dementia itself.

The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition at an average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long term residential and nursing care.

More than half the number of people in this group are over the age of 85 with a total weekly net spend on residential and nursing care of around £128,000. With numbers of people in this age group expected to rise by 60% in the next 10 years, resources will need to focus on keeping people at home for longer and away from more expensive long-term care.

Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m*.

The need to ensure we continue to improve services to meet the needs of people affected by dementia is a high priority. However, the County Council and Clinical Commissioning Group are working with reduced public funding. The strategy has therefore been developed within the context of these financial restraints.

A delivery plan underpins this strategy and includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved within current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available over the course of the strategy.

*People aged 65+ with dementia that are short stays (1 night or less) is estimated to be £1.6m. 2017 data

THE DEMENTIA WELL PATHWAY

The Dementia Well Pathway has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and cares from prevention to end of life care. This strategy has used the dementia well Pathway as a framework with which to present its goals for the next three years.

The Dementia Well Pathway has been used as a <u>foundation</u> for developing the goals of the West Sussex Joint Dementia Strategy 2020-23.

PREVENTING WELL

> *West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves.*

Overview

More people in West Sussex are living for longer, many not in good health and spend years living with complex and long-term health and care needs such as dementia. This puts extra demand on health and care services and makes it more difficult for patients to receive the right level of care. There are some risk factors you cannot change but research suggests up to one in three cases of dementia are preventable. Risk factors that may be preventable include:
Diabetes (type 2) high alcohol intake - high blood pressure - lack of exercise - obesity - poor physical health - smoking.
Other risk factors that could contribute to the risks are: hearing loss, hypertension, depression and social isolation.

Key Issues & Challenges

- West Sussex is a county with easy access to good green spaces that provides opportunities for people to get more physically active.
- The perceived stigma of dementia can prevent people from going to their GP about symptoms they may be worried about. It is important there is good information available about the early signs and symptoms of dementia and positive messages about the benefits of diagnosis.
- Risk factors across the lifecourse approach as identified in the Joint Health & Wellbeing Strategy. For example, educational attainment, physical inactivity etc.
- The diagnosis rate for people from black and minority ethnic (BAME) communities has been historically low even though there is an increased risk of dementia for this group of people. More needs to be done to ensure there is good information about the risk factors, early signs of dementia and the benefits of diagnosis.
- For people with learning disabilities, particularly Down's Syndrome, where there is an increased risk of dementia, there is a need to ensure that they and their families and carers have access to information at an early stage about the risks of dementia and the early signs of dementia in an accessible format.
- Family and friend carers are at increased risk of loneliness and physical and mental health problems.

Prioritising prevention
The recent government policy document 'Prevention is better than cure' (2018) sets out a call to action for prevention to be at the heart of everything we do. This is reiterated by the NHS Long Term Plan (2019) positive shift towards prevention and reducing health inequalities. The Plan also emphasises the need to make better use of Digital Technology.

Our goals	What we mean
People live, work and play in environments that promote health and wellbeing and support them to live healthy lives. For Individuals, families, friends and communities are connected.	The prevalence of smoking is reduced across the county. The increase in people overweight or obese is reduced. More people aware of the impact that their alcohol consumption is having on their long-term health. More people becoming physically active. An increase in the number of people with learning disabilities receiving an Annual Health Check. To work with our communities and partners to empower and support networks of families, friends and communities to find solutions to local problems which have an impact on dementia risk. *(West Sussex Joint Health & Wellbeing strategy 2019-24)*
There is greater awareness and understanding of the factors that increase the risk of dementia and how people can reduce their risk by living a healthier life	For people to have access to information and advice so that they understand the risk factors for dementia and how their risk could be reduced. Carers are supported to remain physically and mentally well (West Sussex Joint Commitment to Carers 2015-20) There is greater public awareness about dementia and increased understanding to reduce stigma. All groups of people including those from black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities as well as people with learning disabilities are aware of the symptoms of dementia and know what steps they can take to reduce their risks. People accessing behaviour change interventions and programmes in mid-life are advised that the the risk of developing dementia can also be reduced. Adults aged 40 to 74 access the free NHS Health Check that is designed to spot early signs of heart disease, diabetes, kidney disease, stroke and dementia. An NHS Health Check also help find ways to lower the risk and provides information on dementia risk.
Early intervention and ongoing support for hearing loss	Given the evidence of a link between hearing loss, cognitive decline and dementia, early intervention and on-going support for any underlying hearing loss may have an important role to play in reducing both the risk and impact of dementia. National Institute for Health & Care Excellent (NICE) recommends that local services consider: referring adults with diagnosed or suspected dementia or mild cognitive impairment to an audiology service for a hearing assessment and referring adults with diagnosed dementia or mild cognitive impairment to an audiology service for a hearing assessment every 2 years if they have not previously been diagnosed with hearing loss. People need to be encouraged to take action when they think they may have hearing loss i.e. get their hearing checked and get hearing aids if appropriate.

PREVENTING WELL

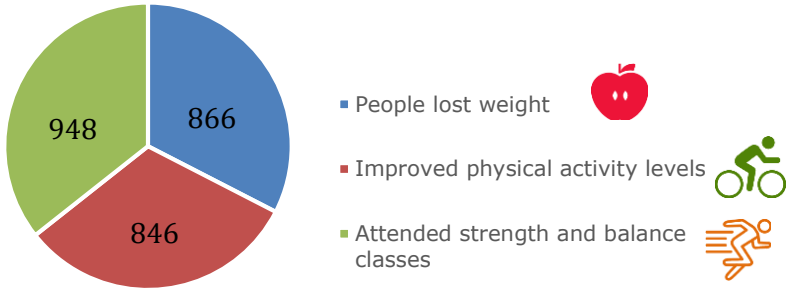
Local Key Initiatives/Examples of Best Practice**

- Public Health initiative/campaign - Ageing Well and Dying Well – compassionate communities.
- Local Wellbeing Walks.
- Coastal Care – Inspiring Healthier Communities Together
- Social prescribing service.
- Community sheds.
- Lifestyle related public health outcomes e.g. smoking prevalence etc.
- Wellbeing programmes and wellbeing deals: partnership arrangements between the County Council and District & Borough Councils.
- Health in all policies is an approach to public policies across sectors including housing, planning, transport etc.
- Public Health's Social Isolation and Loneliness project. For example, Adur & Worthing Council's Thriving Communities.
- Loneliness and social isolation is a priority area for action in the Age Well component of the West Sussex Joint Health and Wellbeing Strategy 2019-24.
- Make Every Contact Count (MECC) – an initiative aimed at providing the knowledge and skills to enable public facing workforces to deliver very brief interventions on health and wellbeing.
- Age UK West Sussex social clubs, gyms and fitness classes for older people.

**commissioned and non-commissioned services

KEY DATA

In 2017/18 948 adults were supported through the Wellbeing Hubs.



In 2017/18:

68% of adults physically inactive

62% adults classified as overweight or obese

13% of adults were smokers

20–40% of people with dementia will have depression.[11] Depression is more common in people with dementia than those without. Depression is also common among family carers

In 2018-19 35.5% of those eligible took up the offer of an NHS Health Check

41%* of adult social care service users who have as much social contact as they would like.

35%* of adult carers having as much social contact as they would like.
*2017/18

DIAGNOSING WELL

> *West Sussex County Council and the Clinical Commissioning Group want to see all groups of people diagnosed earlier and get timely access to good quality post-diagnostic support. With a named coordinator and support to plan their future care along with those people important to them.*

Overview

For many people a diagnosis of dementia can be traumatic but for many people, it can also come as a relief. It helps people to plan ahead while they are still able to make important decisions. A timely diagnosis and follow-up support enable people with dementia and their family and friends the ability to maximize control over their lives and help to ensure that they can manage their condition, with the aim of ensuring they can live independently for longer.

In West Sussex, the pathway to diagnosis is normally through the GP who will refer the patient to the Dementia Assessment Service (DAS) or the Memory Assessment Service (MAS) once all other reversible causes of cognitive decline are ruled out. The MAS/DAS provides a high-quality diagnosis and follow up support for the patient and their family and friend carer from a Dementia Adviser.

Once people have received a diagnosis of dementia, they are provided with advice and given the opportunity to plan their future care along with those people who are important to them. Care planning provides an opportunity for people to be able to draw on their own strengths and assets and identify where additional support is required.

The Prime Minister's Challenge on Dementia recommends that a named co-ordinator is appointed who has a good understanding of the person and their needs along with how to navigate the health and social care system. In West Sussex, the GP is the named co-ordinator and is responsible for ensuring that the person diagnosed with dementia is linked into local support networks.

The Prime Ministers Challenge also recommends that people diagnosed with dementia and their families and carers should be given information about how they can participate in research after diagnosis and at each stage in their journey

DIAGNOSING WELL

Early Onset Dementia
Younger people with dementia (under the age of 65) face different issues, not least that they are more likely still to be working or have a young family. As this disease has been considered 'rare', there is often a long wait to diagnosis as other conditions are explored. Support designed for older people with dementia is often not suitable. This means that people with early onset dementia can find themselves isolated within the community.

Lesbian, gay, bisexual and transgender + (LGBT+) and Dementia
For older LGBT+ people, living with dementia can be additionally stressful. Not only is this group of people less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many people fear that mainstream care services will not be willing or are not able to understand how to meet their needs. As a more vocal and open generation follows behind, dementia services need to consider how they will meet their particular needs.

Learning Disabilities and Dementia
People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s. Symptoms of dementia can present differently so that people often do not recognise changes as being dementia related. Because of this, opportunities for early intervention are lost. In West Sussex, the pathway to diagnosis is patchy. This could be down to the lack of baseline assessments taking place.

Black Asian & Minority Ethnic Communities (BAME) and Dementia
The review of the Dementia Framework identified the need for there to be more support for these communities. Among the UK's BAME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.

Alcohol Related Dementia
Alcohol related dementia is more common in people in their 40s and 50s and comprises about 10% of the cases of young onset dementia diagnosed. The condition is poorly understood and often missed by health professionals. Patients struggle with the 'double stigma' of dementia and alcohol addiction and often end up in accident and emergency units because of a lack of community services or clear pathways to support. They also experience longer stays in hospital.[2]

Key issues and Challenges

- The fear of stigma can prevent a person from accessing a diagnosis, there is a need for good information to be available about dementia and the benefits of diagnosis.
- Early signs of dementia not being recognised in people with learning disabilities and baseline assessments not taking place.
- Long waits to diagnosis leading to people dropping-off the waiting list.
- Lower rates of diagnosis among people from BAME communities and in people with Alcohol Related Dementia.
- At the point of diagnosis, people receive a raft of information and advice, but it is not always easy for them to know where to access information and advice at a later stage.
- A system that is complicated and disjointed where people can get 'lost' along the way particularly when their needs change.
- Care plans not being shared with all those involved in the person's care.
- The need for services to stay connected to the person living with dementia.

Our goals	What we mean
People recognise the early signs of dementia and know what to do to receive a diagnosis	Improved dementia awareness raising through dementia friends training, media communications, social networking. People and organisations supporting the person suspected of having dementia in different settings such as housing support, residential and nursing care are skilled in identifying the symptoms and know what steps to take to support people to receive a diagnosis. This includes people and organisations supporting people with learning disabilities, younger people and people with alcohol related dementia.
All groups of people to receive a timely diagnosis	• For all groups of people suspected of having dementia to receive a timely quality diagnosis in an appropriate setting within a specified number of weeks. This includes people under the age of 65, people with alcohol related dementia, people with learning disabilities and people from BAME and minority groups such as Gypsy and Travelling Communities. • The referral rate for people from BAME groups to reflect the ethnic makeup of that geographic area. • Support is available for the person being assessed and their families throughout the diagnostic process. • For people in care settings showing signs of dementia to receive an alternative diagnosis where the full memory assessment process would not be in the best interests of the individual. GPs and practice nurses to use long term conditions clinics and health campaigns (e.g.: seasonal flu) to consider whether older people at risk of dementia have symptoms that may require further consideration
Improved access to information and advice	People diagnosed with dementia and their family or friend carers have easy access to information on planning and making choices about their care at the end of life. Information and advice should be easily accessible throughout the person's journey and as their needs change.

Improved access to good quality joined up support following diagnosis	• People receiving a diagnosis of dementia from the DAS/MAS together with their family or friend carers receive an offer of support following their diagnosis. This should include an extensive group programme. • Family carers should be given the opportunity to speak openly about the diagnosis their loved one has received either with them or separately. Post-diagnosis support to be tailored to include the needs of people under the age of 65, people with alcohol related dementia, people with learning disabilities, black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community.
People have the opportunity to plan for the future	• A care plan is developed together with the person and those involved in their care that is individual to the person's needs. A plan that includes the person's choices, hopes and aspirations which can guide professionals involved in their care. The care plan should consider cultural identity and faith etc. • The care plan should be used across the whole health, social care and community sector to ensure that all organisations understand the needs of the person with dementia, including recognising any additional conditions the person might have and their potential impact. Emergency and contingency planning needs to be embedded within the care and support plan. • Ongoing review of the care plan at least annually or more often if the person's needs and wishes change, by a health or social care professional skilled in care planning. • There is an easy route back into support if required at any point in the person's journey to ensure that those people affected by dementia do not fall through the 'net'. • People with dementia to be given the opportunity to plan for their end of life care and preferences, beliefs and values regarding their future care. This should take place at diagnosis, review or when circumstances change. There should be opportunities for the individual to change any decisions they have made.

DIAGNOSING WELL

Local Key Initiatives/Examples of Best Practice**

Dementia Assessment Service - a one-stop model to streamline dementia diagnosis within secondary care

DiADeM (the Diagnosis of Advanced Dementia Mandate). DiADeM is a tool to support GPs in diagnosing dementia for people living with advanced dementia.

WSCC Supporting Lives Connecting People - Prevention focused drop-in sessions alongside pre-booked Talk Locals meetings. Drop-in sessions help people to access local advice, information and services to support them to stay as independent as possible in their local communities.

Cognitive Stimulation Therapy Sessions

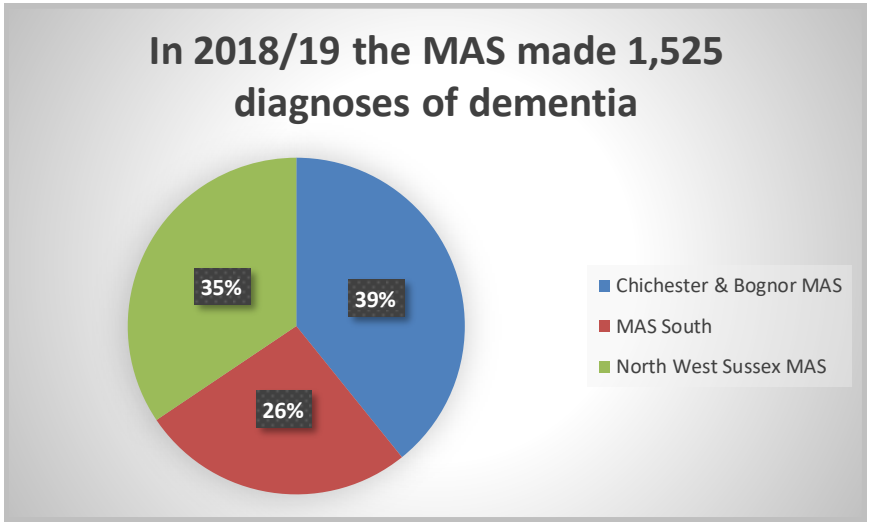
**commissioned and non-commissioned services

DIAGNOSING WELL – Key Data

3% of non-White British people diagnosed through the MAS in 2018/19

Post diagnostic interventions provided by MAS in 2018/19:
1251 people with dementia
990 family and friend carers

1233 referrals into the Dementia Adviser service in 2018/19



In the last 4 years the average percentage of referrals **waiting more than 4 weeks** for an assessment from the MAS was 40% in Coastal, 66% in Crawley and 57% in Horsham and Mid Sussex 57%.

Memory Assessment Service	2014/15	2015/16	2016/17	2017/18	2018/19	%age change (median) over time
Total Referrals	3488	3624	3641	3572	3921	4% increase
No. diagnoses of Dementia	1322	1460	1382	1409	1525	5% increase
%age of diagnoses of dementia to referrals	38%	40%	38%	39%	39%	NA

In 2018/19 4004 people accessed information and advice commissioned through Public Health social support services

SUPPORTING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia and their family and friend carers receive high quality care and support throughout their journey from health and social care staff skilled in good dementia care that is individual to the needs of the person with dementia.

Overview

The best place for someone living with dementia is to remain at home independently for as long as possible but the progressive nature of dementia means that often people will develop increasingly complex needs.

People with dementia and their families need to be confident that, when a need arises, they can readily access support without having to make multiple approaches. Adult Social Care, Proactive Care and Specialist Dementia Care Services are working together to help achieve this through coordinating care and shifting the balance of care away from reactive crisis intervention and unplanned care/hospital towards independent health and wellbeing.

There also needs to be a focus on community led support, prevention and a strengths-based approach to Adult Services.

People with dementia need to live in suitable housing that meets their changing needs with a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence.

The pattern of housing development needs to reflect the changing demographic within West Sussex, including the increase in numbers of people with dementia. Housing providers can play a key role in the development of Dementia Action Alliances and dementia friendly communities, and their staff can play a pivotal role in identifying the symptoms of dementia and encourage people to seek support. At the point of diagnosis, people may require housing advice to help them plan for later life.

As the condition progresses, it may become necessary for the person with dementia to require some extra care and support to enable them to live at home safely. In West Sussex, we continue to actively engage and support the market development of care and support at home providers to ensure excellent delivery for people accessing these services. We recognise that good quality domiciliary care and access to community-based opportunities for active engagement can contribute to maintaining a person's independence, reduce social isolation, prevent admission and/or delay the permanent admission to care homes and/or hospital. We continue to focus on building those opportunities for developing local markets and working with providers to continue to deliver this.

Extra Care Housing can be an attractive option as it offers the security of having care staff on hand but without losing the independence of living in your own home. In West Sussex, there are 13 Extra Care schemes that the County Council nominate customers to, of these 12 schemes have commissioned care contracts through the council.

SUPPORTING WELL

For those people whose needs have increased to the point they are unable to live at home, a residential or nursing care home setting may be more appropriate. Support should be easily accessible for the person and their families and carers to be able to make the right decision about their future care planning including how it will be funded. As a local authority West Sussex County Council (WSCC) has a responsibility for quality of provision, market shaping and sufficiency of supply in its local area, however this is reliant on working with other partners including local planners, health, care providers and on staffing.

For people with dementia there is a greater risk of an unnecessary hospital admission, together with longer stays and delays to discharge. A stay in hospital for someone with dementia can be traumatic and confusing and there can be issues with eating, drinking and pain relief.

Services such as Dementia Crisis, Living Well with Dementia, Community Dementia Matrons and Admiral Nurses are working hard to support people who are at an increased risk of a crisis. In West Sussex, services such as Home from Hospital, Take Home & Settle and Relative Support ensure the patient and their family and friend carer are supported to return home safe and well.

Key issues and challenges

- There is a lack of clarity about eligibility for dementia services.
- The All-Party Parliamentary group (APPG) report from 2016 suggested almost 7 in 10 people with dementia also have one or more other health conditions. However, services often work independently of each other and there is little joined up working.
- Services designed at keeping people at home are stretched and struggle to meet demand.
- People with dementia from the LGBT+ community can feel that mainstream services are not able to understand how to meet their needs.
- Crises are common in people with dementia and can lead to unplanned admissions to hospital and residential care, but services designed at keeping people at home are stretched and struggle to meet demand.
- Lack of 24/7 crisis support.
- Falls and fractures are a particular issue for people with dementia and can lead to hospital admission and loss of independence.
- People with dementia often experience longer stays in hospital, delays in leaving hospital and reduced levels of independent functioning.[3]
- Delays in discharging people with dementia safely from hospital because of issues such as finding placements and packages of care for people living in rural communities or for people with complex and challenging needs; together with delays in social care assessments and funding decisions.
- Sufficient capacity within the care market and recruitment of care staff to meet the needs of people with dementia requiring long term residential and nursing care or short-term respite. Particular issues for people with more challenging needs and people with Young Onset Dementia.
- Over stretched resources including staff and time.
- Gaps in staff training and there is often lack of confidence in supporting someone with complex and challenging needs.

Our goals	What we mean
For people to be enabled to live at home	People have easy access to adaptations to the home and technology that allows people to live at home safely. For example, ramps, grab rails, movement sensors, personal alarms, trackers. People with dementia live in housing that meets their needs such as Extra Care Housing. For the risk of falls to be prevented that are caused through physical inactivity, poor hydration and nutrition, sensory impairment and home hazards. There is a co-ordinated offer of information, advice and guidance that enable people to have choice and control over their health and independence. There is sufficient local provision of care and support at home where more support is required. For services to be flexible in how they support the person living with dementia and help people to help themselves more through focussing on outcomes rather than processes.
For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia	Dementia needs to be seen as a long-term condition that requires on-going management over a period of years. Inevitably it is very common for people with dementia to also have other long-term conditions. Therefore, it is essential that people with dementia, their families and carers know how to access support as their dementia or other health conditions progress. This requires an integrated pathway of support, including between community and hospital provision. The person with dementia and those around them need to be put at the centre of their care. People should not have to re-tell their story every time they encounter a new service, and to not get the support they need because different parts of the system do not 'talk' to each other or share appropriate information and notes. Service providers to ensure that information (such as care and support plans) can be easily transferred between different care settings. Patients should experience a smooth and timely transition from hospital back to their home environment. Hospital and community teams working together from admission, to tackle factors that could prevent a safe and timely transfer of care from hospital and to ensure the patient is at the heart of any discharge planning. People with dementia should be given the opportunity to express their own views and opinions about their care in a format that is appropriate to them i.e. through visual aids, simplified text etc.

Approaches to care and support that are individual to the person's needs	This means: • Building support around the individual with dementia, their carer and family and providing them with more choice, control and flexibility in the way they receive care and support – regardless of the setting in which they receive it. • Care and support are delivered in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities. • Ease of access to information and advice and advocacy services where there is not an appropriate person to represent the individual.
Compassionate care and support from staff skilled in dementia	Education, training and development opportunities available for those people and organisations providing care and support for people with dementia at a level that fits with their individual responsibilities. Education and training should focus on: • identifying symptoms of dementia and know what steps to take to support people to receive a diagnosis. • acquiring greater awareness and understanding of dementia, so that they can help to ensure people are diagnosed and supported earlier. • becoming better equipped to help people in crisis to remain at home or return home after a hospital admission. • having awareness of the impact of dementia on the person living with the condition and their families. • Getting to know the person, their history and interests, and understand how dementia is affecting their life in order to be able to offer care and support that is individual to them. • Giving consideration to the person's individual characteristics including age, disability, gender reassignment, marriage and civil partnership status, race, religion and belief, sex and sexual orientation. • Starting and holding difficult emotionally challenging conversations such as end of life care planning. For there to be a framework for dementia training to ensure all people receive training relevant to their role so that there is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia and is equipped to do so. All healthcare assistants and social care support workers to have under undergone training as part of the national Care Certificate and staff competency and accreditation in dementia care skills should be regularly monitored and reviewed. For workers supporting people with learning disabilities to be skilled in supporting someone with dementia to remain in their normal care setting for longer following their diagnosis. When this is no longer possible, and the person needs to move into a dementia specialist facility, care workers should be trained in supporting the person with both their dementia and learning disability needs.

Dementia friendly health and care settings	If thought is not given to the way that a person with dementia interacts with their environment, this can result in increased agitation and behaviours that challenge, falls, confusion and can hinder the delivery of person-centred care. A dementia-friendly environment is one where buildings and physical environments do not prevent people with dementia from accessing them. The role the family and friend carer plays in the care of the person with dementia cannot be under-estimated and in all care settings they should be: identified and supported and recognised as partners in their loved one's care.
The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support	The following contributory factors to a crisis should be identified and interventions provided where necessary:- • Family and friend carers unable to cope with their caring role. • The person with dementia presenting behavioural and psychological characteristics. • Physical health problems. • Social factors related to the person with dementia or their environment. Wherever possible, admission to hospital, inpatient facilities or residential care should be avoided by a community crisis response and social care support for both the person with dementia and their family and friend carer. Where home treatment is not possible, patients should receive compassionate care by skilled staff, in dementia and carer friendly environments. For only the most complex patients to need admission to an inpatient bed. Where admission is needed, the stay will be as short as possible with integrated discharge support to ensure that discharge home or to care/nursing home is not delayed.

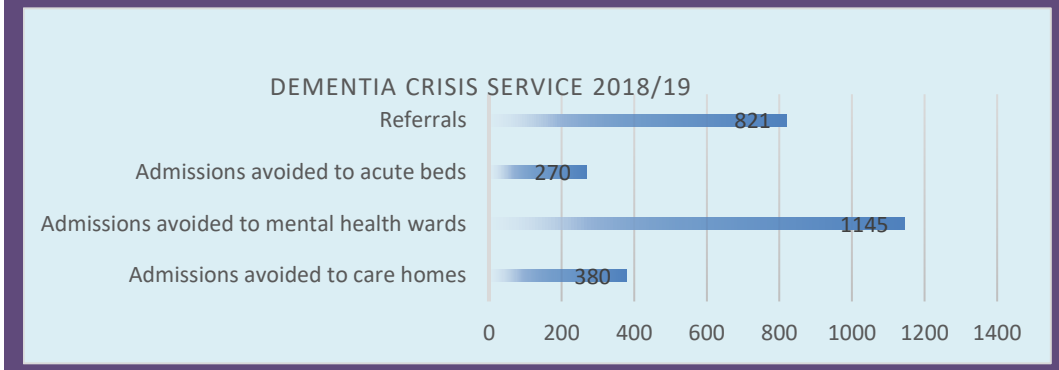
SUPPORTING WELL

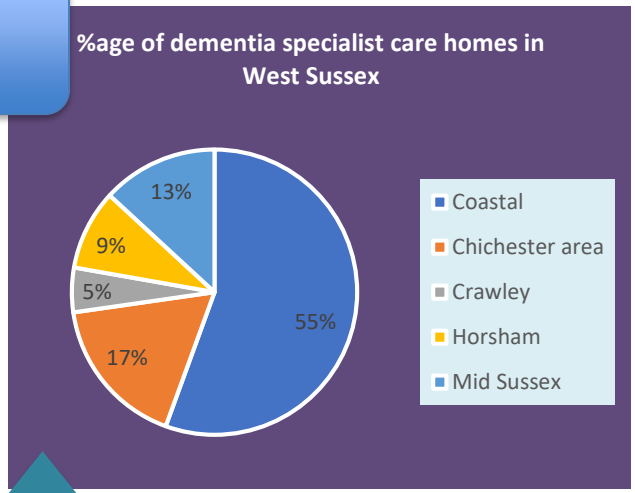
Local Key Initiatives/Examples of Best Practice**

- Information, advice and support for the individual and family and friend carers from Alzheimer's Society Dementia Support Service and Carers Support West Sussex.
- 'Hospital to Home' clinic at Horsham Hospital for providers to come and share information.
- Re-focus of Council's in-house services on delivering support which makes the most of people's wellbeing and independence such as day services, residential care homes and 'Shared Lives' scheme.
- Proud to Care – An initiative run in collaboration with the Council and NHS that works proactively to support the nursing and care sector to develop recruitment, retention and capacity plans and to identify and support providers with workforce training.
- Care & Business Support Service - A Council initiative that provides professional support to local services in the care sector.
- New Dementia In-patient facilities that is a Centre of Excellence in Worthing for people living with dementia which will improve the care for both their mental and physical health needs.
- WSCC Dementia Learning Framework on the Learning & Development Gateway.
- Procurement of the WSCC Care & Support at Home place-based service
- Time for dementia – Initiative to improve patient experience through increased dementia awareness in training for medical students.
- WSCC Technology Enabled Lives Service
- Dementia friendly hospitals charter
- Dementia champions across the Intermediate Care Units and considerable investment to improve environments.
- Dementia friendly Hospital Charter being rolled out by Western Sussex Hospitals Trust
- Robust dementia training programme for all hospital staff in West Sussex.
- 'This is About Me' and 'Knowing Me' tools to provide key information about individuals in hospital.
- A volunteer service 'Connect with dementia' at Crawley Hospital and Zachary Merton in Rustington
- An in-hospital Carer Wellbeing Service for family and friend carers through Carers Support West Sussex.
- 'Dementia Tour' – Immersive/interactive training for care staff.
- PatchCare® trialled by WSCC and Caremark. This initiative works with people living in their own homes and aims to create communities through care
- Home First – Discharge to Assess model. A service that enables people to be effectively and efficiently discharged from hospital.
- The framework for enhanced health in care homes (EHCH) is based on a suite of evidence-based interventions, which are designed to be delivered within and around a care home in a coordinated manner.
- Life Story work is an activity in which the person with dementia is supported by staff and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with past events
- Across the Coastal area people living with dementia can receive support with long term health conditions and social care needs from the community proactive care plus teams.
- Housing providers supporting tenants living with dementia.
- WSCC Supporting Lives Connecting People - Prevention focused drop-in sessions alongside pre-booked Talk Locals meetings. Drop-in sessions help people to access local advice, information and services to support them to stay as independent as possible in their local communities.

SUPPORTING WELL – Key Data

In 2018/19 5327 people used the Home from Hospital, Take Home & Settle and Relative Support services





In 2017/18 there were **2761 per 100,000 emergency admissions** for people with dementia* 848 less than nationally

*Dementia: Direct standardized rate of Emergency Admissions (aged over 65)[7]

Around **65 referrals each month** into the Dementia Support Service with 80% coming from family carers

13 Extra Care Housing schemes commissioned by the council

5,100 referrals to the Hospital carer wellbeing service in 2017/18

In 2017/18 there were 33.9% short stay emergency admissions of people with dementia over the age of 65[7]

132 residential and nursing homes specialising in dementia – offering 5104 beds

In 2017/18 Carers Support WS received 1293 equipment for independence referrals

LIVING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia are supported to live well with dementia by enabling them to: Stay socially active; Keep healthy and well; Access safe and welcoming communities that are responsive to the needs of people with dementia; Have access to quality information about dementia and the support available such as community activities, leisure and transport; Receive support to engage in meaningful activity, doing something that people enjoy or are interested in; and for family and friend carers to receive the support they need to be able to continue in their valuable caring role.

Overview

There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community.

Breaking down the stigma of dementia is key and initiatives such as Dementia Friendly Communities can help people to access their local communities and reduce the risk of social isolation and loneliness. People with dementia have described a dementia friendly community as one that enables them to:

- Find their way around and be safe
- Access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices)
- Maintain their social networks so they continue to feel they belong.

Local Dementia Action Alliances (LDAA) focus on changing public attitudes through the creation of dementia friendly communities so that people affected by dementia have the best possible opportunities to live well. In West Sussex, there are currently 10 Local Dementia Action Alliances (LDAA) throughout the county with almost 300 members. Members include local businesses, community groups, faith groups, schools and colleges, libraries, museums, shopping centres and charities as well as health and social care providers.

The support offered family and friend carers is essential and local authorities have enhanced duties towards carers since the introduction of the Care Act 2014. In West Sussex, there is a consistent offer of support, information and guidance to all carers delivered by a single provider, Carers Support West Sussex. This provides a gateway service to all other carers support services within the County, such as carer break services and more specialist services.

LIVING WELL

Local authority, clinical commissioning group, voluntary and community sector organisations deliver a diverse set of services including daytime activities and short break respite opportunities that provide a much needed break for the carer from their caring role. Services are provided either in the person's own home on a one to one basis, or through group activities away from home this can include: day services; outings and dementia cafes. There are also services in place to provide short term support for someone in their own home including emergency respite for the family carer and support for people to settle back at home after a stay in hospital.

There needs to be a community led support approach to help meet the challenges faced and willingness to innovation and learning. A good example of this is new community led support talk locals and drop-ins.

Access to information and advice and support is key to ensuring all people affected by dementia can continue to live well with the condition. In West Sussex, there is a universal offer of information and advice for people with dementia and their family and friend carers from Alzheimer's Society's Dementia Support Service along with a county-wide information and advice service commissioned by Public Health. In addition, a dementia zone on the West Sussex Connect to Support website provides information about dementia and local services and support.

Key issues and challenges

- Family and friend carers can become cut off from the community leading to social isolation and resultant worsening of health. They need easy access to peer support, carers groups and other initiatives that helps them to stay connected.
- Lack of flexible breaks for carers impacting on the carers ability to continue effectively in their caring role.
- There has been an historically low uptake to services from people with dementia from Black and Minority Ethnic and seldom heard groups.
- People from LGBT+ communities having opportunities to participate in services designed to support them to live well.
- For people with Young Onset Dementia to have support to engage in age appropriate activities.
- Sustainable Dementia Friendly Communities - Local Dementia Action Alliances rely mainly on volunteers and on short term time limited financial support which impacts on the sustainability of this work.
- Transport can be a particular challenge particularly for someone living in more rural communities and/or where they can no longer drive.
- More local activities needed for people with dementia and their family and friend carers to participate in.
- Support for people with dementia to take part in mainstream groups and activities.

Our goals	What we mean
People to have access to a range of affordable flexible activities that reflects their interests and needs	Dementia specific services or support to access mainstream activities to be designed to meet the needs of all people including those who: • do not have a family or friend carer • do not have access to affordable transport, or find transport difficult to use; • have sensory impairment or physical difficulties; • are less likely to access health and social care services such as people from the LGBT+ community, Gypsies and Travellers and black, Asian and minority ethnic groups. Activities thought to benefit the person with dementia include: Physical based activity, Outdoor activity, Reminiscence based, Arts based activities, Music based activities. (A recent systematic review for the What Works Centre for Wellbeing concluded that there was evidence of wellbeing benefits of singing among people with dementia.) Age appropriate activities or support to access mainstream activities for people with Young Onset Dementia and Alcohol Related Dementia.
There is a whole community response to living well with dementia in safe and enabling communities	• Sustainable communities that are inclusive of people living with dementia. • All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and action plans. • The roll-out of dementia friends sessions to enable people to learn what it is like to live with dementia. A Dementia Friend learns what it is like to live with dementia and then turns that understanding into action – for example, by giving time to a local service such as a dementia café or by raising awareness among colleagues, friends and family about the condition • All employers with formal induction programmes including dementia awareness training within these programmes. • For younger people to be more educated and aware about dementia. • Public sector organisations taking a leadership role by becoming dementia friendly organisations. • Environments and physical settings in the community becoming dementia friendly places with people living with dementia being able to take advantage of open spaces and nature. • There is a proactive approach from services such as Fire, Police and Trading Standards that supports people living with dementia to live safely in their communities. • Public transport that enables people with dementia to be able to participate in a wide range of activities and is welcoming and inclusive.

People can maintain and develop their relationships and be able to contribute to their community	• For people affected by dementia to be enabled to maintain and develop social connections through peer support, carers groups and similar initiatives to help build resilience. • Social action solutions such as peer support and befriending services can also provide practical and emotional support to people with dementia and carers, reduce isolation and prevent crisis. • For family members including dependent children of people with Young Onset Dementia to receive practical and emotional support.
Carers of people with dementia are able to access support as needed and feel able to continue with their caring role	For people with dementia and their family and friend carers to be put at the centre of their care and have access to flexible support that is responsive to their personal interests and needs. For family and friend carers to: • be offered an assessment of their own needs that considers their emotional, physical and social care needs. • have access to psychological therapies. • be identified by all those involved in the care and support of the person they care for and treated as partners in their care. • have easy access to information and advice in an accessible format at every stage in their journey from pre-diagnosis through to end of life and bereavement. • have access to education and advice about the most common problems they are likely to meet and how to deal with them. • have an opportunity to access one-to-one support and peer support so as to be able to link up with carers in a similar situation. • have the offer of regular vital breaks from caring. This can be for a few hours, a day or a week, perhaps longer. It may be provided at home or elsewhere. It could be a regular, planned arrangement, or it may be more occasional. This should include emergency respite if necessary.

LIVING WELL

Local Key Initiatives/Examples of Best Practice**

- Training for family and friend Carers such as Carer Information and Support Programme (CrISP) run through Alzheimer's Society and 'Understanding Dementia workshops run through Carers Support West Sussex.
- New Tyne Resource Centre in Worthing offer long stay residential placements, respite and day service for people over the age of 40 who have a diagnosis of dementia.
- WSCC in-house Shared Lives service for people with dementia.
- WSCC Compassionate communities project.
- Dementia Friends training.
- Admiral Nurses - supporting family carers of people with dementia in the community in the north of the County.
- Jointly commissioned county-wide Short Breaks service for family and friend carers through prime providers - Age UK West Sussex, Independent Lives, Carers Trust East Midlands, Age UK Horsham District and Guild Care.
- Specialist support for people with Early Onset Dementia that includes an overnight residential Breaks twice a year north and south of the county, Neil's Club in East Grinstead, Cando@K2 in Crawley and Centre Club in Worthing.
- Dementia Support at Sage House in Tangmere, offering a Wayfinding service to help guide families through their personal dementia journeys, as well as day care, a range of activities for those living with dementia and their carers, therapy rooms, a salon, a smart zone, and a café.
- Countywide activities to stimulate cognition and provide social interaction such as: Sporting Memories, Dance Well and Thrive, gardening clubs, community sheds.
- Herbert Protocol rolled out by Police Service. For carers to compile useful information about the person they care for that can be used in the event of a vulnerable person going missing.
- Safe and Well visits from Fire Service.
- Carers Support West Sussex Dementia Wellbeing programme. Offers practical support and information to carers.
- Library service offering Memory Management Tickets, Books on prescription, Digital Library Plus Home Visits, Reminiscence collections, drop-ins and Melody for the Mind groups.
- Time to talk - intergenerational work with older people aged 65+ who experience feelings of chronic loneliness caused by social isolation.
- West Sussex Mind helping people over 65 in the Bognor and Chichester and Midhurst who are feeling low, have depression, anxiety or other mental health problem, or are simply feeling isolated.

**commissioned and non-commissioned services

LIVING WELL KEY DATA

In 2018/19 2540 people accessed Day Activities commissioned by Public Health.

10 Local Dementia Action Alliances in Arun, Burgess Hill, Chichester, Crawley, East Grinstead, Haywards Heath, Horsham District, Worthing, Selsey with a **membership of 282**.

5 WSCC Older People's Specialist day services – Glebelands, The Laurels, The Rowans, Chestnuts and Judith Adams

5 service user review panels hosted by Alzheimer's Society

32540 Dementia Friends in West Sussex and **127** champions

Short Breaks service offering carers a break from their caring role in Adur, Arun, Chichester, Crawley, Horsham, Mid Sussex and Worthing

Carers Support West Sussex currently have around 25,000 registered carers and **almost 5,000 identify** themselves as caring for someone with dementia.

In 2018/19 almost **200 carers** of people with dementia accessed the Carers Health & Wellbeing Fund and were granted more than **£53,000** to help them in their caring role.

DYING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people with dementia and their families are supported to plan ahead, receive good end of life care and are able to die in accordance with their wishes.

Overview

Research shows that people are more likely to die in the place of their choice if their wishes are known and documented in advance. The government has said that all people with a diagnosis of dementia should be given the opportunity for advance care planning early on to ensure the person and their carer are fully involved in decisions on care at end of life.

It is important to have early conversations with people with dementia and their carers so that they can plan ahead for their future care while they are still able to do so. This reduces the likelihood that difficult and emotional decisions have to be made in crisis, when the wishes of the person with dementia cannot be taken into account.

Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision making is crucial, to ensure that the wishes of the individual living with dementia are reflected in the actions taken. This approach is also helpful for the person's family as they will be directed to services that can support them once their loved one has passed away, such as bereavement services, as well as the formalities that will need to be carried out.

In West Sussex, the CCGs along with, Sussex Community NHS Trust, Sussex Partnership NHS Foundation Trust, Western Sussex Hospitals Trust and local hospices and services have endorsed an Advance Care Plan 'Planning Future Care' to identify wishes and preferences for future care. This is being implemented across West Sussex, in the community, care homes, and virtual wards.

People nearing the end of their life need to receive coordinated, compassionate and care that is individual to their needs. This includes palliative care for the person with dementia and bereavement support for carers. Care needs to be delivered by skilled, trained and compassionate staff throughout the person's life journey.

In West Sussex, local hospices and specialist palliative care providers are commissioned to provide end of life training. The training includes specific programmes for care homes. The CCG also supports an education package for NHS End of Life Care Champions.

DYING WELL

The End of Life Care Hub in Coastal West Sussex (ECHO) helps to improve identification of people in the last year of their life, share care plans between services, and provide a more responsive, proactive and personalised offer of care.

The ECHO hub maintains a register of people in their last year of life accessible for clinicians; it provides patient and carer support through a website and 24-hour telephone line. It plans for newly identified patients and responds and reacts to patients' changing needs by co-ordinating access to services.

Key Issues and Challenges

- People diagnosed with dementia are not supported to plan for their future care soon enough after diagnosis.
- Advance care plans where they exist not always being shared with all those involved in the person's care.
- Hospital staff caring for people in the last stages of their lives are often unaware of the person's end of life wishes.
- People dying away from their usual place of residence or in a place that is not of their choosing.
- The need to ensure that families and carers receive the right level of bereavement support and counselling.

Our goals	What we mean
People living with dementia together with their families and carers are enabled to make decisions about their future health care	• People living with dementia, their families and carers complete advance care plans as soon after diagnosis as possible and that these are reviewed on a regular basis. • People assessed as not having capacity, with no family or friends are referred to an Independent mental Capacity Advocate as appropriate. The advance care plan to be shared with all those health and social care professionals involved in the individual's care.
There is support for people to die with dignity in a place of their choice	• People are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they chose. • People are not delayed from being discharged from hospital. • There is a framework for dementia training to ensure all people receive training relevant to their role. • There is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia in the end stages of life and is equipped to do so.
People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care	• Care staff and family and friend carers are equipped with the ability to develop their knowledge, skills and behaviours in order to deliver co-ordinated, compassionate and person-centred end of life care for people with dementia. • People with dementia at the end of their life receive emotional or spiritual support.
Families and carers are provided with timely co-ordinated support before death, at the time of death and bereavement	• For all those people involved in end of life care, e.g. the GP, district nurses, care staff, speech and language therapists etc to communicate reliably with each other. Without good information-sharing, a person is less likely to receive the care they need. This should extend to ensuring the family understands what is happening and are updated regularly. • Families and carers receive bereavement support at a time that is right for the individual or family. • There is support and signposting available on the hospital ward for friends and family going through the grieving process.

DYING WELL

Local Key Initiatives/Examples of Best Practice**

- The End of Life Care Hub for Coastal West Sussex (ECHO)
- Ageing Well and Dying well - Compassionate communities. Public Health initiative/campaign.
- Clinical Commissioning Group's End of Life Providers Group
- The Clinical Commissioning Group's directly commission End of Life education with local hospices and specialist palliative care providers that are open to partners. An education package for NHS End of Life Care Champions has also been supported.
- The Admiral Nurse Service which provides a proactive approach to ensuring family cares receive support and specialist training and education in their caring role particularly at times of crisis and end of life. Admiral Nurses also help with conversations around end of life and transition to residential care.
- Dementia Community Matrons in Adur, Arun and Worthing who support the individual and their families and carers at the end of life.
- End of Life Champions sitting within SPFT Dementia services.
- WSCC Public Health currently producing a bereavement pathway.
- Time to Talk – talking therapies services in West Sussex - Bereavement and Reactions to Loss.
- Specialist carer bereavement support through Carers Support West Sussex.
- County-wide WSCC Supporting Lives, Connecting People Talk Local Hubs and Community Drop-in sessions.

**commissioned and non-commissioned services

DYING WELL KEY DATA

In 2017/18 **75.5%** of people with dementia over 65 in West Sussex died in their Usual Place of Residence. 7% higher than nationally.[7]

Dementia is now one of the top five underlying causes of death in the UK and **one in three people** who die after the age of 65 have dementia[5]

Echo Evaluation Findings:-

83% of Echo patients with a known preference died in their preferred place.

Only 13.3% of people on the Echo caseload died in hospital.

Rate of admission to hospital in the last year of life was significantly lower for those referred to Echo than those who were not.

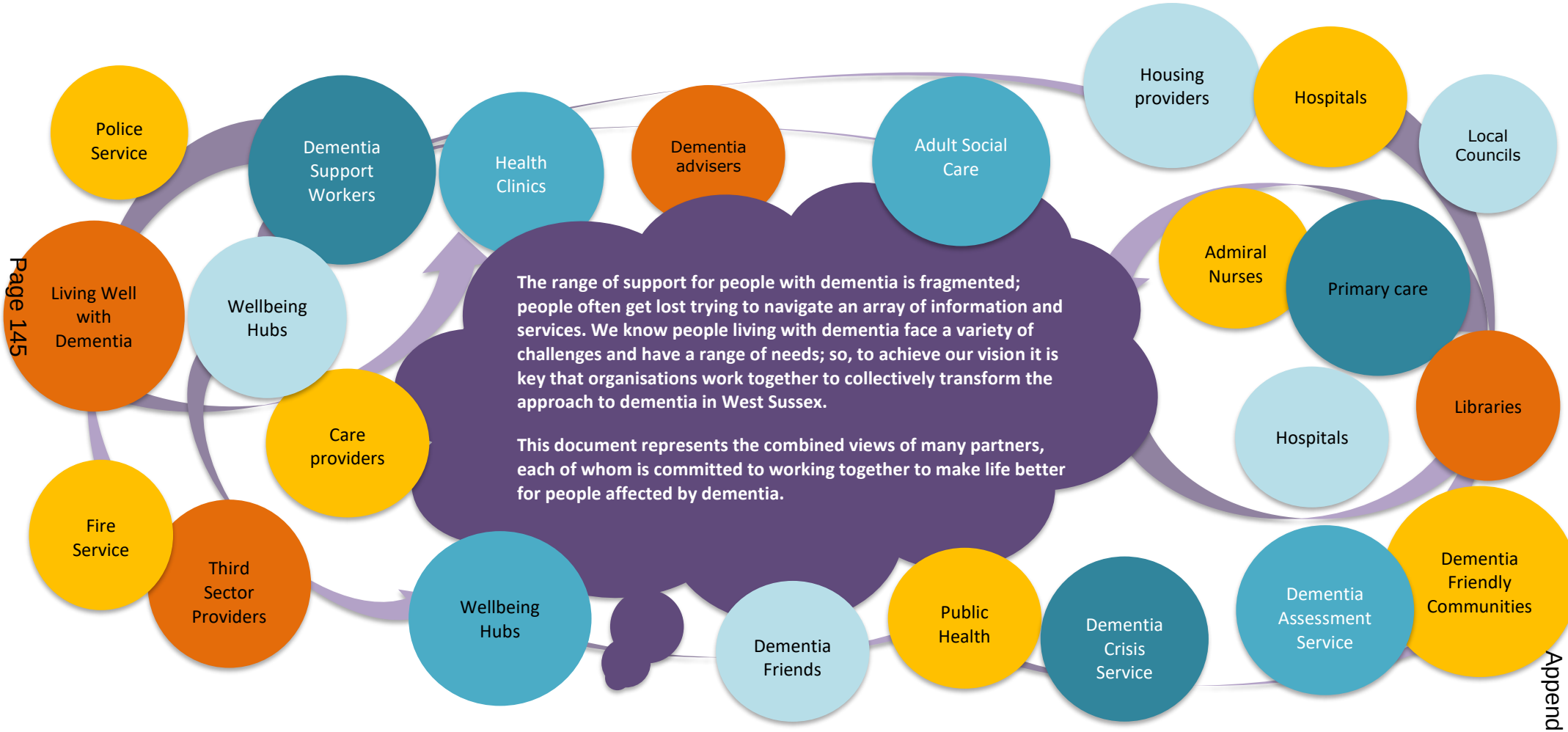
Average hospital length of stay in the last year of life for Echo patients was lower than for people who were not referred to Echo.

In 2017/18 **24%** of people aged over 65 in West Sussex died in hospital. 6% lower than nationally.[7]

In England and Wales, the number of people living with dementia who need palliative care will almost quadruple by 2040.[8]

In the UK, nearly two thirds of people with dementia are women, and dementia is a leading cause of death among women - higher than heart attack or stroke.[6]

A JOINT STRATEGIC APPROACH TO DEMENTIA IN WEST SUSSEX



MONITORING DELIVERY AND IMPACT ACROSS THE PATHWAY

The delivery plan sets out how West Sussex County Council and the Clinical Commissioning Group plan to monitor the progress being made with the goals set out above and looks at what can be achieved with current resources. An additional section has been included that looks at what can be achieved with a little and much more funding.

It is vital that we assess whether this strategy is making a demonstrable difference to the experience of people living with dementia and their family and friend carers. We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this strategy and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

APPENDICES

APPENDIX A - OUR GUIDING PRINCIPLES

These are based on the five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life.

Dementia Statements reflect the things that people with dementia and carers say are essential to their quality of life. These statements were developed by people with dementia and their carers, and the person with dementia is at the centre of these statements. The "we" used in these statements encompasses people with any type of dementia regardless of age, stage or severity; their carers; families; and everyone else affected by dementia.

These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law and are a rallying call to improve the lives of people with dementia. These Statements recognise that people with dementia shouldn't be treated differently because of their diagnosis.

Care - We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

Independence/Interdependence/ Dependence - We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

Community/Isolation - We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

Research - We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

Carers - We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

APPENDIX B - REFERENCES

1 Prime Minister's Challenge on Dementia 2020 (2015)

2 Popoola A, Keating A, Cassidy E. Alcohol cognitive impairment and the hard to discharge acute hospital inpatients. Ir J Med Sci 2008; 2: 141-5. There is a need to ensure that there is therefore a clear pathway to diagnosis and post-diagnostic support for people in this group.

3 CQC 2017, DAA 2016).

4 Public Health England Guidance – Dementia – Applying all our health 2018

5 Brayne C et al, Dementia before death in ageing societies – the promise of prevention and the reality, PLoS Med 2006;3; 10

6 Dementia UK Update, second edition, Alzheimer's Society, November 2014

7 Public Health England Dementia Profile

8 Etkind, S.N. et al (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services BMC Medicine 2017 15:102

9 Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040, CPEC and LSE Raphael Wittenberg, Bo Hu, Luis Barraza-Araiza, Amritpal Rehill

10 Alzheimer's Research UK Dementia Statistics Hub

11 The All-Party Parliamentary group (APPG) report 2016 – 'Dementia rarely travels alone:Living with dementia and other conditions'

SEPARATE APPENDICES:-

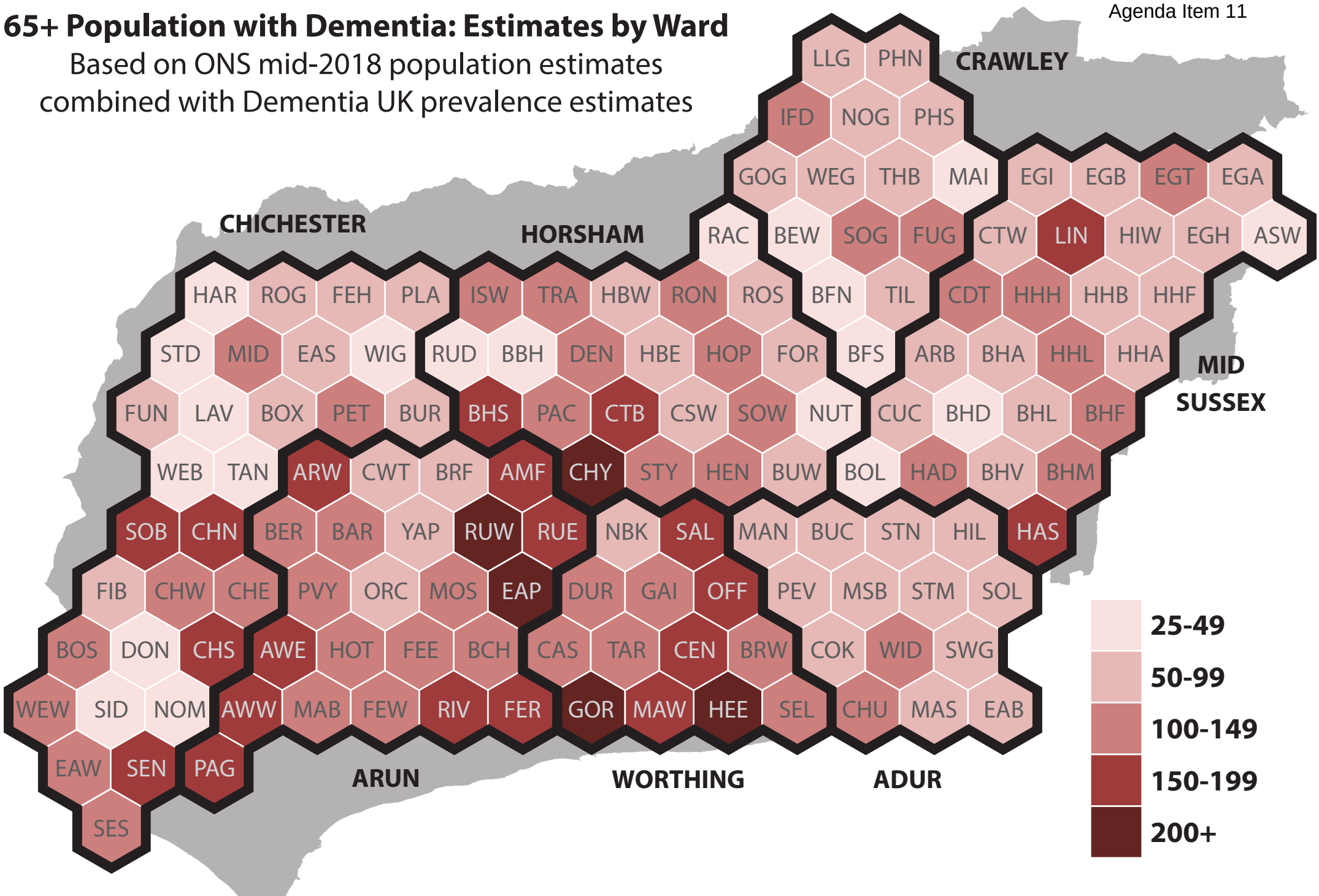
Appendix C - 65+ Population with Dementia: Estimates by Ward

Appendix D – Executive Summary

Appendix E - Delivery Plan (to be ready by spring 2020)

65+ Population with Dementia: Estimates by Ward

Based on ONS mid-2018 population estimates
combined with Dementia UK prevalence estimates



Adur Wards:

BUC	Buckingham
CHU	Churchill
COK	Cokeham
EAB	Eastbrook
HIL	Hillside
MAN	Manor
MAS	Marine (Shoreham)
MSB	Mash Barn
PEV	Peverel
SOL	Southlands
STM	St Mary's
STN	St Nicolas
SWG	Southwick Green
WID	Widewater

Arun Wards:

AMF	Angmering & Findon
ARW	Arundel & Walberton
AWE	Aldwick East
AWW	Aldwick West
BAR	Barnham
BCH	Beach
BER	Bersted
BRF	Brookfield
CWT	Courtwick with Toddington
EAP	East Preston
FEE	Felpham East
FER	Ferring
FEW	Felpham West
HOT	Hotham
MAB	Marine (Bognor)
MOS	Middleton-on-Sea
ORC	Orchard
PAG	Pagham
PVY	Pevensey
RIV	River
RUE	Rustington East
RUW	Rustington West
YAP	Yapton

Chichester Wards:

BOS	Bosham
BOX	Boxfgrove
BUR	Bury
CHE	Chichester East
CHN	Chichester North
CHS	Chichester South
CHW	Chichester West
DON	Donnington
EAS	Easebourne
EAW	East Wittering
FEH	Fernhurst
FIB	Fishbourne
FUN	Funtington
HAR	Harting
LAV	Lavant
MID	Midhurst
NOM	North Mundham
PET	Petworth
PLA	Plaistow
ROG	Rogate
SEN	Selsey North
SES	Selsey South
SID	Sidlesham
SOB	Southbourne
STD	Stedham
TAN	Tangmere
WEB	Westbourne
WEW	West Wittering
WIG	Wisborough Green

Crawley Wards:

BEW	Bewbush
BFN	Broadfield North
BFS	Broadfield South
FUG	Furnace Green
GOG	Gossops Green
IFD	Ifield
LLG	Langley Green
MAI	Maidenbower
NOG	Northgate
PHN	Pound Hill North
PHS	Pound Hill South & Worth
SOG	Southgate
THB	Three Bridges
TIL	Tilgate
WEG	West Green

Horsham Wards:

BBH	Broadbridge Heath
BHS	Billingshurst & Shipley
BUW	Bramber, Upper Beeding & Woodmancote
CHY	Chantry
CSW	Cowfold, Shermanbury & West Grinstead
CTB	Chanctonbury
DEN	Denne
FOR	Forest
HBE	Holbrook East
HBW	Holbrook West
HEN	Henfield
HOP	Horsham Park
ISW	Itchingfield, Slinfold & Warnham
NUT	Nuthurst
PAC	Pulborough & Coldwaltham
RAC	Rusper & Colgate
RON	Roffey North
ROS	Roffey South
RUD	Rudgwick
SOW	Southwater
STY	Steyning
TRA	Trafalgar

Mid Sussex Wards:

ARB	Ardingly & Balcombe
ASW	Ashurst Wood
BHA	Burgess Hill St Andrews
BHD	Burgess Hill Dunstall
BHF	Burgess Hill Franklands
BHL	Burgess Hill Leylands
BHM	Burgess Hill Meeds
BHV	Burgess Hill Victoria
BOL	Bolney
CDT	Crawley Down & Turners Hill
CTW	Copthorne & Worth
CUC	Cuckfield
EGA	East Grinstead Ashplats
EGB	East Grinstead Baldwins
EGH	East Grinstead Herontye
EGI	East Grinstead Imberhorne
EGT	East Grinstead Town
HAD	Hurstpierpoint & Downs
HAS	Hassocks
HHA	Haywards Heath Ashenground
HHB	Haywards Heath Bentswood
HHF	Haywards Heath Franklands
HHH	Haywards Heath Heath
HHL	Haywards Heath Lucastes
HIW	High Weald
LIN	Lindfield

Worthing Wards:

BRW	Broadwater
CAS	Castle
CEN	Central
DUR	Durrington
GAI	Gaisford
GOR	Goring
HEE	Heene
MAW	Marine (Worthing)
NBK	Northbrook
OFF	Offington
SAL	Salvington
SEL	Selden
TAR	Tarring

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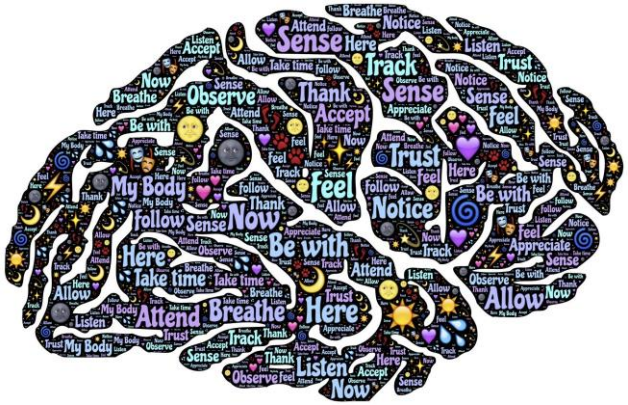
APPENDIX D



WEST SUSSEX

JOINT DEMENTIA STRATEGY 2020 TO 2023

EXECUTIVE SUMMARY

Developed in partnership with
West Sussex County Council and
NHS Clinical Commissioning Group

CONTENTS

ACKNOWLEDGMENTS

We are very grateful to the residents of West Sussex, our partners, staff and other stakeholders who were instrumental in the successful development of this strategy through their participation and feedback.

Particular thanks goes to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains and Worthing Town Cryers. Age UK's K2 Club, Sangam Women's Group and Carers Support West Sussex East Grinstead carers group.

FOREWARD

With the ageing population of the county expected to rise exponentially in the next 10 years, a timely diagnosis for those with dementia is vital not only for them, but also for their family and friends. A timely diagnosis enables them to maximise control over their lives by planning ahead and accessing support to ensure that they can enjoy an active and independent life for as long as possible.

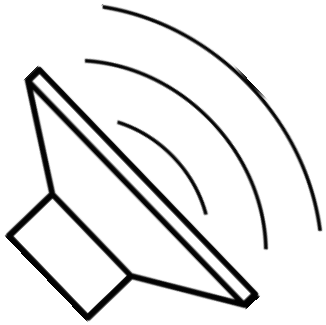
The County Council and the Clinical Commissioning Group are resolved to make West Sussex the best place to live well with dementia. This strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to delivery of services, we must ensure that there is adequate and meaningful provision to help and support those with dementia, as well as their family and friends.

Promoting self-care and self-empowerment is often a primary requirement for those who want to stay in their own homes. Family and friend carers are influential in supporting those living with dementia and it is therefore key that we support them in their caring role. Carers tell us that their wellbeing is as much about their experience of the health and social care system as it is about services for them. We need the system not only to recognise carers, but to listen to them and involve them as appropriate.

I hope you will find this strategy informative and of interest. I believe that the more we engage and plan together with those who need our support, the better quality of life will be achieved for them which for me is of paramount importance.

Amanda Jupp

Chair – West Sussex Health and Wellbeing Board Cabinet Member for Adults and Health West Sussex County Council



INTRODUCTION

This strategy has been developed by the West Sussex County Council and Clinical Commissioning Group in partnership with our stakeholders and includes direct input from people with the lived experience of dementia. It builds on the progress of our first dementia strategy and the progress that has been made. The Strategy sits within the context of national and local policies, guidance and legislation.

The primary audience for the West Sussex Joint Dementia Strategy 2020-23 is the Health & Wellbeing Board, local leaders, officers, commissioners and providers responsible for its delivery. However, care has been taken to make the strategy as accessible as possible for residents, staff and partners in understanding priorities and how all partners can contribute to them.

Purpose of the strategy

To build on the work of the 2014-19 Dementia Framework, refresh our goals and set out the plan for action for the next three years.

Understanding the challenges

There are 3 main challenges we face:

1. An ageing population. Although dementia is not a natural part of growing older, it is more prevalent in people over the age of 65. The population of older people is set to rise in the next 10 years and the highest increase will be in people over aged 80 (60%). Older people are more likely to have other significant and life limiting chronic conditions, this will result in the need for an increase in Health and Social Care spending where there is already a reduction in public funding.
2. Timely diagnosis can enable people to maximize control over their lives, plan ahead and access support that can help them live well with the condition. The increase in the number of people with dementia is however impacting on how quickly people receive their diagnosis.
3. Recruitment and capacity challenges within the care market that is impacting on the availability of good dementia care.

OUR VISION

To improve the health and wellbeing of local people and for those people who develop dementia to be supported to maintain their independence for as long as possible.
For people with dementia and their families and carers to:

- receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice;
- have access to timely, skilled and well-coordinated support throughout their journey;
- receive care and support that focuses on an individual's strengths and looks to promote their wellbeing;
- be central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

For there to be supportive communities, where people feel able to participate in community life without stigma.

Where we are now

In 2018, a full review of the Dementia Framework West Sussex 2014-19 took place. It was led by the County Council and all three Clinical Commissioning Groups and included a public engagement with around 400 different people and organisations. The review suggested there had been some good progress made in the last five years but there was still quite a lot left to do to improve the experience of people living with dementia and their families. This Strategy sets out what we plan to do about this.

How we will get there

To work closely with health, social care, community, voluntary, private providers and local people. Work to a delivery plan which will support the goals of this strategy and will include clear measures and points of review at regular intervals.

Meeting the challenges faced needs a commitment and willingness to innovation and learning. There needs to be a focus on community led support and prevention and for Adults Services to look at enabling an individual to see the value they bring and the resources around them rather than focusing on any negative characteristics.

National and Local Context

This strategy is based on relevant national and local policy, guidance and legislation. The **NHS Five Year Forward View** and the Department of Health **Prime Minister's challenge on Dementia 2020** set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers.

Ageing well and caring for people with dementia are both key priorities in the **NHS Long Term Plan**. The Plan focuses on the need for people to be helped to stay well and to manage their own health, possibly with the use of digital tools. It also calls for a transformed workforce with a more varied and richer skill mix.

Care Act 2014 created a new legislative framework for Adult Social Care. Local Authorities have new functions to ensure people living in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs. People should also have a range of high quality, appropriate services to choose from.

Five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life. (See Appendix A of full strategy.)

West Sussex Plan – Priorities around Independence for Later Life.

Sussex Health and Care Partnership Strategic Delivery Plan – **Appendix -** West Sussex Place Based Response to the Long-Term Plan October 2019.

Joint Commitment to Carers 2015-20 – states the main priority areas for family and friend carers for health and social care. This document to be refreshed over the course of this strategy.

West Sussex Joint Health & Wellbeing Strategy 2019-24 - the Health and Wellbeing Board's vision, goals and ways in which it will work to improve the health and wellbeing for all residents in West Sussex. It is anticipated this document will be refreshed over the course of this strategy.

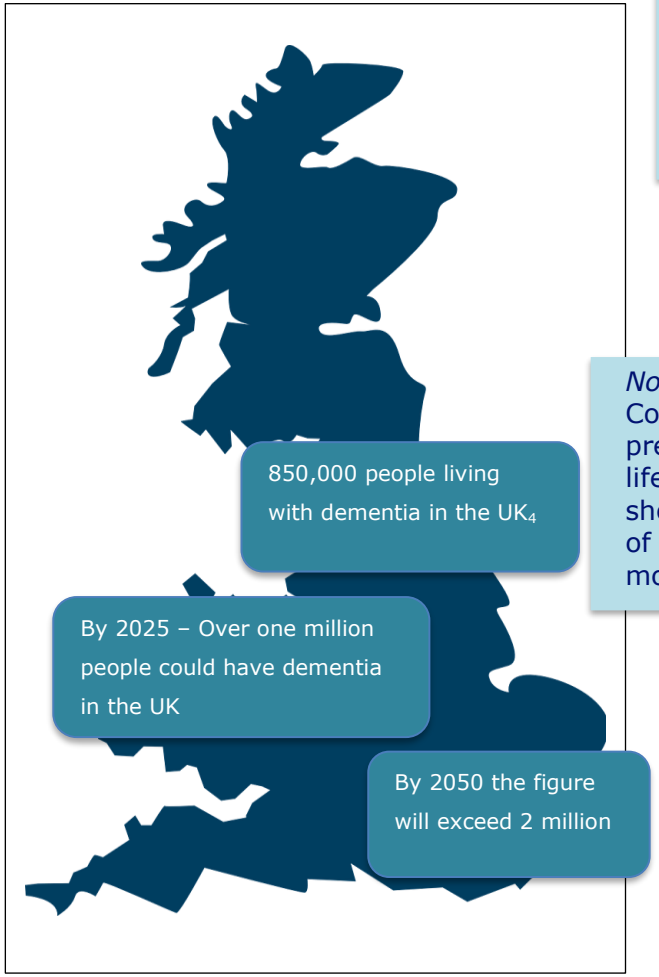
Adult Social Care in West Sussex – Our vision and strategy 2019-21 - sets out how we will continue to work together to build on the good progress we have made to implement a strength-based community-led approach, focusing on prevention and reablement, supporting family and friend carers, and working towards the integration of services.

Sussex Community NHS Foundation Trust Dementia Strategy

Western Sussex Hospitals NHS Trust Dementia Strategy

THE NATIONAL PICTURE

Most people associate dementia with older people but there are more than **40,000 younger people in the UK living with dementia under the age of 65** years who are affected by this condition.



Note: The Lancet Commission presents a new life-course model showing that 35% of risk factors are modifiable.

THE LOCAL PICTURE

How dementia might look in next 10 years:

	2020	2025	2030
Early onset (under 65)	500	550	600
Late onset	15,700	18,250	21,300
Total dementia	**16,650**	**19,350**	**22,450**

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800
TOTALS	**16,650**	**19,350**	**22,450**

People with mild symptoms will be able to remain independent in their own home. For some people in the 'Moderate' and those in the 'Severe' categories, more support and perhaps long-term care may likely be needed.

No. People with Down's Syndrome in West Sussex likely to have dementia

Age in Years	2009	2015	2020	2025	2030
45 -54	9	10	10	10	8
55-64	18	18	18	21	21
Sub-Total: 35 - 64	**27**	**28**	**28**	**31**	**29**
65 and over	1	2	2	2	2
TOTAL	**28**	**30**	**30**	**33**	**31**

Source: www.pansi.org.uk/index and www.poppi.org.uk/index

Many people with dementia also live with one or more other health conditions.

THE ECONOMIC COST

There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn[10].

West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)[9]					
	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

The total costs here include all those associated with supporting older people living with dementia rather than the extra costs attributable specifically to dementia itself.

The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition, half of this number are aged over 85. There is a total weekly net cost of £290,000 and much of this cost (85%) is accountable for by long term residential and nursing care.

The total net spend on residential and nursing care for people over age 85 requiring memory and cognition support is around £128,000 each week. The number of people in this age group is expected to rise by 60% in the next 10 years and resources will therefore need to focus on keeping people at home for longer and away from more expensive long-term care.

Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m*.

The need to ensure we continue to improve services to meet the needs of people affected by dementia is a high priority. However, the County Council and Clinical Commissioning Group are working with reduced public funding. The strategy has therefore been developed within the context of these financial restraints.

*People aged 65+ with dementia that are short stays (1 night or less) is estimated to be £1.6m. 2017 data

THE DEMENTIA WELL PATHWAY

The Dementia Well Pathway has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and cares from prevention to end of life care. This strategy has used the dementia well Pathway as a framework with which to present its goals for the next three years.

The Dementia Well Pathway has been used as a foundation for developing the goals of the West Sussex Joint Dementia Strategy 2020-23.

Preventing Well

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves."

There are some risk factors that you cannot change but research suggests up to one in three cases of dementia are preventable. Risk factors that may be preventable include:

Diabetes (type 2), high alcohol intake, lack of exercise, obesity, poor physical health, smoking. Hearing loss, hypertension, Depression and social isolation are other factors that could contribute.

Key issues & challenges

Green spaces in West Sussex providing opportunities for people to get more physically active.**Risk factors across the lifecourse approach as identified in the Joint Health & Wellbeing Strategy. For example, educational attainment, physical inactivity etc. **Information about the early signs and symptoms of dementia and positive messages about the benefits of diagnosis to encourage people to access a diagnosis. **Low diagnosis rates in people from black and ethnic minority groups (BAME).**Improved access to information about dementia for people with learning disabilities.**Greater risk to family and friend carers of loneliness and physical and mental health problems.

DIAGNOSING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves."

A diagnosis of dementia provides the opportunity to be able to plan ahead while the person is still able to make important decisions. In West Sussex the pathway to diagnosis is normally through the GP who will refer the person to the Dementia Assessment Service (DAS) or Memory Assessment Service (MAS) once all reversible causes of cognitive decline are ruled out.

The MAS/DAS will provide a quality diagnosis and follow-up support for the patient and their family and friend carer. At this point, a care plan will be developed which provides an opportunity for the person to be able to draw on their own strengths and assets and identify where additional support is required.

The Prime Minister's Challenge recommends that people receiving a diagnosis should have a named coordinator with a good understanding of the person and their needs along with how to navigate the health and social care system. In West Sussex, this is normally the person's GP.

Key issues & challenges

Fear of stigma preventing someone accessing a diagnosis, more information about benefits needed.**Early signs of dementia not being recognised in people with learning disabilities.**Long waits to diagnosis.**Low rates of diagnosis in people from Black Asian & Minority Ethnic Communities (BAME) and people with Alcohol Related Dementia.**Accessing information and advice after diagnosis.**A system that is complicated and disjointed where people can get 'lost' in the system.**Care plans not being shared with all those involved in the person's care.**The need for services to stay connected to the person living with dementia.

SUPPORTING WELL

***"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia and their family and friend carers receive high quality care and support throughout their journey from health and social care staff skilled in good dementia care* that is individual to the needs of the person with dementia."**

The best place for someone living with dementia is to remain at home independently for as long as possible but the progressive nature of dementia means that often people will develop increasingly complex needs. Suitable housing and assistance to live at home is therefore necessary.

It is important there is joined up support when a need arises. Adult Social Care, Proactive Care and Specialist Dementia Services are working together to help achieve this by working together, shifting the balance of care away from reactive crisis intervention to independent health and wellbeing. There also needs to be a focus on community led support and prevention and for Adults Services to look at enabling an individual to see the value they bring and the resources around them rather than focusing on any negative characteristics.

As the dementia progresses, some extra care and support to enable the person to live at home may be necessary. WSCC continues to actively engage and support the market development of care and support at home providers and focus on building opportunities for developing local markets. Extra Care Housing can also be a good solution as it offers the security of having staff on han and the Council currently commission 12 out of the 13 Extra Care Schemes in the County.

For people who can no longer live at home, the Council has a responsibility for ensuring there is an offer of good quality residential and nursing care and sufficiency of supply. Support should be easily accessible for the person and their families and carers to be able to make the right decision about their future care planning and how it will be funded.

Services such as Dementia Crisis, Living Well with Dementia, Community Dementia Matrons and Admiral Nurses are working hard to support people at an increased risk of an unplanned hospital admission. A stay in hospital for someone with dementia can be traumatic and confusing and there can be issues with eating, drinking and pain relief. For those people going into hospital, the Home from Hospital, Take Home & Settle and Relative Support services provide support for the person and their family.

Key issues & Challenges

Lack of clarity about eligibility for dementia services.**People with dementia often have more than one health condition but health services do not always work together.**Services designed at keeping people at home are stretched and struggle to meet demand.**People with dementia from Lesbian, gay, bisexual and transgender + (LGBT+) communities can feel mainstream services do not meet their needs.**Lack of 24/7 crisis support - Falls and fractures are common in people with dementia.**Unplanned admissions to hospital, longer stays and delays in discharge.**Insufficient capacity within care market and challenges with recruiting care staff.**Overstretched resources.**Gaps in staff training and often lack of confidence in supporting someone with complex and challenging needs.

LIVING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia are supported to live well with dementia by enabling them to: Stay socially active; Keep healthy and well; Access safe and welcoming communities that are responsive to the needs of people with dementia; Have access to quality information about dementia and the support available such as community activities, leisure and transport; Receive support to engage in meaningful activity, doing something that people enjoy or are interested in; and for family and friend carers to receive the support they need to be able to continue in their valuable caring role."

Breaking down the stigma of dementia and support are key to ensuring people with dementia can live meaningful and satisfying lives. Dementia Friendly Communities can help people to access their local communities and reduce the risk of social isolation. Local Dementia Action Alliances (LDAA) focus on changing public attitudes through the creation of dementia friendly communities. In West Sussex there are 10 LDAA's with a membership of local businesses, community groups, faith groups etc.

Support for the family and friend carer is essential and the Care Act 2015 gave the council enhanced duties towards carers. In West Sussex, there is a consistent offer of support, information and guidance to all carers delivered by Carers Support West Sussex. This provides a gateway to all other carers support services throughout the County. There is a diverse set of services for carers provided by the local authority, clinical, voluntary and community sector providers.

There needs to be a community led support approach to help meet the challenges faced and willingness to innovation and learning. A good example of this is new community led support talk locals and drop-ins.

In West Sussex, there is a universal offer of information and advice for people with dementia and their families from Alzheimer's Society's Dementia Support Service along with a county-wide information and advice service commissioned by Public Health. A dementia zone on the West Sussex Connect To Support website provides information about dementia and local support.

Key Issues & Challenges

Family and friend carers becoming socially isolated.**Lack of flexible breaks for carers.**Historically low uptake of services from BAME communities.**Accessing suitable activities for people from LGBT+ community.**Age appropriate activities for younger people with dementia. **Sustainable dementia friendly communities.**Transport**Local activities.**Support to access mainstream activities.

DYING WELL

"West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people with dementia and their families are supported to plan ahead, receive good end of life care and are able to die in accordance with their wishes."

All people with dementia should be given the opportunity to plan for their future care as early on as possible. The person with dementia and their family and friend carer should be involved in any decisions about end of life care, this reduces the likelihood that difficult and emotional decisions have to be made in a crisis and/or when the person's wishes can no longer be taken into account. Where necessary, advocates need to be identified to support the person with health and welfare decision-making to ensure their wishes are reflected. In West Sussex, the Clinical Commissioning Group along with health services and local hospices have endorsed an Advance Care Plan called 'Planning Future Care'. This is being used to identify people's wishes and preferences for future care.

People nearing the end of life need to receive coordinated compassionate care that is individual to their needs. This includes palliative care and bereavement support for the family. Care should be provided by skilled, trained and compassionate staff and family and friend carers throughout their life journey. In Coastal West Sussex, the End of Life Care Hub (ECHO) works proactively to support people in the last year of their life and provides a more responsive, proactive and individual offer of care.

Key issues & Challenges
People with dementia not supported to plan for their future care soon after diagnosis.**Advance care plans not being shared with all those involved in the person's care.**Hospital staff unaware of the person's end of life wishes.** People dying aware from their usual place of residence or a place not of their choosing.**Lack of bereavement support.

Dementia in Different Groups of People

Early Onset Dementia
Younger people with dementia (under the age of 65) face different issues to someone older. There is often a long wait to diagnosis as other conditions are explored and support designed for older people is often unsuitable for someone younger and more active. This means that this group of people can often find themselves feeling isolated.

Lesbian, gay, bisexual and transgender + (LGBT+) and Dementia
Older people from this community are less likely to have the support from family members and children and they often live on their own. Many people fear that mainstream care services will not be willing, or are not able to understand how to meet their needs.

Learning Disabilities and Dementia
People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome. Symptoms are often not realised as being dementia related because they can present differently. In West Sussex, the pathway to diagnosis is patchy.

Black Asian & Minority Ethnic Communities (BAME) and Dementia
Among the UK's BAME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.

Alcohol Related Dementia
More common in people in their 40s and 50s it comprises about 10% of cases of Early Onset Dementia. The condition is poorly understood, and patients struggle with the 'double stigma' of dementia and alcohol addiction. There is a lack of community services and clear pathways to support.

OUR GOALS

THE DEMENTIA WELL PATHWAY

This strategy is based on the Dementia Well Pathway's five elements from the Prime Minister's Challenge on Dementia

Preventing Well
People live, work and play in environments that promote health and wellbeing and support them to live healthy lives and for individuals, families, friends and communities to be connected. **There is a greater awareness of factors increasing the risk of dementia and what can be done to reduce them.Early intervention and ongoing support for hearing loss.

Diagnosing Well
People recognise the early signs of dementia and know what to do to receive a diagnosis. All groups of people to receive a timely diagnosis. **Improved access to information and advice.**Improved access to good quality joined up support following diagnosis.**People have the opportunity to plan for the future.

Supporting Well
For people to be enabled to live at home. For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia. **Approaches to care and support that are individual to the person's needs.**Compassionate care and support from staff skilled in dementia. **Dementia friendly health and care settings.**The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support.

Living Well
People to have access to a range of affordable flexible activities that reflects their interests and needs. There is a whole community response to living well with dementia in safe and enabling communities. **People can maintain and develop their relationships and be able to contribute to their community. **Carers of people with dementia are able to access support as needed and feel able to continue with their caring role.

Dying Well
People living with dementia together with their families and family and friend carers are enabled to make decisions about their future health care. **People are supported to die with dignity in a place of their choice.Families and carers are provided with timely, coordinated support before death, at the time of death and bereavement.

A JOINT STRATEGIC APPROACH TO DEMENTIA

The range of support for people with dementia is patchy; people often get lost trying to navigate an array of information and services. We know people living with dementia face a variety of challenges and have a range of needs; so, to achieve our vision it is key that organisations work together to collectively transform the approach to dementia in West Sussex.

This document represents the combined views of many partners, each of whom is committed to working together to make life better for people affected by dementia.

MONITORING DELIVERY & IMPACT ACROSS THE PATHWAY

The delivery plan sets out how West Sussex County Council and the Clinical Commissioning Group plan to monitor the progress being made with the goals set out above and looks at what can be achieved with current resources. An additional section has been included that looks at what can be achieved with a little and much more funding.

It is vital that we assess whether this strategy is making a demonstrable difference to the experience of people living with dementia and their family and friend carers. We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this strategy. We will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

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NHS
Coastal West Sussex
Clinical Commissioning Group

NHS
Commissioning Alliance
(North Place)
Crawley CCG
East Surrey CCG
Horsham and Mid Sussex CCG

West Sussex Dementia Strategy 2020-23

Irene Loft
Senior Commissioning Officer, Adults & Health, WSCC

Tracey Wooldridge
Commissioning Manager, Mental Health & Dementia
Horsham and Mid Sussex CCG and Crawley CCG, Coastal West Sussex CCG

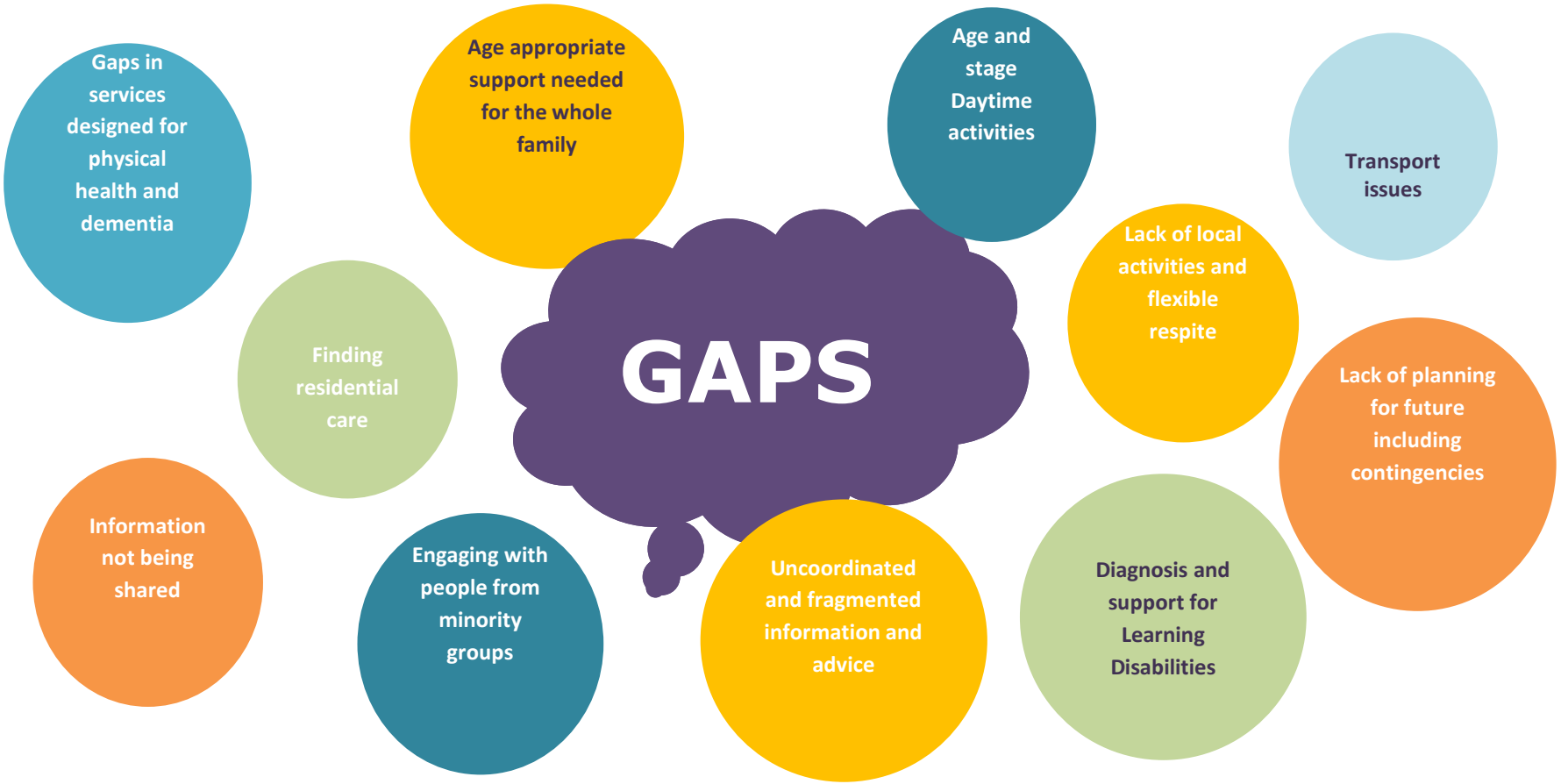
west sussex county council

THE WEST SUSSEX WAY

www.westsussex.gov.uk

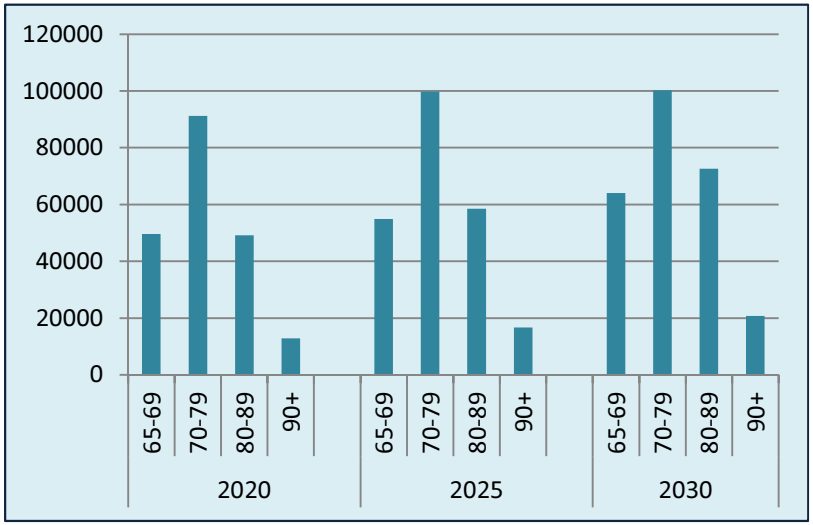
Where we are now

- Review of the Dementia Framework 2014-19.
- Feedback from almost 400 people through 2 on-line surveys, focus groups with people living with dementia, family and friend carers and health and social care staff, library drop-ins, presentations etc.
- Progress but still lots more to do.


Gaps in services designed for physical health and dementia
Age appropriate support needed for the whole family
Age and stage Daytime activities
Transport issues
Lack of local activities and flexible respite
Finding residential care
GAPS
Lack of planning for future including contingencies
Information not being shared
Engaging with people from minority groups
Uncoordinated and fragmented information and advice
Diagnosis and support for Learning Disabilities

The Local Picture

The population of people over aged 65 is set to rise in the next 10 years



Dementia	2020	2025	2030
Early onset (i.e. under 65)	500	550	600
Late onset	15,700	18,250	21,300
Total Dementia	16,650	19,350	22,450

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800

- Ageing population and prevalence impacting on capacity within services.

People with mild symptoms will be able to remain independent in their own home. For some people in the 'Moderate' and those in the 'Severe' categories, more support and perhaps long term care may likely be needed.

The Economic Cost

West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)[9]	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

The total costs here include all those associated with supporting older people living with dementia rather than the extra costs attributable specifically to dementia itself.

County Council and Clinical Commissioning Group are working with reduced public funding. The strategy has therefore been developed within the context of these financial restraints.

- WSCC support around 850 people over the age of 65 requiring support with their memory and cognition
- Average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long term residential and nursing care.
- More than half the number of people in this group are over the age of 85 - numbers of people in this age group expected to rise by 60% in the next 10 years.
- Resources will need to focus on keeping people at home for longer and away from more expensive long term care.
- NHS commissioned dementia services cost in excess of £10m annually.
- Cost of emergency inpatient admissions est. £1.6m.

National & Local Context

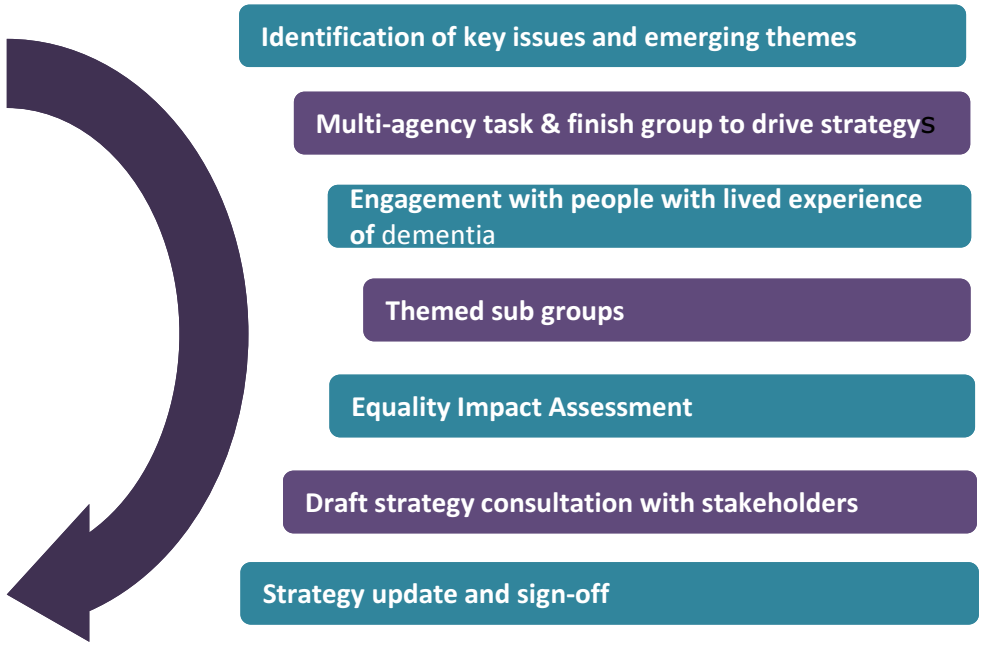
- NHS Five Year Forward View
- DoH Prime Minister's challenge on Dementia 2020
- NHS Long Term Plan
- Care Act 2014
- West Sussex Plan
- Sussex Health and Care Partnership Strategic Delivery Plan
- Joint Commitment to carers 2015-20
- Health & Wellbeing Strategy 2019-24
- Adult Social Care in West Sussex – Our vision and strategy 2019-21
- Sussex Community NHS Foundation Trust Dementia Strategy
- Western Sussex Hospitals NHS Trust Dementia Strategy

NHS Coastal West Sussex Clinical Commissioning Group

Dementia Strategy Development

NHS Commissioning Alliance (North Place) Crawley CCG East Surrey CCG Horsham and Mid Sussex CCG

Review of the Dementia Framework West Sussex 2014-19 including engagement with wider stakeholders



OUR VISION

To improve the health and wellbeing of local people, and for those people who develop dementia to be supported to maintain their independence for as long as possible.

People with dementia and their families and carers receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice.

People with dementia and family and friend carers have access to timely, skilled and well-coordinated support throughout their journey.

People with dementia and their family and friend carers receive care and support that focuses on an individual's strengths and looks to promote their wellbeing.

People with dementia, along with their families and carers are central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

For supportive communities, where people feel able to participate in community life without stigma.

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Preventing Well - Goals

> *We are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves.*

People live, work and play in environments that promote health and wellbeing and support them to live healthy lives and for Individuals, families, friends and communities are connected.

Early intervention and ongoing support for hearing loss.

There is a greater awareness of factors increasing the risk of dementia and what can be done to reduce them.

Diagnosing Well - Goals

> *"We want to see all groups of people diagnosed earlier and get timely access to good quality post-diagnostic support. With a named co-ordinator and support to plan their future care along with those people important to them."*

People recognise the early signs of dementia and know what to do to receive a diagnosis

All groups of people to receive a timely diagnosis

People have the opportunity to plan for the future

Improved access to information and advice

Improved access to good quality joined up support following diagnosis

Supporting Well - Goals

> *We are committed to ensuring that people living with dementia and their family and friend carers receive high quality care and support throughout their journey from health and social care staff skilled in good dementia care* that is individual to the needs of the person with dementia.

The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support

Approaches to care and support that are individual to the person's needs.**

Compassionate care and support from staff skilled in dementia

For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia

Dementia friendly health and care settings

For people to be enabled to live at home

Living Well - Goals

"We are committed to ensuring that people living with dementia are supported to live well with dementia by enabling them to: Stay socially active; Keep healthy and well; Access safe and welcoming communities that are responsive to the needs of people with dementia; Have access to quality information about dementia and the support available such as community activities, leisure and transport; Receive support to engage in meaningful activity, doing something that people enjoy or are interested in; and for family and friend carers to receive the support they need to be able to continue in their valuable caring role."

People to have access to a range of affordable flexible activities that reflects their interests and needs

People can maintain and develop their relationships and be able to contribute to their community

Carers of people with dementia are able to access support as needed and feel able to continue with their caring role

There is a whole community response to living well with dementia in safe and enabling communities

Dying Well - Goals

> We are committed to ensuring that people with dementia and their families are supported to plan ahead, receive good end of life care and are able to die in accordance with their wishes.

People living with dementia together with their families and carers are enabled to make decisions about their future health care

There is support for people to die with dignity in a place of their choice

People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care

Families and carers are provided with timely co-ordinated support before death, at the time of death and bereavement

Joint Strategic Approach to Dementia in West Sussex

The range of support for people with dementia is fragmented; people often get lost trying to navigate an array of information and services. We know people living with dementia face a variety of challenges and have a range of needs; so to achieve our vision it is key that organisations work together to collectively transform the approach to dementia in West Sussex.

This strategy represents the combined views of many partners, each of whom is committed to working together to make life better for people affected by dementia.

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Monitoring delivery and impact across the pathway

- Delivery Plan with aspirational ideas for any future funding.
- Engagement with people living with dementia and family and friend carers.

Next Steps

- Sign-off by Health & Adult Social Care Select Committee in March
- Public Launch of new Strategy in Spring 2020
- Set up Dementia Strategic Partnership Group to monitor progress

NHS
Coastal West Sussex
Clinical Commissioning Group

NHS
Commissioning Alliance
(North Place)
Crawley CCG
East Surrey CCG
Horsham and Mid Sussex CCG

Any questions?

Date of meeting:	**30th January 2020**
Item Title:	**West Sussex Better Care Fund Programme**
Executive Summary:	This paper provides a summary of the funding sources and expenditure plan for the West Sussex Better Care Fund in 2019/20 along with the regular monitoring of performance against the 4 national metrics for Quarters 1 and 2, 2019/20.
Recommendations for the Board:	The Health and Wellbeing Board is asked to: 1) Note the West Sussex Better Care Fund funding sources and expenditure plan. 2) Note the West Sussex performance against the national metrics at Q2 2019/20. 3) Note the 2019/20 schedule for quarterly returns.
Relevance to Joint Health and Wellbeing Strategy:	• Living and working well • Ageing well
Financial implications (if any):	**None**
Consultation (undertaken or planned):	Not applicable
Item author and contact details:	**Paul Keough, paul.keough@nhs.net**

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Better Care Fund Monitoring

Date 30th January 2020

Report by Better Care Fund Coordination Team

Executive Summary
This paper provides a summary of the funding sources and expenditure plan for the West Sussex Better Care Fund in 2019/20 along with the regular monitoring of performance against the 4 national metrics for Quarters 1 and 2, 2019/20.

The Health and Wellbeing Board is asked to:

1) Note the West Sussex Better Care Fund funding sources and expenditure plan.
2) Note the West Sussex performance against the national metrics at Q2 2019/20:
   - Non-Elective Admissions are higher than planned and higher than the previous year.
   - Residential Admissions are currently on track although delays in the availability of data mean that overall numbers are likely to rise.
   - Reablement/Rehabilitation is lower than planned although performance has improved since Q1.
   - Delayed Transfers of Care are significantly higher than planned but lower than the same period in the previous year.
3) Note the 2019/20 schedule for quarterly returns.

1. Background

The Better Care Fund (BCF) is a programme spanning both the NHS and local government which seeks to join-up health and care services, so that people can manage their own health and wellbeing, and live independently in their communities for as long as possible.

For the current year, all BCF-funded schemes were reviewed and rationalised by the Joint Commissioning Strategy Group, with some smaller schemes being grouped together by theme. This resulted in a final portfolio of 13 schemes including the Winter Pressures Grant, paid to local authorities and brought within the scope of the Better Care Fund for 2019/20.

2. Better Care Fund Plan 2019/20

2.1 Funding Sources/Income

Capital Funding	
Disabled Facilities Grant	£8,297,662
Total Capital Funding	**£8,297,662**
Revenue Funding	
NHS Horsham and Mid Sussex CCG	£14,309,047
NHS Crawley CCG	£8,097,596
NHS Coastal West Sussex CCG	£35,200,718
West Sussex County Council Additional Contribution	£1,878,300
Improved Better Care Fund	£16,703,222
Winter Pressures Fund	£3,303,452
Total Revenue Funding	**£79,492,335**
Total Better Care Fund Budget	**£87,789,997**

2.3 Expenditure Plan

Committed Funding Scheme	Horsham and Mid Sussex CCG	Crawley CCG	Coastal West Sussex CCG	West Sussex County Council	Total
1. Disabled Facilities Grant	-	-	-	£8,297,662	£8,297,662
2. Maintaining (Protecting) Social Care	£3,757,796	£ 2,110,670	£9,582,999	-	£15,451,465
3a. Meeting adult social care needs (iBCF)	-	-	-	£7,638,222	£7,638,222
3b. Reducing pressures on the NHS, including supporting more people to be discharged from hospital when ready (iBCF)	-	-	-	£6,448,000	£6,448,000
3c. Ensuring that the local social care provider market is supported (iBCF)	-	-	-	£2,617,000	£2,617,000
4. Proactive Care	-	-	£6,566,814	-	£6,566,814

Committed Funding Scheme	Horsham and Mid Sussex CCG	Crawley CCG	Coastal West Sussex CCG	West Sussex County Council	Total
5. Communities of Practice	£2,801,893	£1,420,336	-	-	£4,222,229
6. BCF Programme Supt	£44,713	£25,118	£110,169	-	£180,000
7. Step Up Step Down	£4,252,633	£2,667,288	£10,078,604	-	£16,998,526
8. Prevention Initiatives	£454,837	£148,756	£335,000	-	£938,593
9. Care Act Initiatives	£509,747	£286,314	£1,299,939	-	£2,096,000
10. Carers Services	£460,232	£258,502	£1,173,666	£1,878,300	£3,770,700
11. Telecare	£205,215	£116,897	£538,689	-	£860,800
12a. Community Equipment	£960,812	£539,736	£2,450,852	-	£3,951,400
12b. Community Equipment (Health)	£861,169	£523,979	£3,063,986	-	£4,449,134
13. Winter Pressures Grant	-	-	-	£3,303,452	£3,303,452
TOTAL	**£14,309,047**	**£8,097,596**	**£35,200,718**	**£30,182,636**	**£87,789,997**

3. BCF Performance Q1 & Q2 2019/20

3.1 Metrics Overview

The national BCF policy framework establishes the national metrics for measuring the progress of integration through the BCF as shown below:

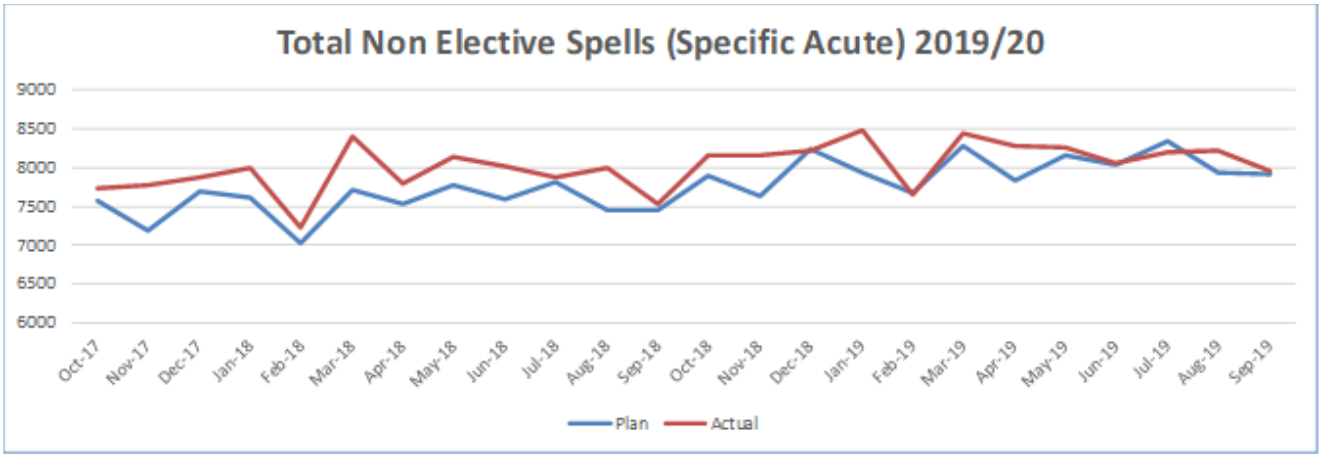
Indicator	Required Trend	Plan at Q2 End	Actual at Q2 End
1. Non-Elective Admissions (Specific Acute.)	Lower	48,244	48,978
2. Long-term support needs of older people (aged 65 and over) met by admission to residential and nursing care homes, per 100,000 population.	Lower	297.4	254.1
3. Proportion of older people 65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services.	Higher	88.2%	66.5%
4. Delayed transfers of care from hospital per 100,000 population 18+ (Delayed Days.)	Lower	13,230	16,105

Key:	Meets Plan	Within -0.1% to -5% of Plan	Greater than -5% from Plan

3.2 Non-Elective Admissions (Specific Acute)

This metric measures the outcome, a reduction in the number of unplanned acute admissions to hospital.

Effective prevention and risk management of vulnerable people through effective, integrated Out-of-Hospital services will improve outcomes for people with care needs and reduce costs by avoiding preventable acute interventions and keeping people in non-acute settings.



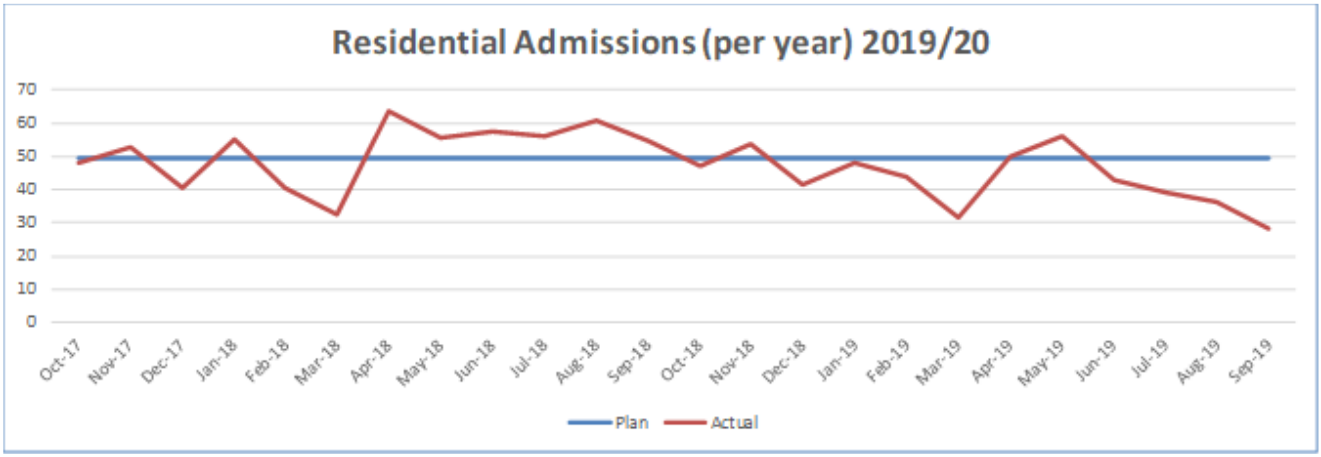
At Month 6 2019/20, Non-Elective Admissions (NEAs) across West Sussex are above plan by 0.5% and above previous year by 5.7%. For quarters 1 and 2, NEAs are above plan by 1.5%. The gap between the planned and actual figures during 2019/20 remains relatively narrow compared to the previous year.

There is a complex range of variables which contribute to the number of emergency admissions to hospital particularly as this metric is for all ages rather than the typical cohorts of many BCF schemes.

3.3 Residential and Nursing Care Admissions

This metric measures the outcome, reducing inappropriate admissions of older people (65+) in to residential care.

Avoiding permanent placements in residential and nursing care homes is a good measure of delaying dependency, and the inclusion of this measure in the framework supports local health and social care services to work together to reduce avoidable admissions. Research suggests that, where possible, people prefer to stay in their own home rather than move into residential care. However, it is acknowledged that for some client groups that admission to residential or nursing care homes can represent an improvement in their situation.



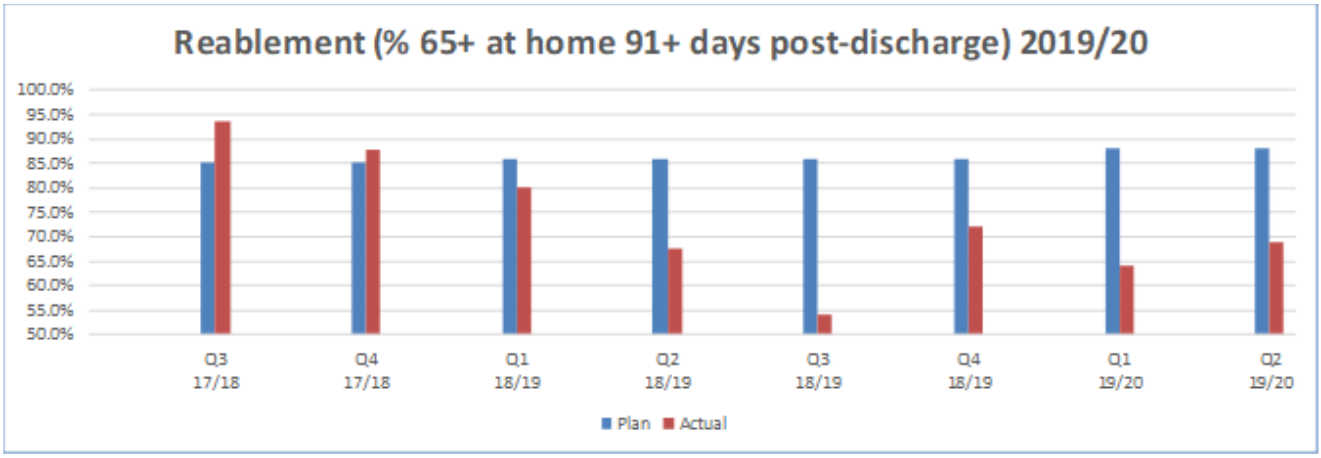
At Month 6 2019/20 and for quarters 1 and 2, Residential Admissions are below plan and therefore on track. However, this figure will possibly rise over subsequent months as there is significant lag in data collection which means the true figure will not be apparent for some time.

Residential Admissions in West Sussex have tended to be above plan. However, the Step Up Step Down programme and the new operating model for social care, building on community strengths/assets, should result in a reduction in residential admissions over the course of the full year.

3.4 Reablement/Rehabilitation

This metric measures the outcome, increase in effectiveness of these services whilst ensuring that those offered service does not decrease.

Improving the effectiveness of these services is a good measure of delaying dependency, and the inclusion of this measure in the scheme supports local health and social care services to work together to reduce avoidable admissions. Ensuring that the rate at which these services are offered is also maintained or increased also supports this goal.



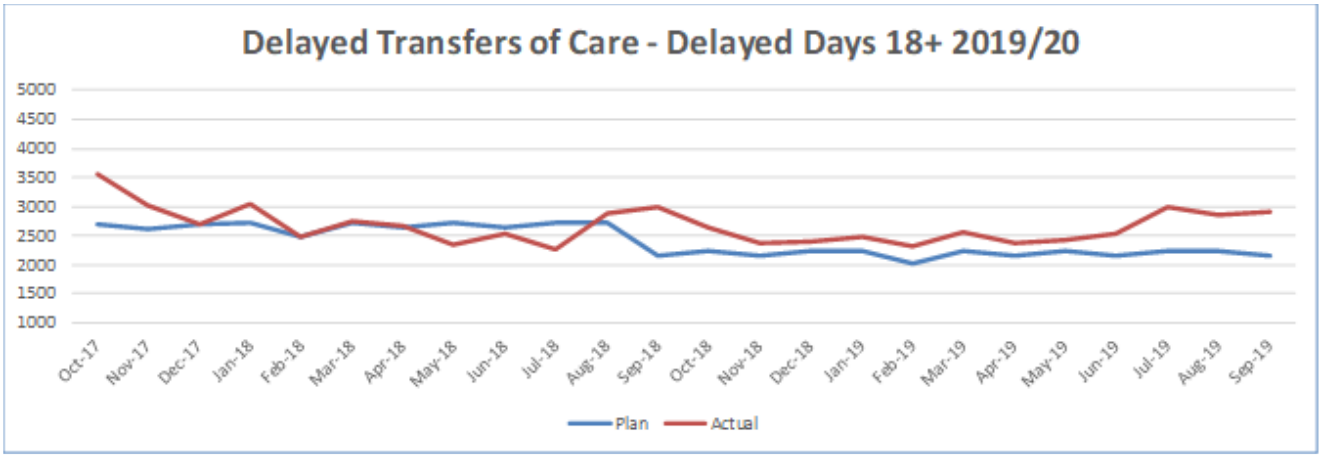
An ambitious Reablement target of 88.2% was set for 2019/20. This follows a year of below plan performance thought to be due to changes in provider and data collection, particularly around follow-ups to establish people still at home after 91 days.

In 2019/20, the Step Up Step Down programme, looking at discharge pathways from hospital, will support improvement of this metric, particularly through the Home First project, developing and improving home-based health and social care services enabling people to be discharged directly to their home with the right services and support.

2.5 Delayed Transfers of Care

This metric measures the outcome, effective joint working of hospital services (acute, mental health and non-acute) and community-based care in facilitating timely and appropriate transfer from all hospitals for all adults.

This is an important marker of the effective joint working of local partners, and is a measure of the effectiveness of the interface between health and social care services. Minimising Delayed Transfers of Care (DToCs) and enabling people to live independently at home is one of the desired outcomes of social care. The DToC metric reflects the system wide rate of delayed transfers and activity to address it will involve efforts within and outside of the BCF.



At Month 6 2019/20, Delayed Transfers of Care (DToC) across West Sussex are above plan by 34.4% but lower than previous year by 2.5%. For quarters 1 and 2, DToCs are above plan by 21.7%. Performance has yet to match the centrally set target of 72.3 daily delays in force since September 2018. There is a worsening of performance in Q2 2019/20 when compared to Q1.

4. BCF Quarterly Returns 2019/20

4.1 Overview

The quarterly reporting requirements and deadlines for 2019/20 differ slightly from previous years:

- Quarter 1: No reporting required.
- Quarter 2: Wednesday, 30 Oct 2019 (only Improved Better Care Fund (iBCF) grant related reporting is required)
- Quarter 3: Friday, 24 Jan 2020 (includes Winter Pressures Grant)

- Quarter 4: Friday, 01 May 2020 (includes Winter Pressures Grant, iBCF, and year-end.)

The Quarter 2 Return was submitted on 30th October following sign-off by the Joint Commissioning Strategy Group and final approval by the HWB Chair.

Paul Keough
Better Care Officer

Contact: Paul Keough, BCF Officer – paul.keough@nhs.net

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