Brighton & Hove City Council

Title:	**Health Overview & Scrutiny Committee**
Date:	**14 October 2020**
Time:	**4.00pm**
Venue	**Council Chamber, Hove Town Hall**
Members:	**Councillors:** Evans (Chair), Deane (Group Spokesperson), McNair (Group Spokesperson), Barnett, Grimshaw, Lewry, Osborne, Powell, West and Wilkinson **Co-opted Members:** Caroline Ridley (Community Sector Representative), Fran McCabe (Healthwatch), Colin Vincent (Older People's Council)
Contact:	**Giles Rossington** Senior Policy, Partnerships & Scrutiny Officer 01273 295514 giles.rossington@brighton-hove.gov.uk

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AGENDA

PART ONE   **Page**
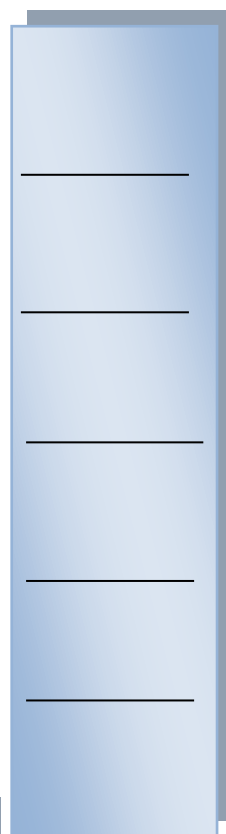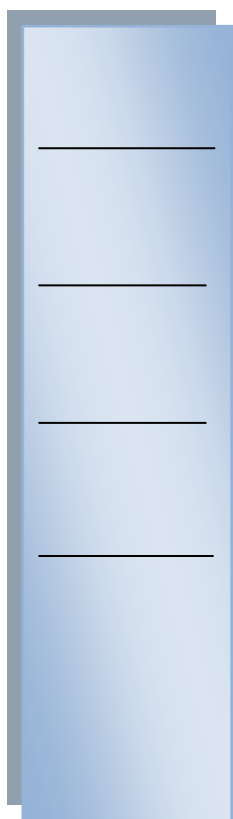
8   PROCEDURAL BUSINESS

(a)   **Declaration of Substitutes:** Where Councillors are unable to attend a meeting, a substitute Member from the same Political Group may attend, speak and vote in their place for that meeting.

(b)   **Declarations of Interest:**

(a)   Disclosable pecuniary interests;
(b)   Any other interests required to be registered under the local code;
(c)   Any other general interest as a result of which a decision on the matter might reasonably be regarded as affecting you or a partner more than a majority of other people or businesses in the ward/s affected by the decision.

In each case, you need to declare:
(i)   the item on the agenda the interest relates to;
(ii)   the nature of the interest; and
(iii)   whether it is a disclosable pecuniary interest or some other interest.

If unsure, Members should seek advice from the committee lawyer or administrator preferably before the meeting.

(c)   **Exclusion of Press and Public:** To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

NOTE: Any item appearing in Part Two of the Agenda states in its heading the category under which the information disclosed in the report is exempt from disclosure and therefore not available to the public.

A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls and on-line in the Constitution at part 7.1.

9   MINUTES   7 - 74

To consider the minutes of the previous Health Overview & Scrutiny Committee meeting held on 15th July 2020, (copy attached).

OVERVIEW & SCRUTINY COMMITTEE

10   CHAIR'S COMMUNICATIONS

11   PUBLIC INVOLVEMENT

To consider the following items raised by members of the public:

(a)   **Petitions:** To receive any petitions presented by members of the public to the full Council or to the meeting itself;
(b)   **Written Questions:** To receive any questions submitted by the due date of 12noon on the (insert date) 2017.
(c)   **Deputations:** To receive any deputations submitted by the due date of 12 noon on the (insert date) 2017.

12   MEMBER INVOLVEMENT

To consider the following matters raised by Members:

(a)   **Petitions:** To receive any petitions submitted to the full Council or to the meeting itself.
(b)   **Written Questions:** A list of written questions submitted by Members has been included in the agenda papers (copy attached).
(c)   **Letters:** To consider any letters submitted by Members.
(d)   **Notices of Motion:** To consider any Notices of Motion.

13   COVID: LOCAL HEALTH & CARE SYSTEM RESPONSES AND PLANNING

Report of the Executive Lead, Strategy, Governance & Law on health and care systems actions and planning regarding the Covid emergency (copy attached)

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

14   SUSSEX HEALTH & CARE PARTNERSHIP (SHCP) WINTER PLAN

Report of the Executive Lead, Strategy, Governance & Law on the Sussex Health & Care Partnership Winter Plan (copy attached).

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

15   FOUNDATIONS FOR OUR FUTURE – THE FINAL REPORT FROM THE SUSSEX WIDE CHILDREN & YOUNG PERSON'S EMOTIONAL HEALTH & WELLBEING SERVICE REVIEW

Report of the CCG Managing Director on 'Foundations Of Our Future' review of children and young people's emotional health & wellbeing services in Sussex (copy attached)

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

OVERVIEW & SCRUTINY COMMITTEE

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Date of Publication - Tuesday, 6 October 2020

BRIGHTON & HOVE CITY COUNCIL

HEALTH OVERVIEW & SCRUTINY COMMITTEE

4.00pm 15 JULY 2020

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

Present: Councillor Deane (Chair)

Also in attendance: Councillor McNair (Group Spokesperson), Barnett, Grimshaw, Hills, Lewry, Osborne, Powell and Appich

Other Members present: Fran McCabe (Healthwatch); Caroline Ridley (CVS rep)

PART ONE

1   PROCEDURAL BUSINESS

1.1   Apologies were received from Grace Hanley, Assistant Director, HASC.

1.2   Cllr Carmen Appich attended as substitute for Cllr Jackie O'Quinn.

1.3   There were no declarations of interest.

1.4   The press & public were not excluded from the meeting.

2   MINUTES

2.1 The minutes of the 22 January 2020 HOSC meeting were agreed as an accurate record.

3   CHAIR'S COMMUNICATIONS

3.1   The Chair gave the following statement:

Good afternoon everyone and welcome to today's meeting.

There was a time, when the pandemic was at its peak, that I thought it would be too risky to convene a meeting just yet, and was reluctant to tear health professionals away from there vital work to focus on us , but thankfully Covid has been on the decline in Brighton and Hove in recent weeks, and I believe it is vital that we have the opportunity to look at how the pandemic has affected the city and the local response to
it.

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So I am very grateful to HealthWatch and the CCG who have taken the time to prepare the presentations that we will be looking at later on, And world also like to welcome the members of the public who have joined us today to ask questions.

One thing that has become abundantly clear to us all is how much we value our frontline workers and all medical professionals. This pandemic has shed a stark light on how the NHS has been supported and funded in the past and how a decade of austerity has placed hospitals and social care perilously close to the wire. If there is one thing that is pulling us through this greatest health challenge for a century is the dedication of individuals, going way beyond the call of duty, and how they need to be fully supported both now and looking forward.

There are many lessons to be learned from the past few months and will be the subject of future reports for many months to come, as we look to recovery: things we could have done differently, and examples of best practice we can share with others as we look to the future in terms of how well we are prepared should there be a second wave, and what plans are in place for any future pandemic.

It is also devastatingly clear that inequalities have been exposed and exacerbated by this pandemic. We need to scrutinise what we know about the impact of Covid-19 on our BAME communities, for example, and address how and why inequalities persist. We also need to consider the bereavement being felt by so many, the outbreak in our care homes – and the human impact this has all had. It is important to say today that these topics and others will be the focus of future reports and presentations to this committee. We owe it to the memory of those who have died is to give attention to the lessons learned, and ways we can prevent such deaths happening again.

There were a number of reports that should have come to this committee both back in March and today, most notably Cancer care, hospital discharge and children's mental health. All these and other outstanding reports will be coming to HOSC in due course, but as you can imagine, things have moved on so much just recently that all of them will have changed significantly since they were first mooted.

A couple of other things have emerged since we last met that I think Members will want to take a look at at later meetings. The first is the proposed merger of the Royal Sussex County Hospital with West Sussex, which has come as a surprise as there appears to have been no consultation with locally elected Councillors, and I will be asking the Chair of the Health and Wellbeing Board what conversations they have had with local NHS.

The other, as members may have become aware, is that the Brighton and Hove CCG is one of 16 throughout the country to have been written to by NHS England for falsely claiming to have met its mental health investment standard, and I would anticipate that Members will want to explore this further.

Before we move on to the public questions and reports, I would just remind Members of my regular update meetings with Adam Doyle along with East and West Sussex. These present a chance for us to raise questions, and I would urge members of all parties to send these to myself and Giles in good time for answers to be prepared. As with the last meeting Giles will send you all a reminder note.

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It's difficult to predict how long we will be in session this afternoon, but I will be calling a break approximately every hour or when there is a natural time to do so.

4   PUBLIC INVOLVEMENT

4.1   Janet Strang

4.1.1   Janet Strang asked the following question:

"At the beginning of the current pandemic, local MP Peter Kyle was expressing dismay at the vulnerability of patients and staff in care homes. At the same time, the GMB trade union was reporting that at the Royal Sussex County Hospital, BAME staff were being bullied, discriminated against, and pressured to work without adequate PPE.

Does the HOSC share my concern about the high proportion of BAME deaths due to Covid-19, and if so, will the HOSC invite a senior officer to appear at its next meeting to provide the relevant statistics for Brighton & Hove?"

4.1.2   The Chair responded:

 "I certainly share your concerns about the impact of Covid on BAME communities. The HOSC will definitely want this to be a major focus of its scrutiny of health & care system recovery planning and I will ensure that this issue is addressed at the future HOSC meetings when we look more closely at the local Covid response and at local system recovery and resilience planning."

4.1.3   Ms Strang asked a supplementary question:

I understand that the CCG has been working to assess the impact of Covid 19 on BAME communities within the city. Can the Chair confirm which BAME groups and networks the CCG has engaged with and what the outcomes of this work have been?

4.1.4   The Chair agreed to provide a written response to this query.

4.2   Valerie Mainstone

4.2.1 Valerie Mainstone asked the following question:

"The founding ethos of the NHS was that it would provide healthcare for everyone, free at the point of need. Now, voluntary organisations such as Medact, and Docs Not Cops, are extremely concerned about migrants who are unwilling to access NHS services, for fear of being charged sums of money that they cannot afford, and/or of being deported if NHS staff report them to the Home Office.

"Does this HOSC deplore the fact that current rules deter some people from seeking NHS help during the pandemic, and agree that NHS services throughout the country should be free and available to all at the point of need, regardless of ethnicity/nationality/immigration status?"

4.2.2 The Chair responded:
Aside from the moral of the Hippocratic Oath which compels medical people to treat anyone in need, I believe it is dangerous and counter-productive to bar anyone from medical help during a time of pandemic. We should bear in mind that many migrants and asylum seekers are barred from seeking employment, which in turn precludes them from paying NI contributions, even though they would dearly love to do so, and to make a contribution towards society. However, returning to the issue at hand, which is Health, it makes no sense to leave untreated conditions to get worse, which may in turn adversely affect the population at large.

4.3   Dr Yok Chang

4.3.1 Dr Chang asked the following question:

"It seems that HOSC has not met because NHS bodies have been charged with the following tasks, but were not ready with responses yet:

- An evaluation of the local Covid response across the health and care system.
- An explanation of the changes made to NHS services in recent months made under urgency powers (i.e. service changes that in normal circumstances would have required consultation with HOSCs).
- Plans for recovery across the local health and care system – i.e. returning services to 'normal' including dealing with the backlog of elective procedures etc."

Please would you clarify what service changes were made under the corona crisis and are these changes permanent or reversible if now open to scrutiny."

4.3.2 The Chair responded:

"CCGs have spoken to me about bringing a report on NHS service changes made under urgency powers to all Sussex HOSCs. This needs to be a coordinated approach as some of the changes will impact on more than one local authority area. The earliest point at which these reports can be presented more or less simultaneously to each of the HOSCs is early autumn. Brighton & Hove HOSC will therefore consider this issue at its October meeting. In instances where the NHS wants to make a temporary service change permanent, the HOSC will want to understand the rationale for this move, including its impact on the patient experience, particularly in terms of equalities."

4.4   Madeleine Dickens

4.4.1 Ms Dickens asked the following question:

"Various Government initiatives to deal with Covid- 19 have proved tragically ineffectual. Net result one of the highest death tolls. One such failing was the guidance issued that "negative tests are not required prior to transfers / admissions into the care home", contributing to a public health disaster.
HOSC members are no doubt extremely concerned about the Government failure to liaise and share intelligence with Local Authorities which has exacerbated the crisis.

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With so many unnecessary deaths and grieving families across the city, will members call on the Full Council to convene public enquiry into this issue to ensure concerns and questions can be answered and guidance developed to avoid any re-occurrence?"

4.4.2   The Chair responded:

It's evident that the Covid crisis has exposed a number of weaknesses in resilience planning; and I agree that there is a pressing need to learn from the events of the past few months, so that we can be better prepared for future outbreaks and better able to protect our most vulnerable communities. A full 'public enquiry' is something that can only be established at a national level, and we don't currently know what the Government's plans are regarding this, although the Secretary of State for Health & Social Care has said today that there will be an enquiry. Given this current uncertainty, I'm not sure that it would be a good use of resources to seek to establish a purely local enquiry at the present time. There is a real risk that we would end up duplicating the work of a national enquiry.

4.4.3   Ms Dickens noted that she had concerns about the timing and form of any national enquiry and reiterated the need for a local enquiry. The Chair responded that we will need to wait to see what the Government plans. However, the HOSC will definitely be looking at the local Covid response and at system plans going forward.

4.5   Chris Tredgold

4.5.1 Mr Tredgold asked the following question:

'Care Home residents have been the most severely affected by Covid-19 - accounting for over 40% of England's high death rate.
Age and undiagnosed infected patients discharged from hospital have been causes of this - but so have a lack of testing and adequate PPE.
Testing is at last planned - weekly for the staff, monthly for the residents.
Homes and Local authorities need the results quickly.
How will the HOSC ensure that all staff and residents in Care Homes receive clear test results and that all staff have access to adequate PPE?'

4.5.2   The Chair responded:

The impact of Covid 19 on people living in residential care is something that should concern all of us; and as your question says, the issues of PPE and testing are particularly crucial.

I'm glad to say that there is some positive news locally. In terms of PPE, all care homes have access to PPE. If they are unable to purchase themselves via their usual supply routes, they can access government stocks via the Local Resilience Forum (LRF). The LRF delivers the stocks to the Local Authority, and in BHCC we have put in place a distribution Team to distribute this PPE to all care providers who require it. This includes care homes, home care, childcare settings, education settings and other commissioned and partner organisations and to individuals providing care. The use of PPE is monitored via Care Quality Commission, and through the Council Quality Monitoring Team, and also via additional Infection Control input to all care homes for advice and support.

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In terms of testing Public Health and Commissioning & Contracts leads are communicating regularly with care homes to ensure they know how and when to register for whole home testing and to monitor the results of the tests and any issues with registering, receiving tests and receiving results. An inbox has been set up to monitor queries from homes and to collect results. Support and guidance is available on how to effectively swab people and on infection control to prevent outbreaks. At this point regular testing is only available for care homes for people over 65 or with dementia. Specialist care homes for people under 65 have received 1 round of whole home testing.

Staff from care homes, adult social care, teams across the council and partner organisations have worked really hard together to support residential care throughout the crisis and I'd like to commend their efforts.

Of course, we need to be assured that the system is robust enough to cope with a second wave of infections and this will definitely be something that the HOSC focuses on when it scrutinises the health and care system's recovery and resilience planning in the coming months.

4.6   Ken Kirk

4.6.1   Mr Kirk asked the Does the HOSC share my concern that the government's Test and Trace system run by Deloitte, see the answer to a parliamentary question, does not require Deloitte to pass positive cases to local authorities. Do you agree that the HOSC should require B&H director of public health to its meeting to ensure scrutiny of his planned response to a possible second Covid wave?

https://www.theyworkforyou.com/wrans/?id=2020-05-19.48980.h
Stella Creasey MP: To ask the Secretary of State for Health and Social Care, whether the contract with Deloitte for covid-19 testing requires that company to report positive cases to Public Health England and to local authorities.
Nadine Dorries (Minister of State): As an existing professional services provider to the public sector, Deloitte's expertise is being used to supplement in-house resource to deliver significant programmes of work, which currently includes the national response to COVID-19. The contract with Deloitte does not require the company to report positive cases to Public Health England and local authorities.

4.6.2   The Chair responded:

 "Deloitte deliver a contract to national Government to oversee aspects of the Pillar 2 Covid-19 testing programme provided by commercial labs.
Since the beginning of July, Public Health England have provided postcode level data for Pillar 2 cases to Directors of Public Health under a data sharing agreement. This is provided for local analysis under a data sharing agreement.
Contact tracing of these individuals continues to be managed within the NHS Track & Trace system. Where appropriate Public Health England work jointly with the Council on responding to outbreaks. These arrangements are described in our Local Outbreak Plan available at:
        https://new.brighton-hove.gov.uk/local-covid-19-outbreak-plan

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Until recently data on Pillar 2 cases was not published at nation, region or Local Authority level. Since the beginning of July, data relating to Pillar 2 cases is now included in the national and local daily dashboards available to the public.
These are available at:
      https://coronavirus.data.gov.uk/
      https://new.brighton-hove.gov.uk/covid-19-key-statistics-brighton-hove "

We will definitely be looking at local Covid outbreak planning as part of the HOSC's scrutiny of local health & care system recovery and resilience planning.

4.6.3   Mr Kirk asked a supplementary question about how local test & trace service relate to Deloitte. The Chair agreed to provide an answer in writing.

5   MEMBER INVOLVEMENT

5.1   There were no member questions.

6   PRESENTATION FROM HEALTHWATCH BRIGHTON & HOVE ON THE COVID 19 CRISIS

6.1   The committee saw a presentation from David Liley, Chief Executive of Healthwatch Brighton & Hove.

6.2   In response to a question from Cllr Appich on patient experience of GP services during the pandemic, Mr Liley told members that things were very different from the beginning of the crisis where all services had been caught unawares to some degree. GP services had very quickly adapted to the crisis, for example in moving to telephone consultations. Patients had experienced some issues with this service at first, as the sheer volume of calls mean that there were some long waits. This situation has improved, although some patients still report excessive wait times. Patients have also reported problems with some of the social distancing requirements at GP surgeries: e.g. having to queue outside the surgery in inclement weather even though there is ample space inside for people to wait. Again though, the situation is generally much improved from the early weeks of the pandemic. There were also very significant access issues experienced by hearing impaired people at the start of the crisis, although again services responded quickly once the extent of the problem was recognised.

6.3   In answer to a question from Cllr McNair on likely second wave scenarios, Mr Liley told the committee that no one could confidently predict the form that any second wave of Covid would take. However, it is reassuring that the Local Covid Outbreak Control Plan looks thorough and robust. Emotional health & wellbeing is bound to be a major issue going forward, whether or not there is a major second wave: there is likely to be significantly increased demand for mental health support.

6.4   In response to questions from Cllr Powell on equalities issues and access to GP services, Mr Liley told the committee that most people (80%) Healthwatch had spoken

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with were happy with digital appointments, but a significant number (20%) were not. Healthwatch believe that a relatively large number of people have delayed presenting for diagnosis or treatment due to the Covid crisis. Responses to Healthwatch surveys have had a good demographic mix, and the CCG has involved Healthwatch in the work it is carrying out with city BAME communities.

6.5   In answer to a query from Cllr Osborne on which bodies had been quick to respond to the Covid situation, and which slow, Mr Liley told members that BHCC Health & Adult Social Care (including Public Health) had been very quick to respond and had done amazing work. The same was true of the CCG, and in general of senior NHS leaders. For example, Adam Doyle, the Accountable Officer for Sussex CCGs, has been meeting weekly with Sussex Healthwatch organisations. Dental services have been problematic, both in terms of providing access and of charging. South Central Ambulance Services NHS Foundation Trust (SCAS), which runs non-emergency patient transport in Sussex, has also been slow to respond to patient information requests.

6.6   In response to a question from Cllr Osborne on future priorities and opportunities arising from the Covid crisis, Mr Liley told the committee that the expansion of digital services offers great opportunities. An increased focus on care homes and on end of life care is also potentially useful, as these service areas need more attention.

6.7   In response to a question from Cllr McNair on the challenges Healthwatch has faced during the crisis, Mr Liley responded that staff and volunteers have been extremely busy. There is a risk of burn-out, particularly as routine work like post-discharge calls with Royal Sussex in-patients picks up as the hospital returns to near-normal activity levels. Healthwatch has received additional funding from HASC and the CCG during the crisis and this has been very helpful.

6.8   In answer to a question from Cllr Powell on the impact of Covid on community and voluntary sector (CVS) organisations, Mr Liley told members that many CVS organisations had been hit hard by the crisis, with much lower than normal levels of charitable giving. Caroline Ridley (HOSC CVS representative) added that this problem was particularly acute for CVS organisations that don't do commissioned work for the council or the NHS as they have no income source to fall back on.

6.9   Rob Persey, BHCC Executive Director Health & Adult Social Care, responded to a question from Cllr Grimshaw on engagement with care workers, explaining that listening to care workers is a key element in the council's Care Home Support Plan. The council communicates with care homes across the city on a daily basis and is always keen to hear the views of care workers.

6.10   In response to a question from Cllr Powell on PPE, Mr Persey told members that there is currently enough PPE, but the situation is being closely monitored. PPE is currently treated as clinical waste for disposal purposes. Going forward, the council is keen to explore opportunities for minimising the employment of single use plastics in PPE.

7   **PRESENTATION FROM BRIGHTON & HOVE CLINICAL COMMISSIONING GROUP (CCG) AND BHCC HEALTH & ADULT SOCIAL CARE (HASC) ON THE COVID 19 CRISIS**

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7.1   This item was presented by Rob Persey, BHCC Executive Director, Health & Adult Social Care; Ash Scarff, Deputy Managing Director, CCGs; and Alistair Hill, Brighton & Hove Director of Public Health.

7.2   In response to a complaint from Cllr Powell that links on the BHCC website Covid pages were not working properly, officers agreed to investigate. (It appeared that, although all the appropriate information was on the website, some faulty links meant that not all pages were linked correctly to other pages. The issue was subsequently resolved.)

7.3   In response to a question from Cllr Grimshaw on how the NHS planned to manage a possible second wave of Covid, Mr Scarff told members that the CCG was working with NHS Trusts to optimise workforce planning and flexibility. Moving some services to digital interfaces may also increase productivity, particularly where social distancing or PPE issues have made face-to-face interactions less productive. Mr Persey added that partners were working on the Mental Health Collaborative: developing new pathways around wellbeing and community mental health to ensure that there is additional capacity to meet demand spikes.

7.4   In answer to a query from Cllr McNair on messaging around face masks, Mr Hill confirmed that there is a role for local Public Health teams to promote the appropriate use of face coverings.

7.5   In response to concerns raised by Cllr McNair about tourists and/or protestors congregating in large numbers in the city, Mr Hill agreed that this was a worry. It is important that everyone continues to practice social distancing.

7.6   In answer to a question from Cllr Hills on transport and air pollution worsening the impact of Covid, Mr Hill agreed that this is a real issue. The city Joint Health & Wellbeing Strategy already recognises the connections between air quality and health and wellbeing and Public Health works closely with transport planners to improve air quality and to encourage active travel. This has led to the recent successful active travel funding bid.

7.7   In response to a query from Cllr Osborne on whether Covid mortality data can be broken down into demographic groups, Mr Hill agreed to look into this, but noted that there is a lack of mortality data relating to certain demographics (e.g. ethnicity). It is still too early to know how many more deaths there will be this year than against the five-year average.

7.8   In answer to a question from Cllr Osborne on the timing of lockdown, Mr Hill told members that it was difficult to say whether lockdown came at the right time, in part because public behaviour was already changing before lockdown – e.g. the week prior to lockdown saw significant drops in transport activity.

7.9   In response to points raised by Cllr Osborne regarding care homes data and test & trace, Mr Hill responded that he would look at how data on care homes is represented as this may appear confusing.

7.10   In answer to a question from Cllr Osborne on test & trace, Mr Hill explained that if people develop Covid 19 symptoms then they should self-isolate (as should their household members) and seek a test. If the test is positive, then they will be put in touch with the national test & trace service which will follow-up any contacts they have made. Contacts will be instructed to self-isolate for 14 days and to seek for a test if they show any symptoms. Local Public Health teams do not directly deliver this test and trace service however where a case is associated with a 'complex setting' (e.g. a school or care home etc.), the local Public Health England Health Protection Team will lead contact tracing and the local BHCC Public Health team are likely to be involved.

7.11   Fran McCabe noted that she was concerned about staff burn-out given the long and intense hours that staff across NHS and care services had been working during the crisis. She was also eager to know whether the successful Integrated Discharge and Responsive Services teams would be retained following the crisis. Mr Persey agreed that staff burn-out is a critical issue affecting back-office as well as front-line staff. There are no guarantees that funding will continue for any specific service, but there is definitely a case to be made to protect successful interventions as much as possible. Mr Scarff added that CCGs are currently evaluating the success of Covid measures. There is a particular concern about waiting times, especially for cancer services. This is something that should be scrutinised by the HOSC. Although cancer services continued throughout the crisis, there have been issues with diagnostics and robust recovery planning is needed here.

7.12   Ms McCabe added that there has been an understandable focus on the success of digital during the crisis; but whilst it certainly has an important role to play, it needs to be recognised that digital has its limitations, and it is questionable whether it is really what patients want. Mr Persey agreed that this was a valid point and is something that services are aware of.

7.13   In response to a question from Cllr Appich on data for local health and care worker deaths, and whether any of these came from BAME communities, Mr Hill said he did not have data on this but would investigate.

7.14   In response to a query from Cllr Appich on test & trace communications to the deaf community and to BAME and other potentially hard to reach groups, Mr Hill told members that communications would build on current good practice on engaging with various communities. Community Works and the BHCC Communities team are actively involved in this work, and a guiding principle is that this will be done with communities rather than top-down. The Public Health team is also happy to engage directly with communities, and translated resources are being developed.

7.15   Cllr McNair commented that he was worried about any wholesale move to digital for mental health services, given the therapeutic value of developing face-to-face relationships. Mr Persey agreed, and told members that thought needed to be given to mental health workforce planning given the likely future demand for services.

The meeting concluded at Time Not Specified

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Signed   Chair

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Dated this   day of

The Trust for Developing Communities

The NHS, COVID-19 and Lockdown:
The Black, Asian and Minoritised Ethnic Refugee Experience in Brighton and Hove

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Contents

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Brighton and Hove interviewees and survey respondents: most crucial to this report is the involvement of all the people who took the time to fill in the survey, take part in an interview or focus group. This report has benefited greatly from the knowledge and insights you have shared, thank you.

Bilingual Interviewers: Dr Mohanad Badeen; Juliet Batista; Tella Butler; Chi Ling Chan; Julia Encarnacao; Shiqpe Gjomakaj; Fares Hadison; Herietta Izso; Aleceia de Juan; Jingyisun; Nora Mzaoui; Magda Pasiut; Oana Patap; Gosia Pollard and Lai Lai Wu.

Focus group Facilitators: Terry Adams; Vikki Gimson and Maha Mustafa.

Interviewers: Nina B Bishop, Ceza Da Luz; Aleya Khatun and Katie Merrien.

Interpreters: Jahanara Ahmad; Airini Botros; Monica Al Housary; Hawar Qaradaghi and Hocine Baiche.

BAMER reference group: Terry Adams; Nora Mzaoui and Louise Yu Wai Shan.

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Freelance consultant: Dr Anusree Biswas Sasidharan.

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Executive summary

This report was produced on behalf of Sussex NHS Commissioners. The lead organisation was the Trust for Developing Communities. Partners contributed to the conducting interviews, focus groups, awareness of the online survey and developing the direction of the areas to be explored. The research partners were:

- Sussex Interpreting Services;
- Hangleton & Knoll Project;
- Voices in Exile;
- Network of International Women and
- Fresh Youth Perspective.

The agreed purpose of the survey was for Sussex NHS Commissioners to:

- Gather feedback from key BAME groups and communities, including Refugees and Migrants, on their **experiences of Covid-19**
- Gather feedback about the **information these groups and communities have received related to Covid-19**, and the degree to which this has been appropriate and useful
- Gain an increased **understanding of the issues and barriers related to accessing care**, whether Covid-19 related or other health care during the Covid-19 crisis period
- **Receive recommendations** that will ensure these communities are supported as we move to a recovery phase from Covid-19, and that can help shape our health and care services in the future

The research and the subsequent report explore Black, Asian and minoritised ethnic people and refugees (BAMER) experiences of COVID-19, the NHS, and access to the NHS and information about COVID-19. The study was widened to explore:

1. Experiences of lockdown;
2. Working during lockdown;
3. COVID-19 treatment and testing and
4. Sense of wellbeing.

When the UK went into lockdown on 23rd of March 2020, the everyday lives of the majority of the population changed. In doing so it exposed significant structural inequalities. This research involved 310 BAMER people in Brighton and Hove, who generously shared their experiences for this report. There were 56 different self-defined ethnicities in the research reflecting the diversity within Brighton and Hove, the reach and networks of the partnership. Females respondents were in the majority. People in the age category 35 – 54 were the highest number of respondents. Participants lived across all but one ward in the City. Most respondents when asked about religion or belief stated they had no religious affiliation, followed by Islam, Christianity and then Hinduism.

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Range of interpreting support offered
to 73 interviewees by SIS
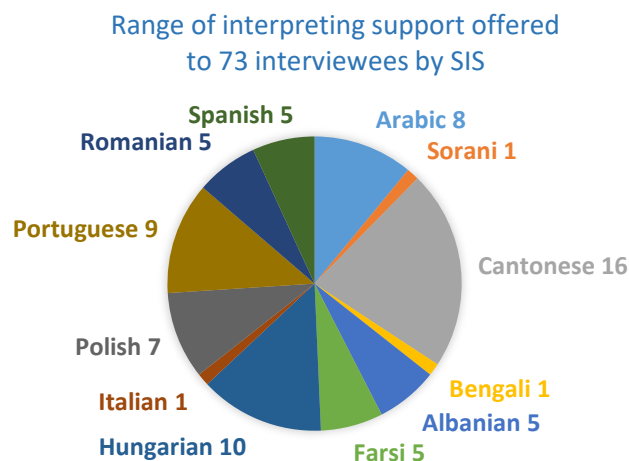
National analyses and surveys show that COVID-19 disproportionately impacts BAMER people. Evidence has been gathered by Public Health England[1], The Runnymede Trust[2], The Royal College of Nursing[3] and clinicians in Health Service Journal articles[4]. The Public Health England publication 'Beyond the Data', compares all-cause mortality in this year to previous years:

> *Comparing to previous years, all-cause mortality was almost 4 times higher than expected among Black males for this period, almost 3 times higher in Asian males and almost 2 times higher in White males. Among females, deaths were almost 3 times higher in this period in Black, Mixed and Other females, and 2.4 times higher in Asian females compared with 1.6 times in White females.* [5]

The Public Health England (2020) report explored the impact of COVID-19 on BAMER groups. They identified concern that the experience of racism, discrimination, stigma, fear and lack of trust among BAMER communities, including key workers within the National Health Service, increase vulnerability to COVID-19.

What we learnt

Contracting COVID-19. 13 per cent of all respondents believe that they have had COVID-19. An estimated further six per cent are unsure whether they have had COVID-19 because they had not been tested.

Working conditions and COVID-19. Many BAMER people who contracted COVID-19 did so as key workers. In Brighton and Hove, 31.3 per cent of the whole workforce are key workers[6]. The link between key workers and their households developing COVID-19[7] is well documented. This is significant because of disproportionate number of BAMER people working as key workers. BAMER women are particularly disproportionately represented in health and social care[8] key worker roles.

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[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

[2] https://www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf

[3] https://www.rcn.org.uk/news-and-events/news/uk-bame-nursing-staff-experiencing-greater-ppe-shortages-covid-19-280520

[4] https://www.hsj.co.uk/exclusive-deaths-of-nhs-staff-from-covid-19-analysed/7027471.article

[5] Ibid.

[6] https://www.ons.gov.uk

[7] https://www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf

[8] Ibid.

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Another layer of complexity is the level of BAMER people subject to unfavourable working conditions, including zero-hour contracts, lack of Personal Protective Equipment (PPE) and high levels of risk[9]. 21 per cent of the BAMER key workers participating in this research felt that they were expected to take a higher risk compared to white colleagues. A further 35 per cent of respondents felt similarly but were less able to point to specific instances to evidence their perceptions. Studies show that BAMER people are more likely to experience unfavourable working conditions and less likely to receive sick pay. Research attributes these disparities to systemic racism and poorer experiences of healthcare.[10]

Information, communication and messaging. There was a high level of awareness of COVID-19 symptoms with only five per cent of interviewees expressing uncertainty.

The main sources of information were television, social media, friends and family, government briefings, local newspapers and voluntary sector groups. Respondents reported high levels of trust in the NHS and saw it as best placed to give out information around COVID-19.

Addressing barriers to accessing NHS care. Appreciation and praise for the NHS was high. 70 per cent (122) of BAMER interviewees and focus group respondents expressed an overwhelmingly positive response to the NHS. However, other BAMER people reported a negative or a mixed experience. Of the 175 interviewees and focus group respondents, 49 per cent (86) expressed a negative experience. Negative experiences included communication and language difficulties, cancellation of appointments often leading to poor health outcomes and perception of discriminatory treatment. Respondents reported that patients, particularly those with language needs, did not understand that they could contact GP Surgeries.

I have had very bad experiences. The services were terrible. I was mistreated with disrespect. I couldn't communicate at A&E and explain my issues because of lack of knowledge in English language and language barriers. They didn't use interpreting services to help me to explain my health condition. I felt so frustrated.
Interpreting support provided to interviewee

They didn't understand the nuanced messages and thought GP Surgeries were closed completely rather than just not seeing patients in person. Others didn't understand the text messages from GP`s or the long answerphone messages.
SIS Linguists

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[9] https://www.rcn.org.uk/news-and-events/news/uk-bame-nursing-staff-experiencing-greater-ppe-shortages-covid-19-280520
[10] https://www.england.nhs.uk/wp-content/uploads/2020/01/wres-2019-data-report.pdf
https://www.nursingtimes.net/news/coronavirus/workplace-racism-described-as-factor-in-bame-nurses-higher-virus-risk-16-06-2020/

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COVID-19 and the lockdown experience

Mental health. The emotions most commonly reported by survey respondents included a deep sense of anxiety; distrust; stress; conflict; confusion; fear and panic. This reflects ongoing UCL research findings,[11] showing increased levels of anxiety amongst BAMER individuals.

In the August 2020 report from the NHS Confederation 'Preparing for the Rising Tide'[12] there is a clearly articulated expectation of additional demand for mental health services, with particular concerns raised that the stark inequalities already faced by BAMER people in accessing mental health services will be further exacerbated.

Respondents in this research highlighted how the issue of difficulty in accessing physical health services had a negative effect on mental health.

> *I wasn't able to book appointments with my GP during lockdown. By not being able to see my GP I wasn't able to get a mental health medication.*
>
> **Interpreting support provided to interviewee**

> *My daughter had toe injury and her toenail was infected. GP (Surgery name provided), proscribed her antibiotic, which didn't help so we took her to the hospital. They send us back home with nothing. Eventually, we went private and pay few hundreds of pounds for the procedure. It was important for us to get this done as soon as possible as our daughter already suffers from depression and has problem with self-harming… I had to live with tooth ache, my husband with backache also whole situation and lack of support has negative impact on my daughter's mental health.*
>
> **Interpreting support provided to interviewee**

Inequalities and poor outcomes in the face of COVID-19. This research concurs with the Runnymede Trust's *State of the Nation* report[13] which states that poverty, health inequality and poor housing conditions impact BAMER communities hardest. These communities can also be among the poorest socio-economic groups and are more likely to be at the frontline of this crisis in low-paid and precarious work.

The Marmot Review[14] highlighted that people living in deprived areas and those from BME backgrounds were not only more likely to have underlying health conditions because of their disadvantaged backgrounds, but they were also more likely to have shorter life expectancy as a result of their socioeconomic status.

> *Have needed help with finances. Friends and family abroad have sent them money. No recourse to public funds. My husband applied for benefits for first time in late February and now that is helping – but no allowance for me.*
>
> **Interviewee 127, a woman of Arab heritage**

Mitigating risk and negative impacts of lockdown. Interviewees and focus group participants recognised the need to find self-help strategies to mitigate possible negative impacts of lockdown and COVID-19. Many did so successfully. Others identified resources and support that would have been beneficial through lockdown. These included support to build confidence, maintain a routine and having someone to talk to.

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[11] https://www.ucl.ac.uk/news/2020/jul/levels-depression-and-anxiety-higher-amongst-those-bame-backgrounds-during-lockdown

[12] https://www.nhsconfed.org/-/media/Confederation/Files/Publications/Documents/Report_Mental-health-services-NHS-Reset_FNL.pdf

[13] https://library.oapen.org/bitstream/handle/20.500.12657/22310/9781447351269.pdf?sequence=4&isAllowed=y

[14] https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on

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Recommendations

1. **Working conditions and COVID-19**

   Support and encourage employers to implement Equality Assessment Frameworks to incorporate all staff who are recognised as a Protected Characteristic under the Equalities Act 2010. This should include the local NHS as one of the most significant employers and contractors of BAMER people. Specifically, introduce BAMER-specific risk assessments in the workplace and review the use of zero-hour contracts in the light of COVID-19 risk. Measures such as reducing exposure to COVID-19 risk at work, offering the opportunity to work from home, ensuring access to adequate PPE and sick leave provision should be considered.

   Employers should explore ensuring that workers are entitled to Statutory Sickness Pay (SSP). The Runnymede Trust identifies SSP as a tool to 'increase the chance of compliance with self-isolation and quarantining to minimise the spread of the coronavirus, and to shield vulnerable groups'[15]. This is particularly important for agency workers and those on zero-hours contracts within which BAMER groups are overrepresented.   This recommendation should be seen alongside recommendation 4 of `Beyond the data: Understanding the impact of COVID-19 on BAME groups'.

   > *Accelerate the development of culturally competent occupational risk assessment tools that can be employed in a variety of occupational settings and used to reduce the risk of employee's exposure to and acquisition of COVID-19, especially for key workers working with a large cross section of the general public or in contact with those infected with COVID-19.*[16]

2. **Information, communication and messaging**

   Provide unambiguous and simple information about the local health context. Clear signalling of messaging and guidelines is needed in a variety of formats. This information needs to be culturally appropriate and translated as reasonably required. Such resources would reassure BAMER people. Clarity and certainty are key because of the overwhelming amount of COVID-19 information and would help mitigate misinformation.

   This report found that BAMER people have significant distrust of central government messaging around COVID-19. Messaging was perceived as contradictory to scientific evidence, hypocritical, and politically motivated. In contrast, the NHS was regarded as a trusted information source. NHS Commissioners can build on this trust. Understanding and use of the most effective communication channels for the target audience is crucial. NHS Commissioners can build on this trust by implementation of the World Health Organisation (WHO) Guidance and the five WHO Outbreak Communication Principles which are summarised as:

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[15] https://www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf
[16] Public Health England (2020a) Beyond the Data: Understanding the Impact of COVID-19 on BAME Groups, London. https://assets.publishing.service. gov.uk/government/uploads/system/uploads/ attachment_data/file/892376/COVID_stakeholder_ engagement_synthesis_beyond_the_data.pdf

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- trust
- announcing early
- transparency
- listening
- planning

Communication resources should be tailored. The needs of different communities must be considered; especially the need to provide communications in languages and formats as required. Understanding and using the most effective communication channels is crucial.

3. **Addressing barriers to accessing NHS care**

Carry out Equality Impact Assessments on access to healthcare including supporting GP surgeries to target support to vulnerable patients through the Locally Commissioned Service, working with partners on the restore and recover agenda and seeking ways to mitigate the mental health impact of Covid-19.

This chimes with the Public Health England Report, recommendation 7, June 2020[17].

> *Ensure that COVID-19 recovery strategies actively reduce inequalities caused by the wider determinants of health to create long term sustainable change. Fully funded, sustained and meaningful approaches to tackling ethnic inequalities must be prioritised.*

Fund and sustain meaningful approaches to tackling racial inequalities. Consideration should be given to creating a programme of training across the NHS in response to the recent discourse on race in the UK and in accordance with the Equalities Act 2010.

The programme of change should seek to address intentional, unintentional and casual incidents of discriminatory practices and behaviour towards people from BAMER backgrounds. This would improve NHS experience for BAMER people even when faced with communication issues or difference.

4. **COVID-19 and the lockdown experience**

Build closer, collaborative relations with the BAMER communities in Brighton and Hove.
Statutory bodies need knowledge of and insight into the communities they serve in order to gain a better understanding of those individuals. Participatory research with BAMER-led groups and organisations will help develop stronger and more meaningful relationships between health institutions and BAMER communities. These measures will also provide a strong platform to implement programmes to improve health outcomes and mitigate risk, being mindful of research and consultation fatigue.

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[17] Public Health England (2020a) Beyond the Data: Understanding the Impact of COVID-19 on BAME Groups, London. https://assets.publishing.service. gov.uk/government/uploads/system/uploads/ attachment_data/file/892376/COVID_stakeholder_ engagement_synthesis_beyond_the_data.pdf

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5. **Promote health education by co-producing approaches with BAMER communities**

Create an on-going dialogue with BAMER communities such as a forum that is able to respond to issues as they emerge. Fund, develop and implement culturally competent health education, risk reduction strategies and prevention campaigns with BAMER groups. Build relationships and trust to encourage positive engagements with the NHS.

6. **Further analyse survey data to learn more and explore intersectional experiences of life in lockdown**

Whilst this research has explored a broad range of themes, time constraints and funding has meant that it has not been possible to undertake extensive analysis of the data collected for this study. The data could be further analysed to explore what it tells us about, for example, housing conditions, female perspectives, mental health and poverty. The intersection of gender, ethnicity and language barriers, coupled with the trauma of their past experiences could be further explored. The data could also be used to gather the self-help strategies developed by BAMER people during lock-down and would reveal the breadth of resourcefulness and resilience.

It is recommended commissioners and all stakeholders read, understand and implement the recommendations of the report alongside national reports such as 'Beyond the Data: Understanding the impact of Covid-19 on BAME Groups Public Health Executive, June 2020), which give a national context. Particular attention in this report to be focused on Recommendations 2 – 7. The recommendations of that study, coincide, reflect and endorse findings and recommendations of this work.

Executive summary: Dr Anusree Biswas Sasidharan and Kaye Duerdoth

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Introduction

This report was produced on behalf of Sussex NHS Commisioners by the Trust for Developing Communities and partners to explore experiences of Black Asian minoritised ethnic and refugee (BAMER)[18] groups' access and consumption of information about COVID-19, experience of the NHS, experience of COVID-19; the study was widened in scope to incorporate experience of lockdown, sense of wellbeing, experience of working during lockdown and treatment and testing of COVID-19.

The research, gathered through interviews, focus groups and surveys, paints a complicated picture of Black Asian and minoritised ethnic and refugee (BAMER) people in Brighton and Hove, which are made up of communities, individuals and households. People from BAMER communities range in:

- wealth and income
- education
- experience of the health service
- barriers faced in shielding
- occupation
- access to technology
- socio-economic background
- the gendered experience
- immigration status
- financial security

- experience of mental health
- living conditions
- neighbourhoods
- social networks
- access to appropriate PPE (personal protective equipment) at work
- if they are key workers
- literacy
- proficiency in the English language
- access to wider services.

What was shared however, was the recognition and acknowledgement that COVID-19 was impacting BAMER groups disproportionately compared to other groups.

In May 2020, a Royal College of Nursing survey[19] further revealed that BAMER nursing staff had less access to personal protective equipment (PPE) compared with white British colleagues.

Brighton and Hove
As of August 14th 2020, Government figures[20] cite that based on tests conducted in both NHS and commercial laboratory settings there have been 826 confirmed cases of COVID-19 in Brighton and Hove, which saw the reproduction number (known commonly as the 'R rate') for Brighton and Hove stand at 0.28[21] on August 14th. There were 163[22] recorded deaths in 2020 up until 31 July 2020 in Brighton and Hove which mention COVID-19 on the death certificate. More detailed statistical evaluation of the impact of COVID-19 on Brighton and Hove can be found elsewhere.[23]

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[18] The term Black Asian and minoritised ethnic and refugee is used rather than 'Black Asian and minority ethnic' in order to stress the process of minoritising; that is, in societies where whiteness prevails, Black and minoritised ethnic communities are actively excluded and subordinated. This is processual. See also http://eprints.leedsbeckett.ac.uk/3625/3/Connecting%20%27Englishness%27%2C%20Black%20and%20minoritised%20ethnic%20communities%20and%20sport%20-%20a%20conceptual%20framework.pdf

[19] https://www.rcn.org.uk/news-and-events/news/uk-bame-nursing-staff-experiencing-greater-ppe-shortages-covid-19-280520

[20] https://coronavirus.data.gov.uk/

[21] https://coronavirus.data.gov.uk/

[22] https://new.brighton-hove.gov.uk/covid-19-key-statistics-brighton-hove/deaths-brighton-hove; https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/datasets/deathregistrationsandoccurrencesbylocalauthorityandhealthboard

[23] LG inform; NHS Digital; NHS England; Office for National Statistics; Brighton and Hove Healthwatch's The impact of COVID-19 on Brighton and Hove: a statistical evaluation; Brighton and Hove Council website,

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Methodology

Data sources
This report has been developed from contributions from 310 individuals who lived in Brighton and Hove and who predominantly self-identified as Black Asian and minoritised ethnic and refugee. This cohort consisted of 13 people who took part in focus groups, 135 people who filled in a survey and 162 people who took part in interviews. The template for the survey, focus group template and interview guidance was developed by the author of this report with contributions from the partners to this report. The templates were shared with partner agencies in East Sussex and West Sussex. For purposes of anonymity, particularly if a person can be easily identifiable or if the issues are sensitive, interviewees and survey respondents' identifiable information will be kept to a minimum and broadened to obscure identity.

Online Survey
The survey was launched on the 14th of July and ran until the 31st of July and was completed by 135 individuals in Brighton and Hove. The survey used SurveyMonkey, an online survey tool, which consisted of six parts:

- 'NHS services';
- 'experiences of COVID-19';
- 'employment situation';
- 'working during COVID-19 lockdown',

- 'information and concerns' and
- 'about you' which captured diversity monitoring.

'Experiences of COVID-19' section was only activated if a person or their household had experienced COVID-19 and the 'working during COVID-19 lockdown' was only activated if a person had worked outside the home as an essential worker during lockdown. As not all people answered all questions (whether through choice or skipped past because they either had not worked in the lockdown or had not contracted COVID-19) the actual numbers of people alongside the percentages are given in parenthesis to give the most accurate and meaningful data. The survey had a series of multiple-choice questions and included free space to provide more qualitative answers.

The survey was self-selecting and anonymous and allowed for comments in free text, for those who wanted to comment further. It was open to anyone in Brighton and Hove and was publicised through voluntary and community channels who were encouraged to share it within their networks, social media platforms and through word of mouth.

Interviews
There were 162 structured interviews[24], the interviewer asked each respondent the same series of structured questions, unless they worked during lockdown or contracted COVID-19, where upon they were asked an additional set of questions that were asked to ensure consistency. The interview structure can be found in the appendix.

Focus groups
There were four focus groups comprised of 13 individuals that were conducted over a chat-based, online video and audio-conferencing platform. They followed the same structure as the interviews addressing:

- 'NHS services';
- 'employment situation';
- 'information and concerns' and
- 'about you'.

Sensitive topics such as 'experiences of COVID-19' and 'working during COVID-19 lockdown' were not discussed to ensure participants' privacy.

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[24] Conducted by Trust for Developing Communities, Sussex Interpreting Services, Voices in Exile, The Hangleton and Knoll Project, The Network of International Women and Fresh Youth Perspectives.

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Demographics[25]

Ethnicity

Of the 135 survey respondents, 85 per cent (111) identified with being BAMER [26], 66 per cent (89) chose to share what ethnic group they identified with and there were 28 different self-defined ethnic groups. The rate of non-recorded ethnicities was much higher amongst survey respondents at 34 per cent, in comparison with only ten per cent of interviewees and focus group participants who did not record ethnicity.

Ethnicity of interviewees and focus group participants

Ethnicity of survey respondents

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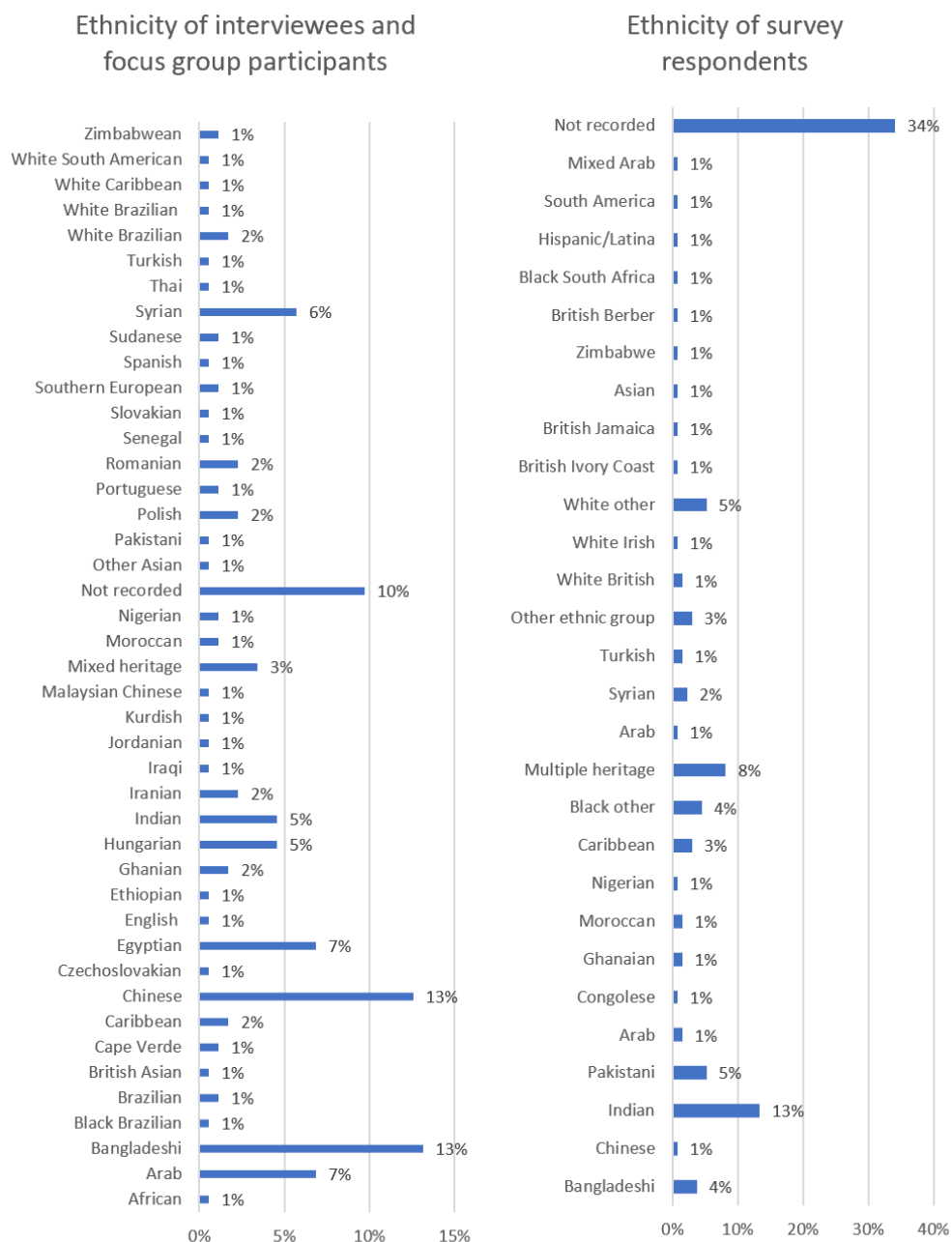
[25] Because of time restrictions and variance of data collection for interviewees and focus group participants demographics will only be broken down for ethnicity, gender and age.
[26] The remainder of people chose not to answer this question.

Out of the 310 participants in this study, there were 56 different self-defined groups, 43 of them represented within the 175 interviewees and focus group participants, and 28 different ethnic categories captured within the survey. The large number of self-defined groups attest to the diversity of ethnic groups in Brighton and Hove that exist in the city. The graphs above capture how both independent individuals and those who engage with partner organisations have participated in this survey. Those who filled in the online survey independently, identified as being of Indian heritage (at 13 per cent) followed by dual or multiple heritage (at eight per cent), other notably larger-sized groups included Pakistani and 'white other' groups (at five per cent) and Bangladeshi and 'black other' (at four per cent).

The biggest groups who took part in interviews and focus groups identified as Bangladeshi and Chinese which suggest that these are the most engaged with communities from partners organisations (at 13 per cent each), followed by Arab and Egyptian (at seven per cent each), Syrian (at six per cent), then Hungarian and Indian (at five per cent each) and mixed heritage (at three per cent), the rest of the groups made up one or two per cent of the participants.

Gender
Females represented the majority of respondents in the self-selecting online survey, with 44 per cent identifying as female, compared with only 14 per cent of men and 42 per cent not disclosing their gender. For the interviews and focus groups, who engaged with partner organisations, women comprised of 65 per cent, compared with 23 per cent of men, with 12 per cent either not disclosing gender, or gender was not recorded. There is clear under-representation of men in this study as well as a significant non-disclosure of gender, particularly in the online survey.

Gender of interviewees and focus group respondents
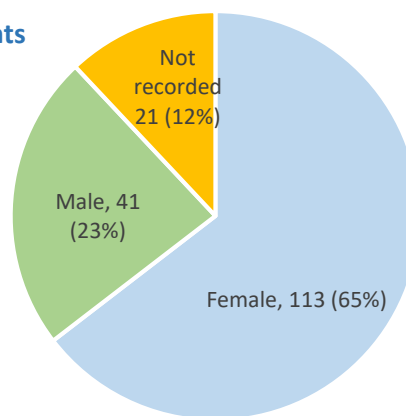
Gender of survey respondents

14
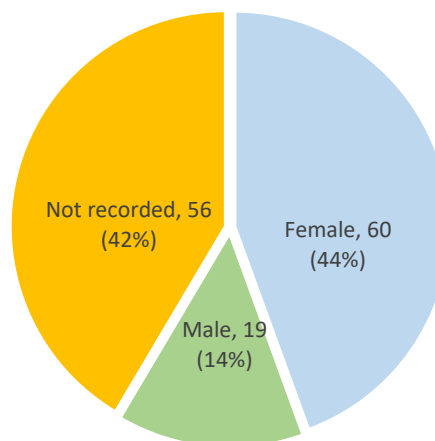
Age range of survey participants[27]

The largest age group cluster who disclosed their age was within the 35-44 and 45-54 age range making up 41 per cent of interviewees and focus groups respondents and 38 per cent of all participants in the survey. The 45-54 age range made up more than a quarter of survey respondents and the 35-44 age range were the most engaged with by partner organisations groups in terms of interviewees and focus group participants.   People over the age 55 were much less likely to take part in the online survey, representing only 12 percent of participants, but significantly better represented in the interviews and focus groups at 33 per cent. Noticeably only two per cent of participants were under the age of 24, regardless of method used. Under 35s stayed identical at nine percent, regardless of method used, which is a very under-represented group in this study. The survey did not capture the age of 41 per cent of all participants, the interviewees and focus groups managed to half the number of unrecorded age range at 19 per cent.

Age range of interviewees and focus group participants
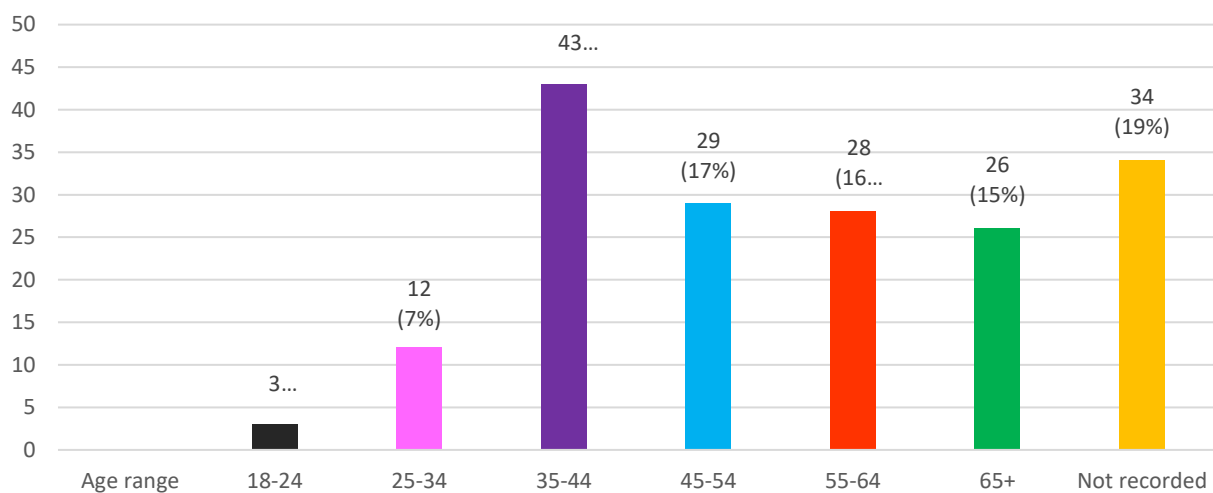
Age range of survey respondents

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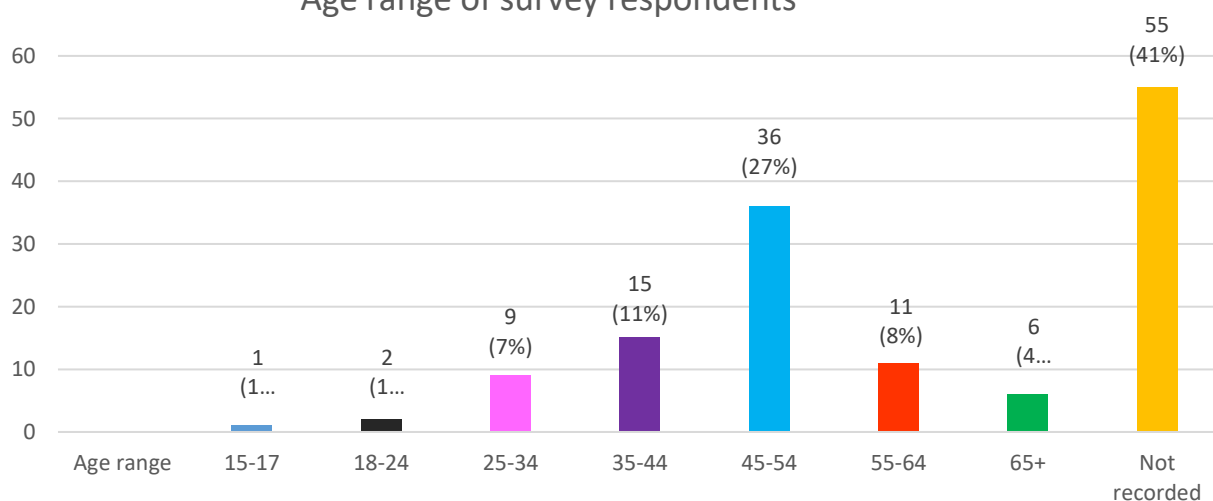
[27] 80 out 135 people answered the question on their age range.

Religion

From the survey, most people who disclosed their religious affiliation did not identify with a religious group, 31 per cent (23) identified with 'no religion', the second largest was Islam at 28 per cent (21), followed by Christianity with 24 per cent (18). Hinduism and Buddhism also feature as well as self-defined classifications[28].
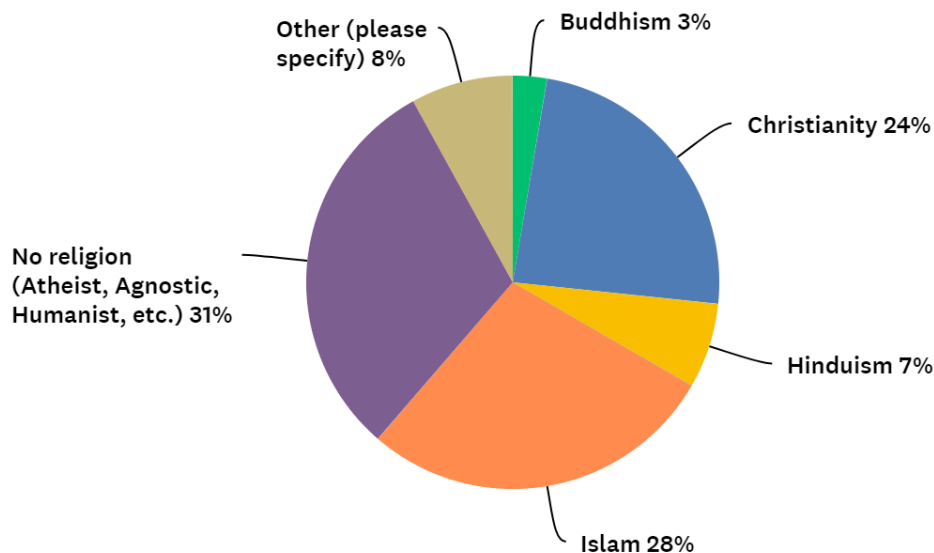
Whether participants were born in the UK

There were 53 per cent (39) of people not born in the UK, the majority of those, 47 per cent (18) had lived in the UK for more than 20 years, 26 per cent (10) lived in the UK for over ten years and those who lived more than five years and between one to five years were each at 13 per cent (5) each.

Length of time in the UK when born outside the UK

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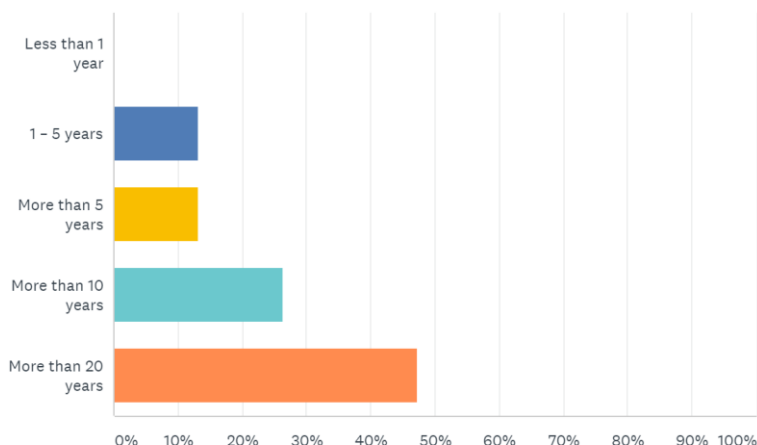
[28] Several people self-described as 'spirituality' and one as 'Jedi' and another as 'Magic'.,

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Location

There was a broad representation from across the city from survey respondents, there was small showing in BN41 (Portslade, parts of Hove and Southwick) with only 3 per cent. Breaking the location down into wards shows great level of participation across the city with respondents to the survey, all but 1 of the 21 wards (Brunswick and Adelaide) was represented in the survey responses.

Postcode distribution of survey participants[29]
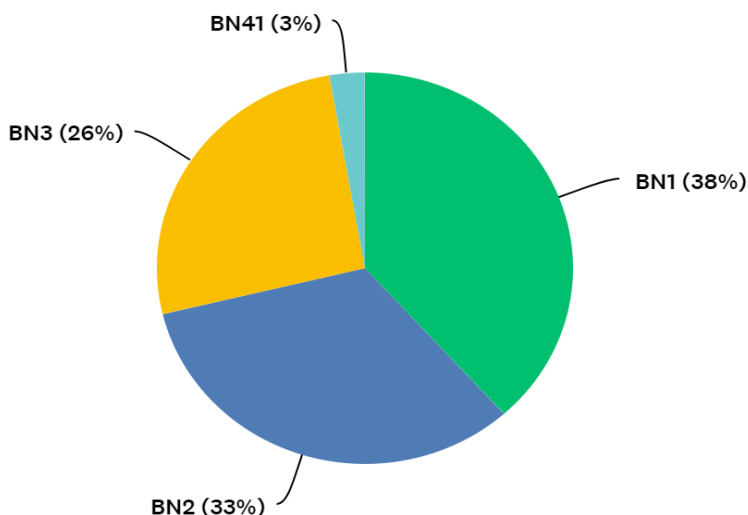
Ward distribution of survey participants[30]

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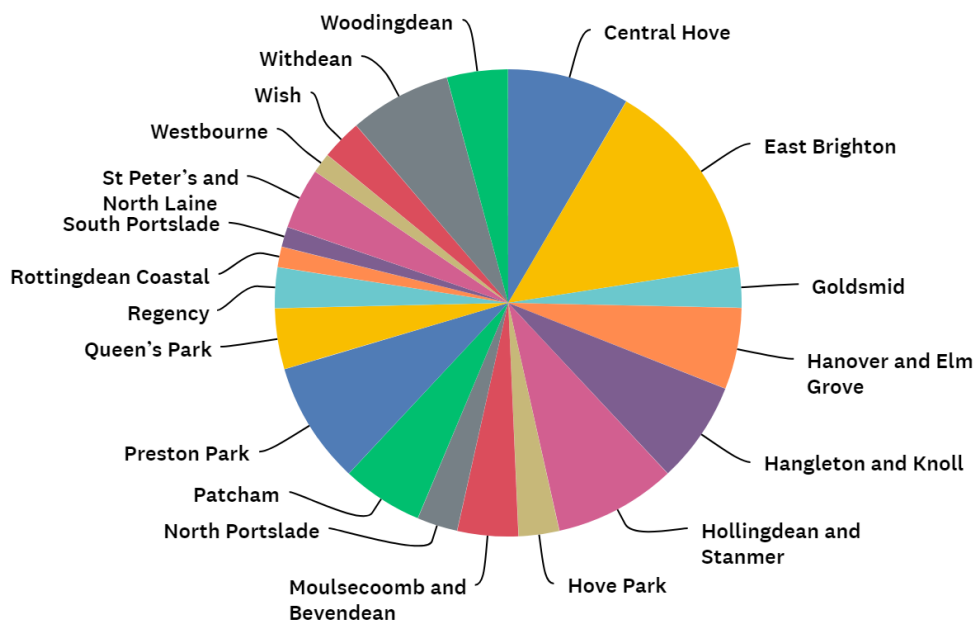
[29] 73 people answered this question.
[30] 71 people answered this question.

Results and key themes: Black, Asian and minoritised ethnic experience in the face COVID-19

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Contracting COVID-19

There are some very notable barriers faced by many BAMER people, which have not been created by COVID-19 but the Public Health Report[31] has identified as , 'longstanding inequalities …. exacerbated by COVID-19'. The rationalisations as to disproportionate impact on BAMER people are varied to date but there are strong associations drawn from reports[32] and ONS data sources, suggesting that socio-economic disadvantage, incidence of co-morbid conditions, mental health, racism, stigma, fear and trust, key workers occupations, housing and financial vulnerabilities may all impact BAMER communities disproportionately.

This research shows that 13 per cent of all respondents (40) across surveys, interviews and focus groups said that either they or a household member had contracted COVID-19, a further six per cent said that they were not sure if they had had it. From this cohort, 32 people gave further information, 53 per cent (17) had contracted it themselves, 31 per cent (11) said a household member had contracted the virus and 19 per cent (6) said that more than two people in their household had caught COVID-19[33]. A South Asian woman describes how many of her family members caught COVID-19, which resulted in her mother-in-law's death, after contracting it whilst abroad. Her mother-in-law was tested for COVID-19 once she was admitted to hospital, where it was confirmed. She explains:

> She [her mother-in-law] went in with breathing difficulty, high temperature, had underlying health conditions and it got to her lungs. She died within hours . . . she passed away, no time for treatment. We did not receive any treatment, it was really scary as it was at the beginning knowing whether it was COVID or just a flu but this flu lasted longer and the pains were and symptoms of the flu was severe not like other times. There was no test available at that time. My husband had just returned from X   X with his mum. His mum had flu like symptoms in XXX   X which got worse upon her return. He isolated in one bedroom and using his own bathroom whilst the rest of the family used a different bathroom with constant cleaning etc.

Her mother-in-law had received a shielding letter, because of her underlying health conditions of diabetes, high blood pressure and heart issues.

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[31] Public Health England (2020a) Beyond the Data: Understanding the Impact of COVID-19 on BAME Groups, London. https://assets.publishing.service. gov.uk/government/uploads/system/uploads/ attachment_data/file/892376/COVID_stakeholder_ engagement_synthesis_beyond_the_data.pdf
[32] The Runnymede Trust (2020) 'Economic impact of coronavirus', London. www. runnymedetrust.org/uploads/ policyResponses/ EconomicImpactOfCovid19TreasuryCommittee SubmissionMay2020.pdf; RCN (Royal College of Nursing) (2020) 'BAME nursing staff experiencing greater PPE shortages despite COVID-19 risk warnings', 28 May. www. rcn.org.uk/news-and-events/news/uk-bamenursing-staff-experiencing-greater-ppe-shortagescovid-19-280520; Public Health England (2020) Beyond the Data: Understanding the Impact of COVID-19 on BAME Groups, London. https://assets.publishing.service. gov.uk/government/uploads/system/uploads/ attachment_data/file/892376/COVID_stakeholder_ engagement_synthesis_beyond_the_data.pdf; The Runnymede Trust (2020) 'Over-exposed and under-protected: The devastating impact of COVID-19 on Black and minority ethnic communities in Great Britain', London. www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf
[33] Some respondents filled this in more than one category.

19

COVID-19 and uncertainty of prognosis

There was a lot of uncertainty around whether individuals and households had contracted COVID-19 as many were told that tests were unavailable. **Interviewee 118** is a Southern European woman who worked at the hospital and got mild symptoms of COVID-19 and was not given a test. She was asked if she had been tested:

> *Not at the time. My symptoms were mild, I lost taste and smell but at the time these symptoms had not been approved by the OMS so I was told I didn't need a test. Because I work in the hospital I had the antibodies test, later on and it was positive.*

> *We don't know if they [her household] have had it. They haven't been tested and did not have symptoms. It was the GP who suggested I stay at home. I asked for a test, and he said that if I was feeling well I didn't need it unless I would be admitted to hospital . . . No, no treatment was given, I was told to stay at home and go back to work in 7 days if I felt ok.*

Another respondent explained her inability to access tests, even though she had received an NHS shielding letter. She describes COVID-19 symptoms but is still left unclear as to whether she had contracted the virus.

> *Yes. I had symptoms [of COVID-19] of losing taste and difficult breathing . . . No. They [the tests] weren't available then, so I don't know if I definitely had it or not. I am on lots of tablets for my heart, blood pressure, diabetes and osteoarthritis. I have a memory problem as well – I'm planning to go and get an Alzheimer's test – the doctor recommended it but that's been put on hold due to lockdown.*

> *Yeah, got a letter from the NHS to say they should shield at home. They just stayed at home. And I didn't know for certain, because at that point there wasn't any testing.*

People who believed they had contracted COVID-19 were keen to follow the rules of confinement, self-isolating as best as they could and getting advice from 111.

> *Yes, I had it at the end of March. I had the symptoms but no test. I called 111 and they told me to stay home for 7 days . . . I live with my husband, but he is high risk, so I kept away from him in a different room the whole time I had symptoms . . . my husband has received 2 letters [shielding letters] . . . I called 111 when I had symptoms. They advised to take paracetamol. It was almost 10 days until I felt better.*
> **Interviewee 30, a woman in her 40s self-described as African**

An NHS bank staff member recalls her nervousness of not only fearing she had contracted COVID-19 itself but her fear of losing her accommodation:

> *I may have had coronavirus, as I had some of the symptoms, but it was possibly flu. I had to stop work as this was as a member of the NHS 'bank' staff . . . a test*

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was not available. This was early in the period of lockdown . . . I shut myself in my room for 2 weeks and did not tell anyone at the house about my fears, as this risked losing the place in the house. I went round the house cleaning door handles etc. whenever it was quiet.

Interviewee 132, woman

She had an anti-body test before she returned to work, but her result came out negative.

Of the 23 people in the survey who answered the question of whether they were offered and given a test, 17 per cent (4 people) received a test and only 4 per cent (1 person) said that they received treatment.

Testing of BAMER individuals who said they contracted COVID-19

Got tested, 17%

Did not get tested, 83%
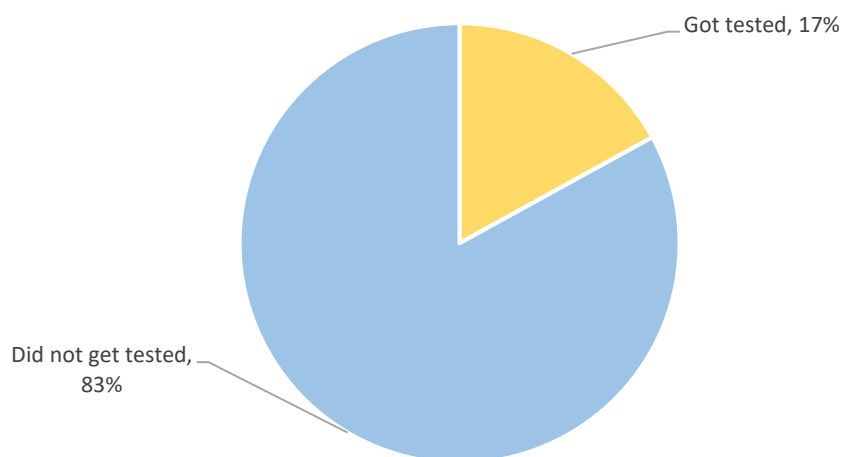
Getting treatment for BAMER individuals COVID-19

Got treatment, 4%

Did not get treatment, 96%

21
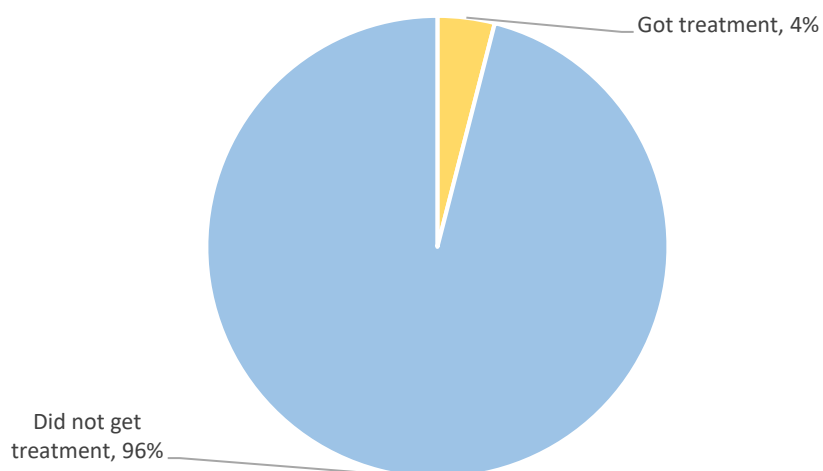
Working conditions and COVID-19

ONS sources state that nationally, 33 per cent of the total workforce were key workers, this is largely in line with Brighton and Hove, where 31.3 per cent of the workforce are key workers[34]. Nationally, approximately 40 per cent of NHS doctors[35], 20 per cent of nurses and 21 percent of adult social workers[36] come from BAMER backgrounds, which is disproportionately high when compared to the British white population. Given that BAMER people make up 14 per cent of the nation's population, it perhaps signals the risks of transmission which may increase occupational risk[37].

Number of key workers by occupation group in UK
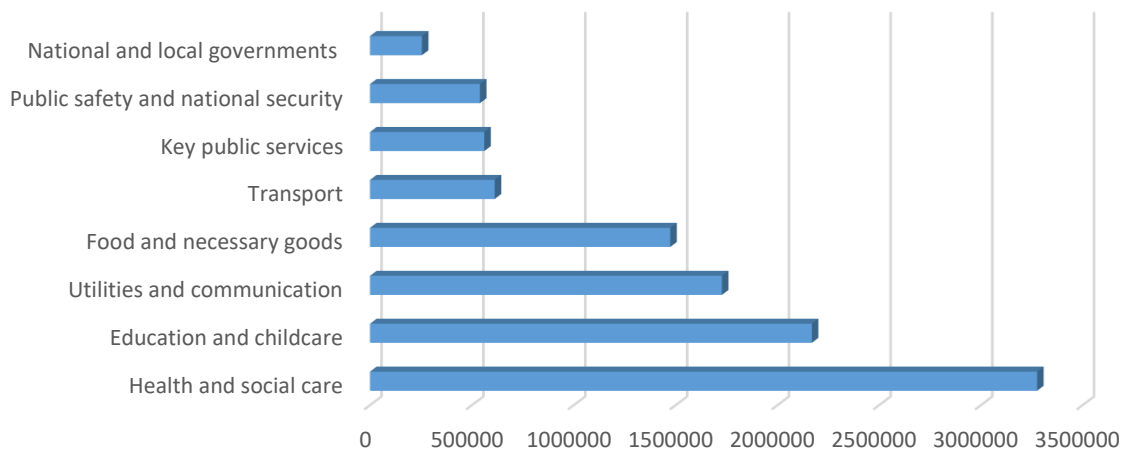
ONS figures 2020

Interviews conducted in this study captured the concerns raised by frontline staff about going to work and the increased risk of exposure to COVID-19 among BAMER staff in many areas of work, but particularly in NHS and social care settings.

Working in the NHS and social care settings

Data from the *Intensive Care National Audit and Research Centre*[38] indicates that 34.5 per cent of critically ill COVID-19 patients are from BAMER backgrounds, given that BAMER people make up 14 per cent of the population, there is an obvious disparity. A letter from NHS England[39] urged NHS trusts and foundations to make 'appropriate arrangements' that could include removing BAMER nurses from frontline roles as it acknowledges that research shows that BAMER workers are being disproportionately affected by COVID-19. Additionally, BAMER workers are often in lower paid roles within the NHS, which means that these roles cannot be done remotely leading to greater exposure with other members of the community[40] or they are on zero-hour contracts or bank staff.

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[34] https://www.ons.gov.uk

[35] https://www.nhsemployers.org/covid19/health-safety-and-wellbeing/risk-assessments-for-staff

[36] https://www.prospectmagazine.co.uk/politics/uk-bame-deaths-coronavirus-covid-19-why-nhs

[37] https://diversityuk.org/diversity-in-the-uk/#:~:text=In%202018%20about%2013.8%25%20of,Minority%20Ethnic%20(BAME)%20background.

[38] file:///C:/Users/sasid/Downloads/ICNARC%20COVID-19%20report.pdf.pdf

[39] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/second-phase-of-nhs-response-to-covid-19-letter-to-chief-execs-29-april-2020.pdf

[40] Public Health England (2020) Beyond the Data, ibid.

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Inequality in the workplace

Structural barriers and systemic discrimination faced by BAMER staff have been documented widely elsewhere[41] and was evident in the research conducted in Brighton and Hove. A 2019 NHS Staff Survey revealed 15.3 per cent of ethnic minority staff reported experiencing discrimination at work from a manager, team leader or other colleague in the past 12 months; more than double the proportion of white staff.[42] This was compounded for those BAMER staff who were working as agency staff/on zero-hour contracts. They would often not be entitled to full sick leave if they contracted COVID-19 nor feel able to challenge working conditions that made them feel uncomfortable or afraid.

Interviewee 132, a BAMER woman whose experience perhaps captures the difficulty faced by key workers who are subject to unfavourable working conditions of zero hours contracts:

> *A zero hours contract with the NHS bank of health care assistants. Not paid when ill, so returned to work as soon as allowed, to pay the rent. The PPE at the hospital was not available at first (except for the usual apron, gloves and simple masks) but was better after a while, for example, a proper medical mask. There was no indication of any coronavirus risk assessment in the early weeks. For example, worked on the respiratory ward, then sent to other wards. Did not feel that this was safe and objected, but had to accept the shifts offered.*

When asked in the survey, if individuals, who worked as key workers, felt that they were expected to take a higher risk compared to white colleagues, 21 per cent (9) answered 'yes', whilst 42 per cent (18) did not feel they were treated differently at work and 35 per cent (15) said they were 'not sure'. This differential treatment is an area worthy of further exploration. It suggests that discriminatory practices were a concern that existed prior to COVID-19, but the consequences had now manifested in contracting a virus. One survey respondent expressed her frustration with her lack of control over her working conditions in a local hospital.

> *I was constantly moved to cover higher risk areas. My white colleague would request the move and my line manager would approve. I am expected to be the one who travels and enters spaces with others who have may have been in situations where social distancing was not observed*
> **A survey respondent that identified as a British Black woman**

There is a deep undercurrent and explicit wish to be treated fairly in the workplace and often an inability to express their concerns effectively and have these issues addressed in a meaningful manner.

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[41] Li, Y. and Heath, A. (2018) 'Persisting disadvantages: A study of labour market dynamics of ethnic unemployment and earnings in the UK (2009– 2015)', Journal of Ethnic Minority Studies 46(5): 857–878. www.tandfonline.com/doi/full/10.1080/136 9183X.2018.1539241;
https://features.kingsfund.org.uk/2020/07/ethnic-minority-nhs-staff-racism-discrimination/index.html?_ga=2.83968145.900437054.1598098687-1079714911.1592215382
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf;
https://www.kingsfund.org.uk/sites/default/files/2020-07/workforce-race-inequalities-inclusion-nhs-providers-july2020.pdf
[42] https://www.england.nhs.uk/wp-content/uploads/2020/01/wres-2019-data-report.pdf

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This survey respondent expressed how contracting COVID-19 meant that not only would she become ill, but she would be without a wage due to her contractual terms:

As a Bank HCA, the nurses always send u [sic] to work closely with serious cases and it's hard because if u [sic] get sick don't get any payment.
A survey respondent that identified as other white ethnic woman

The following healthcare staff expressed their particular fears of working in high risk workplaces as BAMER members of staff. There was heightened fearfulness, powerlessness and vulnerability in the workplace. Two medical staff who filled in the survey expressed the following:

There was no recognition of the relationship of BAMER and COVID, even though it was in the media. I was refused a risk assessment and was still expected to go onto 'Red' wards.
A survey respondent woman of South Asian heritage

. . . assumed to work in clinic when feel anxious about coming in due to heightened BAMER risk.
A survey respondent woman who identified as multiple heritage

The Trust I used to work for contacted me about coming out of retirement, and part of me wanted to but that was before Black Lives Matter, and I thought they'd end up just putting me somewhere.
Interviewee 161, no data given

BAMER staff expressed fears of being put in additional harm to their white counterparts, because of their ethnicity. This was particularly acute for those who were working through an agency and/or on zero hours contracts who were often even less able to negotiate their working conditions.

Another layer of concern was the lack of PPE, **Interviewee 81**, expresses her frustration of not being tested, her concern was centred more about the lack of PPE rather than working as a key worker.

I tried to get a test when I had Coronavirus which was in April but I couldn't get a test, even though I work with the NHS through an agency. This was the NHS's fault as I should have had a test. I did the antibody test in June/July which was positive.

Yes I did take more risks because of the lack of PPE. But I chose to work with COVID, it was my choice. Unnecessary risks were added because of the inadequate supply of PPE. When I got Coronavirus in April I managed the symptoms myself. I didn't call my GP or call 111. I told my employer and I didn't go to hospital. If I got it now I would call Track and Trace and then 111 if it got worse.

I was an agency worker with the NHS on a Zero hours contract . . . I had to work outside the home as I am an essential worker . . . No I didn't feel safe as there was a lack of PPE . . . Give me a pay rise, more PPE, give us what we need to work properly
Interviewee 81, a woman of Eastern European heritage

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The stress, fear and anxiety expressed by key workers whilst caring for or providing services around others is palpable. BAMER key workers are concerned about contracting COVID-19, infecting others, not having enough PPE, the impact of watching people in their care suffer, and not feeling safe in their working environment. This is in addition to the disproportionate impact of the virus on BAMER people.

> *I am a key worker. I do not feel safe at work. I believe I was expected to take higher risks than my white colleagues . . . A mask and gloves. To my knowledge, no risk assessment was carried out. . . . I think I should have been provided a visor too.*
>
> **Interviewee 106, a woman from a West African heritage**

> *. . . yes, I was in high risk because some elderly residents at my workplace had coronavirus. We worked under pressure every day actually.*
>
> **Interviewee 92, a woman of Chinese heritage**

> *It is a very scary time for everybody and when they don't give you information you get more scared. It would be better if I did not have to go to work and the NHS gave us more information on what we should do to really protect ourselves. Is there anything we should be doing or taking? I don't know, they are not telling us enough.*
>
> **Interviewee 141, a woman of West African heritage**

Discrimination was expressed particularly amongst BAMER health key workers and to a lesser extent by care home workers. Whilst discrimination was not expressed of all BAMER key workers within the NHS and social care settings, it was a significant experience that warrants highlighting and worthy of further investigation.

For some other BAMER staff in these settings, whilst fears existed, they did not express the sense of feeling treated differently because of their ethnicity. **Interviewee 133**, was a woman of East African heritage, who was a care worker and explained how she, "*. . . felt safe. It was risky, but no-one got the virus. Worried at first, but not after a while*".   She was satisfied that she had the personal protection equipment (PPE) that she needed and that her employers had treated her respectfully. **Interviewee 102**, a key worker, whilst not feeling discriminated against still expressed not feeling safe in the workplace but did not feel singled out because of her ethnic origins.

> *I did not feel safe at work. I suffer from asthma . . . not all my colleagues wore a mask. My colleagues and I are all from different ethnicities and were treated equally . . . My employer provided us with a mask, but not every day, as they run out. I bought my own mask. As far as I am aware no risk assessment was carried out.*
>
> **Interviewee 102, a woman of West African heritage**

Key workers in other sectors
Outside the health and care sector, many BAMER people held essential jobs in sectors such as retail, public transport, delivery services, putting them on the frontline and at risk of exposure to COVID-19. **Interviewee 109's** husband worked as a delivery driver and had no option but to carry on working outside the home.

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My husband took risks as he carried on working for   during the lockdown, however he accepted this as he needed to work

Interviewee 109, a woman of South American heritage

Likewise, **Interviewee 108's** husband also worked as a delivery driver for another well-known company.

My husband was employed by X   on a zero hours contract. My husband worked all through lockdown for X   . My husband uses his motorbike both before and during lockdown. He doesn't feel safe at work as he has contact with people he doesn't know. Often the customer didn't follow social distancing guidelines and was waiting at the door with door open, which was unsafe.

Interviewee 108, a woman of South Asian heritage

There were other essential workers that did feel supported by their employers. **Interviewee 110** was employed full time with contract in a shop.

Yes I carried on working outside the home all the time in lockdown, with same number of hours. I was an essential worker. Yes I feel safe at work . . . I was not expected to take higher risks than my colleagues. My employer provided me with hand sanitiser and mask . . . my employer carried out a Coronavirus risk assessment. We are a shop and there are restrictions on number of customers entering the shop at one time and social distancing is enforced . . . I did [got] the PPE I needed.

Interviewee 110, a man of South American heritage

Working in catering industry as a chef so business was open for takeaways . . . Yes had to work outside of work and stayed at place of work with colleagues in one room, came home once a week on day off. no not essential worker as in catering sector . . . No PPE provided, still feel safe as had no contact with anyone with virus. No risk assessment done. No . . . [PPE received] . . . just handwashing and cleaning.

Interviewee 46, a man of South Asian heritage

I am at greater risk from the virus due to my ethnicity and this was not taken into account until my organisation was forced to do a risk assessment. I was telling them I was at greater risk but they didn't listen to me and were forcing me to come into base which comprised a busy hotdesking office

Survey respondent

This increased risk of exposure to COVID-19 by key workers, who were most likely to have social contact, were most prone to being infected themselves. Key workers often spoke about the importance of PPE (personal protective equipment) and risk assessments.

Personal protection equipment (PPE) and risk assessments in the workplace

Respondents in this study, who had to work through the lockdown period of the COVID-19 epidemic, expressed the importance of: being provided with adequate in-date PPE , risk assessments in the

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workplace and a duty of care from their employers to them as key workers. They also mentioned their particular vulnerability as BAMER staff when faced with occupational risk.

No I didn't feel safe as there was a lack of PPE . . . The NHS provided PPE within Public Health guidelines, but I didn't feel it was appropriate because it was not in line with WHO guidelines. The Public Health changed the guidelines, which I didn't agree with. We had masks with an expired 'Use by' date which were 'relabelled' with different dates many times and the Government said it was ok to use these masks, but I didn't feel safe with the guidance.

The NHS didn't do a risk assessment for me personally, but probably did for permanent staff. I was on a zero hours agency contract and offered myself to work during the lockdown. I didn't have any underlying conditions so I didn't need a risk assessment.

When asked if she had received enough PPE (personal protection equipment) you needed?

In my opinion No we didn't. I think we should have had more PPE that was not out of date. The PPE was not thorough. We were meant to have full gowns when dealing with positive Coronavirus patients but we only had aprons, which were not safe.

Interviewee 81, a woman of Eastern European heritage

Yes, I work in a school as a ▮▮▮▮▮▮▮. The school was closed for a time, but then it reopened . . . As I was worried about my condition, I asked to wear gloves and a mask, but I was told I wasn't allowed as it would scare the children. Also even though the children were asked to keep socially distant, they are very little, and they didn't. I was worried because most of the children at that time were children of key workers, so I had concerns. [Did you get the PPE you needed?] No, even though I specifically asked for it.

Interviewee 36, a woman of South Asian heritage

Interviewee 25 worked in customer services, she felt safe and did not feel they were faced with any further risk. Their employee offered 'gloves and cleaning' and this level of PPE was satisfactory to her. The BAMER key workers as described by **Interviewee 17**, explained how even with PPE, she did not feel comfortable in her workplace as she was asked to 'cover for' absent staff and as result she was having to take additional risk.

At first was reluctant to go but was my decision to go I was allowed to opt out should I wished to do so. Only few hours a week. Felt like the vulnerable needed the help most during this pandemic. Did not feel safe at beginning as it first happened and no PPE then we were offered PPE. Yes I think we were taking higher level of risk being from BAMER background and having close contact with client. I was often called to cover as some colleagues decided to not to work so felt like being asked a lot taking higher level of risk and bringing it back to my home. Back of mind knew taking risks even with PPE.

Interviewee 17, identified as a British Black woman

Likewise, **Interviewee 108** spoke about her husband's workplace and how '▮▮▮▮▮▮ *didn't provide PPE. He had his own Balaclava and hand sanitizer.* ▮▮▮▮▮▮ *didn't do any risk assessment . . . My husband took it [PPE] himself'* .

Key workers across the sectors expressed the importance of adequate PPE provision, robust systems, wellbeing and risk assessments, occupational risk assessments and their concerns about risk being heard and addressed. Not having these concerns addressed left workers feeling undervalued and vulnerable to the virus. Implementation of demonstrable support of BAMER staff in the face of a pandemic, where staff felt heard, protected and supported could help make BAMER staff feel assured that disparity was being addressed.

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Information, communication and messaging

Understanding of COVID-19

Amongst the interviewees and focus group participants there was a high level of awareness of COVID-19 symptoms with only five per cent (9) of interviewees expressing uncertainty of symptoms. This group was sometimes able to name a symptom or two but also expressing confusion. There were two groups of people that expressed uncertainty, the first were people who had lived in the UK for less than five years such as **Interviewee 126** who was a woman of North West African heritage who had lived in the UK for less than five years, whilst recalling two of the symptoms correctly still expressed confusion.

> *The question is really hard – there has been lots of information and is has become quite confused. Some stomach pains, cough, fever.*

Interviewee 83 a man of mixed heritage who had also lived in the UK for less than five years. When asked about COVID-19 symptoms, he also expressed uncertainty, saying, '*I'm not sure, I know it's dangerous*'.

The other group were older people who often relied on family members to share information about COVID-19. **Interviewee 72**, a woman of East Asian heritage, who had lived in the UK for over 20 years said, '*I do not remember but my husband does and he has had told me before*'. The misunderstanding around COVID-19 however, still elicited an appropriate response on what they would do if they were unwell, they would phone the GP, call 111 or contact a family member or friend to support them to contact medical advice or assistance. Misunderstanding of COVID-19 symptoms did not appear to be centred around a single ethnic group.

In contrast, 95 per cent of people interviewed appeared to have a very good grasp of what COVID-19 symptoms were. Typical answers mentioned a new continuous cough and a high temperature, fewer people mentioned loss or change of taste.

> Fever, temperature and cough
>
> **Interviewee 122, a woman of Nigerian heritage**

> *Cough, chest, breathing difficulty high temp, loss of smell and taste.*
>
> **Interviewee 50, a woman of Jordanian heritage**

There were sometimes the inclusion of additional symptoms such as 'breathing difficulty', 'sore throat', 'headache', 'fatigue' and 'diarrhoea' which whilst not on the NHS website was acknowledged from respected studies, such as the *COVID Symptom Study* led by King's College London.[43] Interviewees were almost united in their understanding in what to do if they contracted COVID-19, even those who were unsure about the symptoms were aware of isolating, calling 111 or calling their GP. For a few others it would be calling a trusted friend and/or family to ask for advice or support to contact 111 or the GP. There was a recognition amongst interviewees about the importance of social distancing, isolating at home and before official guidance, wearing of face coverings. BAMER people appeared to exercise extra precautions and tried to find strategies to mitigate risk. This reality of BAMER people in Brighton and Hove challenges some of the baseless assertions made by a UK

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[43] https://www.medrxiv.org/content/10.1101/2020.06.12.20129056v1

29

Member of Parliament[44], and councillors[45] who sought to blame BAMER groups for the spread of COVID-19. BAMER people interviewed for this research expressed a nervousness about taking additional risks such as going shopping, public transport and going to work.

> No – we didn't go out initially for about a month and a half. We did the shopping in one go. We eat chapattis, lentils and tinned food so we didn't have to go out to get more food. Even now when I go out, I wear a mask and I only talk to people I know and I keep a distance. Even now, the shops are only allowed so many people. We also didn't go out just in case we had it and passed it on.
> **Interviewee 151, a woman of Indian heritage**

There were several concerns expressed about the lack of mask wearing in the UK amongst the general public prior to the 24th of July 2020.

> One thing I was concerned about was the mask wearing. In my country, mask wearing is common so I don't understand why they are not worn here. Also, people look at me when I do wear one, like I have the coronavirus.
> **Interview 125, a woman of South East Asian heritage**

Source of information

From the interviews and focus groups 152 (out of 175 people) and 85 (out of 135 people) survey respondents spoke of how they received their information about COVID-19. These 237 people spoke about the multiple sources that they used to learn more about the virus. It was rare for people to be using a single source of information. Of the 237 who responded to the '*where they got their information about COVID-19*' question, the most popular sources were:

- 79 per cent television;
- 55 per cent through social media and/or Facebook;.
- 52 per cent from friends and family and
- 49 percent from Government briefings

Other sources included:

- 30 per cent newspapers (including online newspapers);
- 21 per cent used local community, voluntary and religious groups as a source;
- 19 per cent news channels outside of the UK;
- 15 percent the NHS;
- 11 per cent radio and
- 11 per cent emails (from various sources including colleges, workplaces, community groups)
- only six percent mentioned word of mouth.

Survey respondents also included alternative sources of information including 'up-to-date research'. 'GP and BHCC' sources, through work and through 'employer briefings'.

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[44] http://www.standuptoracism.org.uk/anti-racists-hit-back-at-tories-and-say-no-covid-racist-scapegoating/
[45] https://www.theguardian.com/world/2020/jun/10/tory-councillors-accused-of-racist-posts-on-social-media

30

Across both survey respondents and interviewees, there was a searching, researching, investigating and scrutinising of information as individuals sought reliable sources that contained 'accurate' data or guidance, local data, trusted information and comparisons with how other countries were dealing with the pandemic. This informed people's measure of how the UK was doing.

> *Before I felt angry because I saw how other countries were doing lockdown and I was angry that nothing was happening here, it was not strict and people were acting as if everything was normal. Now I think we should keep it for longer because otherwise the lockdown we did do and the changes we made would have been for nothing.*
>
> **Interviewee 126, Female Moroccan**

> *I used to watch Moroccan TV channels to get information about coronavirus, including advice about sanitation, washing hands, keeping my family safe etc. I can watch English TV channels and although I don't understand I sometimes get the idea. I find Moroccan TV channels better because they give you more information about the virus.*
>
> **Interviewee 128, Moroccan woman**

> *From the NHS website and also I'm on the Join ZOE app, from King's College. I'm trying not to watch the news. I don't believe the news or the government. I also access the office for national statistics. Basically, not Boris Johnson.*
>
> **Interviewee 33, a woman of Indian heritage**

Interviewees and survey respondents expressed distrust in the Government. Of the 84 people who described their feelings since the lockdown, 50 per cent expressed distrust of the UK government and/or media. Those medical professionals who shared a platform with Government officials were seen as less trustworthy.

> *I've been watching and reading everything coming through and reading between the lines/unpicking it. But I've been getting angry at the TV for not giving enough information about symptoms, and for the lies saying that people on the frontline were being tested. I stopped asking my frontline worker family members and friends about it, because it just wasn't true. They were mixed messaging right from day 1 for everybody, not just BAME or purple people or whatever, and breaking rules came from top government for example Cummins, so I was feeling really sad.*
>
> **Interviewee 161, No information recorded**

The NHS, in contrast, was seen as a trusted source of information. There were a lot of requests for receiving more clarity and guidance from the NHS.

Clear and simple information

Respondents saw the NHS as a trusted organisation that is best placed to give out information around COVID-19. People in this study asked the NHS for guidance, information and media in plain English, that is culturally appropriate and for those who require it in different languages. There were requests

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for information that would alleviate people fears and balance misinformation found elsewhere. There were hopes for preventative advice and culturally competent information around health prevention and disease prevention programmes as explored by the recent Public Health England report, *Beyond the Data*[46]

> *I felt that there was very little shared directly by the NHS, or perhaps it was but it didn't reach me as such. Like most people, I would have preferred clearer guidance, perhaps via a dedicated website or through email.*
>
> **Interviewee 88, woman unknown heritage**

> *Of course it would be much better if we got letters from the NHS. The information would be clearer and more accurate. Leaflets or letters would definitely have helped us as we were confused with lots of different resources.*
>
> **Interviewee 142, woman of Arab heritage**

> *Well maybe some simple language information that told you what to look out for, maybe there was already a lot of it about. But I don't remember seeing much of it. I never saw any leaflets from the surgery or anything. Maybe that would have helped some. Them I would not have to rely on my children as much.*
>
> **Interviewee 143, woman of Nigerian heritage**

> *Clear information, in Bengali, leaflet that I can look at as quick guidance at hand. Being in lockdown for four months regular updates. texts, email , letter.*
>
> **Interviewee 42, woman of Bangladeshi heritage**

> *Someone to help me with my medical problem. I don't feel like my GP is helping me. The information about shielding was not clear or consistent regarding diabetes, so I was confused. The NHS website and other information was contradictory.*
>
> **Interviewee 36, woman of Bangladeshi heritage**

A lack of clarity meant that people had genuine misunderstandings, confusion or concerns about not being able to access the most appropriate care, treatment or source of advice.

> *Self-isolate in house and tell house mates. Take test, however I don't know how to ask for test – I should have been told how to book a test. I wouldn't go to GP or hospital.*
>
> **Interviewee 108, woman of White Brazilian heritage**

> *I would call 109* [the interviewer clarified several times that interviewee didn't mean 111 or 999]. *When we thought my husband had corona virus*

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[46]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

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symptoms we called the GP and they said call a special helpline on 109.
                                                    Interviewee 47, woman mixed heritage

There were also requests to consider giving advice and reassurance around specific religious celebrations such as Eid, which occurred after the strict lockdown rules were relaxed but when the logistics were not clear. The opening up of restaurants, pubs and some workplaces have also made the rules less clear. There was not a request to evade the rules but have clarity.

> *Clear information, leaflets in plain language and where can access directly the information required. It would be good to receive information based on my religious beliefs as we have had Eid during first ease of lockdown and it was scary and confusing as to what is allowed or not. It was extremely difficult and emotional for us. So a direct message during Eid from government or the NHS would have been ideal directly telling us of what is and what isn't allowed. We had spent Ramadan in lockdown with no mosque it was very difficult and emotional and not good for mental health so mental health support and getting support from religious groups would have been ideal during this tough time. Guidance from NHS and government supporting religious cultural groups to support the community*
>   **Interviewee 149, male of Bangladeshi heritage**

The importance of the NHS to provide clear, comprehensive and myth busting advice was critical, particularly when the Government was seen a divisive or untrustworthy. A lack of good quality, trusted information meant that people would search for information elsewhere instead.

> *We got out information from the TV news from our family some on Facebook and some from home Ghana. We had a lot of places to get the news. It was so scary we wanted to make sure we had all the information we needed. You can't trust the Government to tell you everything you need to know. You don't know what they telling you and if it's the truth. I don't believe them sometime the Government.*
>   **Interviewee 141, woman of Ghanaian heritage**

The accurate information void was filled from any number of sources, some of which were well researched, from trustworthy websites, organisations and research bodies; whilst for others this left room for conspiracies, false rumours and fake news stories.

Fake news and conspiracy theories

As there were lots of uncertainty with limited if any prior knowledge of Covid-19 prior to lockdown, some people did their own research instead. For some this meant going to reliable sources, of which there are many, however for others in a heightened state of stress[47] and in search for resolution, they were not always so discerning about reliable sources of information[48].

> *Clearer and trusted information would have helped as there was lack of clarity. We were confused of the contradictions in the news and in social*

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[47] https://www.sciencenews.org/article/coronavirus-covid19-stress-brain
[48] https://www.sciencenews.org/article/coronavirus-covid-19-how-fear-anger-change-risk-perception

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media. To be honest, I am still suspicious about all COVID issue and it's relation to 5G networks and China.   Translated letters and leaflets would have helped.

Interviewee 63, man of Syrian heritage

We were confused with lots of fake news. Some news were scary when you see people dying everywhere. It was a struggle to understand what's happening clearly. A clear translated letters from the NHS about virus and the ways it is transmitted would have helped.

Interviewee 65, woman of Sudanese heritage

At the beginning I was looking at social media like Facebook but I stopped because it was very upsetting and scary to see the death toll increasing every day. There were also a lot of fake and unreliable news. Later, I got my information from my family members who follow the government briefing.

Interviewee 64, woman of Syrian heritage

There were a lot of conspiracy theories which tended to be based on coincidences, misconstrued science, often with emotive language which at a time of public mistrust was readily consumed. Therefore, it is crucial for the NHS, as a trusted organisation to produce and make easily available and accessible a counter-narrative to conspiracies and misinformation.

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Addressing barriers to accessing NHS care

Experiences in the NHS were varied. For many it was the epitome of how a health service can be run, a beacon of how healthcare benefits them when they most need it. For others, this was not how they experienced the NHS. How a BAMER person experienced the NHS could be determined by multiple factors, it could include the colour of a person's skin, their accent, their ability to speak English, their clothes, their religion and/or their difference, perceived or real. Whilst capturing these issues through people's experiences, what must not be lost in the narrative is the staff they encounter, the same BAMER person could experience excellent care in one doctor's surgery or NHS service and then experience racism or bad treatment in another. It was not unusual for interviewees to express positive responses towards the NHS and then later in the same interview relay a negative experience, sometimes racist, sometimes systemic, sometimes organisational, sometimes based on resources and capacity. This creates for some a complicated relationship with the NHS.

Positive experiences in the NHS

Appreciation and praise for the NHS was undeniable, 70 per cent of BAMER interviewees and focus groups (122) respondents expressed an overwhelming positive response. A range of typical positive responses are shown below, beginning with **Interviewee 9**, who despite the long wait for her husband's treatment, expressed her gratitude she and her husband received.

> *Excellent, I love the NHS. My husband was unwell and we had to go to A and E. Yes we had to wait for 9 hours, but they were very busy dealing with emergencies. We were both very scared, but were really taken care of. They were asking about him, but also taking care of me. I am so happy and proud of the NHS.*
>
> **Interviewee 9, woman of Syrian heritage**

> *Whenever I need them, I can access them and they are supportive. My daughter works in cancer research for the NHS, so I really appreciate them.*
>
> **Interviewee 30, woman who self-described as of African heritage**

> *Good, friendly staff*
>
> **Interviewee 20, man of Bangladeshi heritage**

> *Absolutely brilliant. We are really lucky to have the NHS and they have always been very respectful when we have used them. It's a great free medical service and I can't fault it. I have used GP services and the hospital for the birth of both my children. I also had a broken wrist and had to go to hospital for treatment.*
>
> **Interviewee 5, a woman who self-described as of British Asian heritage**

> *Two weeks ago my youngest, the baby who is nearly 3 had fallen. We thought she had a broken hand. We took her to the hospital and we were seen very quickly. My husband couldn't come in with me, as they were being very strict with the rules because of Coronavirus. I was treated very well and received good care. No problems.   Other than that we haven't used any services.*

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Interviewee 4, BAMER woman, no other recorded information

I've used number of services including: GP, pharmacists, dentist, occupation therapist, physiotherapist, direct payment, hospital, pain management clinic. My ▮▮ years old daughter is in wheelchair . . . services here have so much higher standard that in my country of origin. I'm extremely grateful for all the support they give to me and my daughter. Sometimes you have to wait for the appointment for long time especially, for specialist services. Staff being usually very kind and supportive.

Interviewee 101, BAMER woman, no other recorded information

I have always loved the NHS. It provides an amazing service. I have never received treatment or services below my expectations, and I've never been treated like 2nd class, or received a service that was 2nd class.

Interviewee 3, woman of Bangladeshi heritage

Very good care, I get interpreter when I go without someone who can help me translate or they try to find a nurse or someone who speaks my language.

Interviewee 117, woman of mixed heritage

Negative experiences in the NHS

Conversely, other BAMER people either had a negative or a mixed set of experiences. Of the 175 interviewees and focus group respondents 49 per cent (86) expressed a negative experience. This ranged from communications and language barriers to negative impacts on their health when appointments were cancelled due to being treated in a way that was perceived as discriminatory.

Experiencing discrimination
Some BAMER people spoke of experiencing racial discrimination by health professionals. The impact of racial prejudice on a person's life chances can impact their mental and physical health. This can also impact the level of trust that BAMER groups have of NHS services and health care treatment they receive and reluctance to seek care on a timely basis, and reduce late presentation with an illness, condition or disease[49].

I talked to a professional, two years ago, with someone from the hospital and instead of helping, the person I was talking to started talking to someone else and started to make fun of me. After that incident I felt I would never call an NHS service again.

Interviewee 16, man of Arab heritage

I had an appointment with the gynaecologist which has been cancelled many times. During lockdown the face-to-face appointment was changed to telephone appointment but there was no interpreter so they hang up and have not contacted me again.

Interviewee 108, woman who self-described as a white South American heritage

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[49]https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

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Sometimes not taken seriously or feel neglected treatment or care compared with others, feel discriminated. One point was hospitalised as did not diagnose earlier as white friend had same illness and was treated

Interviewee 18, man of South Asian heritage

Keeping family safe, recognising cultural background and not judging and treating differently, as sometimes feel spoken to differently as if I don't understand, but my English is very good and I have a good business and connect with people all the time. I just accept it thinking we are a foreigner but I should not have to.

Interviewee 146, a woman of Indian heritage

Do their job with equality in mind, and provide wellbeing services like mental health support specific to minorities, on their "ask" and not by white lead organisations.

Survey respondent

The first time I came to the UK, my husband took me to register for the NHS, the first time they denied me and my daughter, they said that we couldn't register because we didn't have proof of address, but I had an address on a bank statement so my husband [who is British] had to complain for me. The admin appeared bad and this resulted in denying me and my daughter to register at the local doctors' surgery.

Interviewee 125, woman of South East Asian heritage

At the clinic I did feel that I was not treated fairly. I sensed some bias against women and my race.

Interviewee 131, woman of Arab heritage

My son has been rushed into hospital yesterday after a week's wait and several phone calls to 111 and doctor they advised to stay at home and gave medication. He was not getting any better and finally the doctor made home visit after my sister-in-law [who speaks 'good English'] spoke with doctor and put pressure on. This shows we are not taken seriously and judged. It was appendix which was really bad as soon as he went to hospital he was operated on and got an infection due to being at home with it for too long. Which is really upsetting and frustrating and scary as it could have burst. It is very dangerous.

Interviewee 159, woman of Bangladeshi heritage

. . . compared to my country, when I am sick you can get medicine when you want and advice about how to get rid of the flu . . . One [white] British doctor I saw was quite strictly and said just to take ibuprofen and no other advice. Then I found that I should not ibuprofen because it's bad for your blood, and I have a problem with my blood and have to monitor it regularly . . . I met an Indian doctor after this and she gave me more advice and advised me to go to the hospital, and now whenever I have choice, I choose a doctor of Asian heritage, rather than a [white] British doctor.

Interviewee 125, woman of South East Asian heritage

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Communication and language barriers

Not being understood, whether it is due to language barriers, disability or mental health, had a great impact on how NHS services were experienced. Individuals had reported being ignored, having the phone put down on them and being laughed at for having accents (as described above) or not being able to respond in English. There were also reports of feeling misunderstood due to mental health.

Interviewee 74, a woman of Chinese heritage, spoke of her positive experience with health care, despite being unable to communicate in English, she highlights the value of being understood, "*they* [health care service] *were very good. Due to the language barrier, interpreter always had been booked for each visit which made me feel respected*".

Please open the surgeries doors and tell GPs to give us access to primary care. My surgery has locked their doors and does not answer the telephone. When I get through and arrange for a telephone consultation, they do not call me back. **Interviewee 106, identified as Black Portuguese speaker**

My scan appointment for monitoring my cancer was cancelled. My appointment to scan my eyes as part of my diabetic review was also cancelled… There was a huge negative impact on my health. When my chemotherapy finished on December last year, I have been told the cancer has mostly cured and the chance of it coming back in 2 years is very small. My review scan was cancelled and I had to self-isolate. After lockdown, I had to go to hospital due to severe pain to discover that my cancer is spreading fast. **Interpreting support provided to interviewee**

Language support when I needed to book an appointment to the GP and the GP should have been booked interpreter for all appointments not just when the meeting was obviously unsuccessful due the lack of understanding. I had very bad memories about inconvenient conversations due the missing interpreter. I always asked interpreter, but the GP thought I don't need them. He was wrong and it was terrible for me. I was in pain and dealt with multiply issues. **Interviewee 58, woman of Hungarian heritage**

Generally not great. Mental health causes problem with communication. Don't like the service, threaten to put phone down because I was getting distressed as they would not understand me. I need Medication, relying on them so stressed as they put phone down. They are Slow they don't understand me no empathy very stressful **Interviewee 21, male who self-described as of other Asian heritage**

Not as good as it should have been. I have been chasing information and appointments and it has been confusing. There have been difficulties with language, and I feel no one was taking the symptoms seriously. I have not been treated badly, but I don't feel that I have been given the appropriate attention and time . . . a really important appointment was cancelled. I have been waiting for this appointment for such a long time and have really had to push for it. I have had to ask a friend who translates . . . The appointment was really important and it was cancelled. There was no communication and the condition was really bad and painful. I was on very strong painkillers and it is still going on. **Interviewee 36, woman of South Asian heritage**

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Charges to Overseas Visitors

Although new regulations came into force on the 29th of January 2020, which added COVID-19 to the Schedule 1 of the NHS (charges to overseas visitors) Regulations[50], which meant that there was no charge made to an overseas visitor for the diagnosis, or, if positive, treatment, of the coronavirus. Further, there would be no charge applied to a diagnostic test even if the result is negative. Also there would be no charge applied to any treatment provided for suspected COVID-19 up to the point that it is negatively diagnosed. However, for those non-EEA nationals who do not have settled status in the UK, the fear of being charged was the overriding understanding during this pandemic and as suggested below by **Interviewee 46**.

> *Some kind of support for those who are on case to remain in UK waiting for results on case meanwhile having no access to NHS. What if I got ill or had an accident? Some kind of support from NHS for people like us as its scary if something to happen and not having access to healthcare.*
>
> **Interviewee 46, male Bangladeshi heritage**

COVID-19 lockdown impact on NHS services

Under the COVID-19 pandemic, there was severe disruption to regular NHS services, patients undergoing care for ongoing and new conditions and illnesses, some BAMER people faced deteriorating health and/or increased pain. Individuals were experiencing difficulties contacting services, leaving some people feeling distressed and/or frustrated.

> *My scan appointment for monitoring my cancer was cancelled . . . there was a huge negative impact on my health. When my chemotherapy finished on December last year, I have been told the cancer has mostly cured and the chance of it coming back in two years is very small. My review scan was cancelled and I had to self-isolate. After lockdown, I had to go to hospital due to severe pain to discover that my cancer is spreading fast . . . I believe that the scan and treatment for cancer patients should not have stopped because that would have a serious negative impact on their health and the outcome of the treatment.*
>
> **Interviewee 64, woman of West Asian heritage**

> *The cardiology department cancelled an appointment during lockdown . . . My heart condition has not been diagnosed yet, and I went to A and E three times. I am concerned with my health.*
>
> **Interviewee 102, woman of West African heritage**

> *My daughter has a health condition, she didn't get any letter from the GP. The hospital was supposed to contact us to make an appointment, but nothing happened, they never called us for blood tests and scan of her kidney. If we don't call them, they will not call us, but I guess because of COVID-19 they are not calling us, she is still taking antibiotics every day and we are waiting to see if they will tell us to stop because it has been a long time.*
>
> **Interviewee 122, woman of West Asian heritage**

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[50] https://www.gov.uk/government/collections/nhs-visitor-and-migrant-cost-recovery-programme

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I was pregnant for 3 months of the lockdown, so I didn't go out anywhere. I was using NHS maternity services, and was under an obstetrician care, which was generally positive, but because of coronavirus a lot things have changed. I had some appointments cancelled, and my husband wasn't allowed to attend any of our scans or appointments for last 3 months of my pregnancy, which we were both upset about . . . We were really looking forward to experiencing every part of the pregnancy together, so we feel like we've missed out in a way. I understand why they're doing it, for safety and social distancing. But it took some of the specialness away for us.

Interviewee 153, woman of South Asian heritage

Yes without medication I am suffering. Require injections for arthritis but this was to be changed to a different dose or type of injection before lockdown as the previous ones was not working. They have stopped giving me previous ones to give the new ones. Which I only just received the new one after waiting four months. This has had impacted me and limited my day-to-day activities.

Interviewee 18, man of South Asian heritage

. . . all my appointments were cancelled because of the coronavirus, my physiotherapy appointments were cancelled. The psychologist appointment that I finally got was then also cancelled. I had a phone appointment with the specialist and they said I need a special scan to see the disc but nothing has happened since then. So nothing can move forward with a solution. I have had some depression due to the chronic pain from my back during the lock down time. I asked for an appointment with a psychologist to discussed this and I asked three to four times at my GPs before I finally got an appointment with a psychologist and then it was cancelled because of coronavirus . . . Not having a resolution has been a serious problem because also in lockdown . . . everything falls to me and I struggle because of this pain.

Interviewee 122, woman of Syrian heritage

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COVID-19 and the lockdown experience

Mental health

At the time of writing this report, findings from an ongoing COVID-19 social study by University College London (UCL)[51], is showing that BAMER people have had higher levels of depression and anxiety during the pandemic. This study is believed to be the UK's largest study into how adults are feeling about the lockdown and overall wellbeing and mental health. More than 70,000 participants have been involved in the research project and identifies that:

> *. . . people from BAME backgrounds have had higher levels of depression and anxiety during the coronavirus lockdown, as well as lower levels of happiness and life satisfaction. Overall, 35% of adult participants reported their mental health had been worse than usual, increasing to around half when looking at people from BAME backgrounds, young adults and people with a diagnosed mental illness.[52]*

The UCL findings are certainly reflected in this research, anxieties around employment, financial situation, working conditions (as discussed earlier), children's education, access to health services, mental health and wellbeing, catching COVID-19 (and the consequences), absence of Statutory Sick Pay where they are an agency or on a zero hours contract.

> *Very anxious at the beginning, I had bad nightmares often, and I was very worried about going to work. News created a lot of anxiety. They spoke about deaths in numbers constantly and I was scared of dying . . . The pandemic was very bad but I did what I had to do, kept going to work, didn't isolate, tried to carry on. I don't know what else could have helped . . . During the main lockdown the feeling of stress was bad and not good for everyone.*
> **Interviewee 126, woman of Moroccan heritage**

> *I am very worried, and anxious, I have been very scared, with no way out. I take pills to sleep. So many people dying at the beginning. I am already depressed and take medication for it, and the pandemic made my mental health much worse. Things are a bit better now.*
> **Interviewee 117, woman of mixed heritage**

> *No, my life hasn't changed much as because of my depression and anxiety I like to spend my time mostly in my flat . . . At the beginning my grandchildren also called off all visits . . . I have 2 cats to keep me a company and very lovely and supportive neighbours.*
> **Interviewee 97, woman of Eastern European heritage**

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[51] https://www.ucl.ac.uk/news/2020/jul/levels-depression-and-anxiety-higher-amongst-those-bame-backgrounds-during-lockdown
[52] https://www.ucl.ac.uk/news/2020/jul/levels-depression-and-anxiety-higher-amongst-those-bame-backgrounds-during-lockdown

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The table below shows the range of feelings survey respondents experienced since the lockdown started on the 23rd March 2020 in descending order. Within the top ten emotion most commonly felt by survey respondents were: a deep sense of anxiety; distrust; stress; feelings of conflict or confusion; fear or panic; anger or frustration and feelings of being overburdened with additional work. This reflects the ongoing UCL report, of increased levels of anxiety amongst BAMER individuals. The most felt emotion was that of 'mixed emotions' at 61.9 per cent, interestingly the more 'positive' emotions featured relatively low on the table with the exception of 'pleased with a slower pace of life' expressed by 40.48 per cent. Regrettably, nearly 18 per cent of people were dealing with grief of people who had died, which is strikingly high. Whilst we cannot know if these are COVID-19 related deaths, it does appear unusually high for a cohort of BAMER people.

ANSWER CHOICES	RESPONSES	
Mixed emotions	61.90%	52
Anxious	58.33%	49
Distrustful of the Government/media	50.00%	42
Pleased with a slower pace of life	40.48%	34
Stressed	39.29%	33
Conflicted or confused	33.33%	28
Lonely/ isolated	33.33%	28
Afraid or panicked	32.14%	27
Angry or frustrated	32.14%	27
Feel burnt out from working from home/working alongside other responsibilities	30.95%	26
Finding gratitude and kindness in the coronavirus pandemic	30.95%	26
Increased sense of community	25.00%	21
Happy and contented in household	21.43%	18
Powerlessness	20.24%	17
Coping with grief and loss for people who have died	17.86%	15
In need of lockdown routine to help	17.86%	15
Unsupported or disregarded	16.67%	14
Reluctant or unmotivated	15.48%	13
Other (please specify) Responses	14.29%	12
Relaxed	13.10%	11
Under pressure to return to work	13.10%	11
Uneasy about relationships	13.10%	11
Unprepared	13.10%	11
Like life is unfair	11.90%	10
Total Respondents: 84		

Commonly expressed amongst interviewees and focus group respondents was that of isolation, which was experienced where there was:

• an absence of technology;

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- a disability;
- poor housing conditions;
- financial insecurity ;
- language or communication barriers;
- mental health;
- newly migrated;
- Ill-health;
- being a carer;
- racism and
- experiencing or experienced domestic abuse.

Isolation feelings were expressed by these interviewees.

> *I can only watch TV. I would've loved to talk to friends but I'm reluctant to call others because my mobile is low in credit and I can't top up at the moment. I've tried but the shop said my top up card is invalid . . . I want to feel being cared for. The NHS hasn't sent me anything but my friends have received letters from the NHS. I'm a cancer patient, 83 and live alone. I don't know why I'm not on their list as an vulnerable-elderly person.*
>
> **Interviewee 76, man of Chinese heritage**

> *It was a struggle. We were nervous, scared and lonely. We lost our appetite. It was also difficult to keep a healthy diet.*
>
> **Interviewee 65, a woman of Sudanese heritage**

> *I have felt very lonely and scared. I did not have a routine as I spent all my time in the flat. I cannot do heavy housework due to arthritis and back pain. However, I kept the house cleaned little by little and watched TV a lot.*
>
> **Interviewee 104, a woman of Portuguese heritage**

The importance of access to technology and Wi-Fi/broadband was a major part of people maintaining a sense of wellbeing, whether it was speaking to friends, family, accessing work, schoolwork, or entertainment. For most people they expressed the relief of having technology, being able to speak to friends and family in the UK and abroad, passing the time, searching on the internet, feeling connected to the world. **Interviewee 160**, captures some of the ways she uses the internet.

> *Mental support for those who don't have family and friends. Support groups, chat groups, online network support group. Mum's forum. A platform where anyone can go to with any issues however big or small. Which then can be signposted to relevant agencies/organizations. Alternate support if cannot access online. Supporting the vulnerable, lonely, isolated people. Flagging them up who might require assistance during pandemics. Whether it be mental/emotional support, welfare checks, assistance with shopping, meds delivery etc.*
>
> **Interviewee 160, woman of Arab heritage**

For those who did not have data on their phones, technology to access video calling, internet services or even the possibility of regular phone call the sense of isolation was profound.

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> *We're very frustrated and struggling a lot with current situation. Don't understand why we're not eligible for any support. All those rules don't make any sense. Our daughter friend who lives only with mum got laptop, my daughter didn't (their financial situation is better than ours). Where is a fairness in all of that? We're left alone, with no support.*
>
> **Interviewee 98, a woman of Polish heritage**

> *I can only watch TV. I would've loved to talk to friends but I'm reluctant to call others because my mobile is low in credit and I can't top up at the moment. I've tried but the shop said my top up card is invalid.*
>
> **Interviewee 76, man of Chinese heritage**

Individuals who are on the peripheries of support systems are further isolated and face increased levels of anxiety. **Interviewee 85**, an asylum seeker is under incredible stress with his living situation becoming progressively untenable, buying food and credit for his phone increasingly difficult, his inability to navigate within the UK's systems and his inability to speak English is leading to his deteriorating mental health.

> *I have felt alone and so depressed. It is really difficult time for me as asylum seeker. I feel vulnerable, during the lockdown because, I don't have knowledge and life skills in the UK. I don't have English knowledge either. The National Asylum Support Service (NASS) regarding finance support for Asylum Seeker is very low. I can't afford to buy enough food, put credit on my mobile phone, pay for public transport for going to my appointments at hospital or GP and so on. I cannot be relaxed. Our hostel is overcrowded and not safe. I am spending a lot of time at home and feel my mental and physical health condition have been deteriorated. In my opinion poor people particular, Black, Asian and minority ethnic people have been mostly contracted coronavirus because of their poor live condition.*
>
> **Interviewee 85, man of West Asian heritage**

The Runnymede Trust survey[53] uncovered that there was a significant number of respondents who had been victims of racially motivated attacks (verbal and physical) or treated unfairly. There are direct links to impacts of racism on mental health, particularly on the young[54]. **Interviewee 125** explains how she and her daughter have been impacted by racist prejudice surrounding COVID-19.

> *Also, my daughter has experienced bullying in her school because of her Asian features. Children have taunted her about having coronavirus and have coughed over her saying that they will give it back to her and blaming her for it. My father in law also said similar things to me, saying that the coronavirus is from us and that they must keep away from me and my daughter in the home. But when he smokes he doesn't keep his distance from me.*
>
> **Interviewee 125, BAMER woman**

Inequalities and poor outcomes in the face of COVID-19

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[53] https://www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf
[54] https://youngminds.org.uk/find-help/looking-after-yourself/racism-and-mental-health/

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This research has identified risk factors which points to disparities for some BAMER individuals in the face of COVID-19.   Of course, the relationship is complex. The Runnymede Trust's *State of the Nation* report[55] states that poverty, health inequality and poor housing conditions impact BAMER communities hardest. These groups can also be among the poorest of socio-economic groups and more likely to be at the frontline of this crisis in low-paid and precarious work. These factors need to be explored further. The Public Health England analysis and ONS data suggest that there are strong associations between 'economic disadvantage and COVID-19 diagnoses, incidence and severe disease'.[56] Whilst this report touches on the impact of these issues on contracting of COVID-19, this correlation is largely out of scope of this research study but warrants further exploration. However, there are some observations that can be made from the findings which could make a person more vulnerable

Financial
The Runnymede Trust conducted a survey which they used for the basis for their report, *Over-exposed and under-protected*[57]. They showed how '[t]hree in ten BME people (32%) reported losing some income during lockdown, compared with just over two in ten white people (23%)'. They also reported that just over half of white people (54%) reported that they had not been affected financially by the COVID-19 crisis and lockdown, compared with BAMER people, where a third (35%) said that they had not be affected financially. For some of the interviewees the impact of financial insecurity was very much their reality.

> *My partner is self-employed, so his work over this period has been non-existent. More info and financial advice regarding self-employment would have been useful early on. We did find and understand the information, but it is not straightforward, so to keep stress levels down more info on that would have been good.*
>
> **Interviewee 41, No identifying information recorded**

> *I'm worried about being infected and loss of income as I've lost my job just before the beginning of lockdown. Feeling upset as I hear the numbers of deaths and infected cases. I wasn't allowed to see my grandchild and missed her so much. I had to do more housework and cooking.*
>
> **Interviewee 80, a woman of East Asian heritage**

> *Have needed help with finances . Friends and family abroad have sent them money. No recourse to public funds. My husband applied for benefits for first time in late February and now that is helping – but no allowance for me.*
>
> **Interviewee 127, woman of Arab heritage**

> *I have been feeling ok but worrying the business which has been very low and slow since the lockdown.*
>
> **Interviewee 74, woman of Chinese heritage**

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55 https://library.oapen.org/bitstream/handle/20.500.12657/22310/9781447351269.pdf?sequence=4&isAllowed=y
56 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf
57 https://www.runnymedetrust.org/uploads/Runnymede%20Covid19%20Survey%20report%20v3.pdf

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I called the mortgage company, and they can hold payments for 3 months, but at the end of that you end up paying more so it doesn't help. We also applied for financial help. I didn't know how they calculate it, but we didn't get anything so that didn't help.

Interviewee 2, woman of Arab heritage

Currently, I'm living on Universal Tax credit. I found food packages from the local foodbank very useful. Once a week I had ready dinner, besides that I was getting baked beans, fruit, soups in cans, tuna, eggs, toilet paper, soap, cereal. Thank you for that.

Interviewee 97, a woman of Polish heritage

We have financial problems, quite a lot of debts, including unpaid rent, large council tax bill, council counted twice my husband earnings, it's hard to resolve this as we struggle with communication with the council. In spite of all ongoing issues we still haven't been offered any food packages, which makes us very upset as we've seen people in better financial situation receiving some . . . We're at risk of eviction, as our flat was sold and new landlord gave us notice before the COVID. We also had problems with paying our rent over past few months as we were given wrong bank details. We have only been given current details on 15 July and asked to make all payments, which we can't afford at the moment as my husband lost his main job.

Interviewee 98, a woman of Polish heritage

Interviewee 97 had the additional worries around her residency as well as her financial situation.

I have Polish television and prefer to watch something else than information about the virus. I live in one-bedroom flat which is in very bad condition and landlord doesn't want to do any work there. It's very cold here during the winter and electric heating cost me fortune, even £200 per month. After paying all my bills I have only £8 left for a day. I can't afford better flat and moving. I can't also afford to apply for Polish Passport (which expired) so I can apply for the residence status by the end of the year, which makes me very anxious as I haven't been able to go back to Poland for nearly 7 years.

Interviewee 97, woman of Polish heritage

Being a survivor of domestic abuse was an aspect that **Interviewee 124** faced alongside her difficult financial situation, who had recently escaped from her husband.

Have felt very alone, so lonely, and uncertain. Have no friends, very scared to begin with. Worried about whether to wear masks, but settled down after a bit, and got used to it. Routine is not the same, in the house all the time . . . Using an iPad, but it's hard. Worried about going out so got masks. All my assets are in the name of husband so no money, and for a while we had no food in the house. I was so grateful for the food deliveries, and am now getting it from the Food Bank.

Interviewee 124, BAMER woman

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Mitigating risk and negative impacts of lockdown

Interviewees and focus group participants recognised the need to find strategies to battle possible negative impacts of lockdown and COVID-19. A lot would depend on the BAMER individual's:

- social, community and/or religious networks;
- working and housing conditions;
- childcare arrangements;
- free time;
- if they worked;
- financial security;
- access to technology and Wi-Fi/Broadband and the ability to use it;
- disability;
- age;
- family dynamics;
- ability to speak English and
- mental and physical health.

The ability to control any number of these factors could mitigate negative impacts of COVID-19 and the lockdown, for others these factors were out of their control. People were often clear about what resources or support would be beneficial through lockdown.

I don't know but I would not prefer any more information about Coronavirus. Being alone for long time was very hard. Seeing or talking to people might have helped.

Interviewee 64, a woman of Syrian heritage

I would have liked it if someone would have rung me to find out how I am doing and to reassure me that all is fine. When you hear of so many people dying it's scary.

Interviewee 16, a man of Arab heritage

Confidence gone, scared to go out used to four walls like own prisoner. Before always out and about routine always out just come home for lunch then go out again. Now panicky as life had changed total contrast to what I was before. Need to build my confidence. If I continue like that I will deteriorate. Children centre calling welfare check with family members. Chased up if not answered and boosted up my confidence. Telling me to go out for half hour at a time and build up. Go out necessary but told to meet up with friends and children friends build up confidence.

Interviewee 45, a woman of Bangladeshi heritage

Others were in a position to make the best of the lockdown.

I've tried to get back to old hobbies, to keep myself away from TV reports. I've started reading again and making handmade clothes and altering my old ones. I used to alter clothes, but didn't have time when I was working. I'm also talking to friends and family from all over the world for most of the day. I've got the chance to see everyone and speak to them.

Interviewee 30, a woman who identified as of African heritage

Exercising, walking, field at back which is people free. Read a lot, phone and video calls friends. I have a lovely circle of friends who are 70s and over calling them and checking up on them most of their spouses have passed away. We were all nurses in Brighton . . . as I have family and friends, keeping well gentle walk not mixing with people.

Interviewee 43, BAMER woman, no information available

Having faith, religious, praying for protection and keeping good diet and exercise. It is scary to know BAME being at high risk and we live in our multi generation house. I have my children, their wives and grandchildren in the house (three generation).my boys go out to work.

Interviewee 42, a woman of Bangladeshi heritage

I have been speaking with my daughter a lot on the phone, but I didn't have contact with anyone else. Getting out to my allotment everyday has helped me.

Interviewee 1, no information available

Some were in contact with organisations, voluntary and religious groups who were able to support individuals and families.

I think the help from Migrant Help at the beginning calling me to see how I am doing was good. That has stopped. Also, Voices in Exile called me a few times mainly about food delivery.

Interviewee 12, a woman of Zimbabwean heritage

It was a difficult time . . . I was totally isolated in the house with my family not seeing anyone. Like everyone else I had concerns about the virus, and on top of that there was the anxiety of being isolated all that caused stress. But we tried to find things to do and keep ourselves busy at home. The Network of International Women for Brighton and Hove had a big role it involving us in activities that was productive and that had a positive effect and helped. It also helped that I am a strong person and I am religious and that enabled me to cope. The most difficult time was at the beginning of lockdown, then we got used to it and we coped.

Interviewee 137, a woman of Arab heritage

. . . for a while we had no food in the house. I was so grateful for the food deliveries and am now getting it from the Food Bank.

Interviewee 124, a woman of who identified as a white South American

The data collected through surveys, interviews and focus groups perhaps highlighted the depth and breadth of information shared by BAMER people, of which only a fraction was showcased. Further research and analysis to explore the diversity of experience within Brighton and Hove BAMER citizens city development work would identify details of an asset-based approach to enable individuals feel empowered in their lives. A broad range of BAMER-led, community ,and voluntary sectors, alongside religious groups who can help reach the most vulnerable to look at befriending schemes, food banks, digital inclusion schemes (including broadband), benefit and health advice to build community assets.

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Appendix

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All Question Interview: Interviewer's guidance notes

WELCOME SCRIPT

> ℹ️ *Interviewer: Thanks for agreeing to this interview. This project is examining the impact coronavirus has on BAMER people in Brighton and Hove.*
>
> *Interviewer: We have been asked to conduct interviews by the Clinical Commissioning Group/NHS. This project is examining the issues surrounding coronavirus has on BAMER people in Brighton and Hove. .*
>
> *Interviewer: Everything you say will remain anonymous/private, no one outside of this project will be able to identify you in the report.*
>
> *Interviewer: Are you still happy with that?*

PART 1:   NHS Services

> ℹ️ The first element of the project assesses the relationship that BAMER people have with NHS services.
>
> **Interviewer:** *What is your experience using the NHS?* _____
>
> _____
>
> _____
>
> **Prompts:** *Thinking back over the last year or two, what were the different NHS services that you used? Were the services good, did you get good care? How were you treated by the staff?*_____
>
> _____
>
> _____
>
> _____
>
> _____
>
> _____
>
> **Interviewer:** *Did you have any NHS appointments cancelled during the coronavirus lockdown? Or did you cancel any NHS appointments? Why did you cancel it?*
>
> _____
>
> _____

Interviewer: By missing your appointment(s) did it impact you negatively? _____
_____
_____

Interviewer: Have you or anyone in your household had coronavirus?

IF THE PERSON OR THEIR HOUSEHOLD DID NOT GET CORONAVIRUS, GO ONTO PART 3.

PART 2   Experience of coronavirus

ℹ️ *This part asks people who have tested positive with coronavirus or believe they had the coronavirus symptoms, whether they had underlying health conditions, about their recovery, what services they accessed and the experience of those services accessed.*

Interviewer: *Who in your household has caught the coronavirus? [**Prompt:** Was it you, someone else in the house?]* _____
_____

Interviewer: *Did you/they get a test?* _____
_____
_____

Interviewer: *Was anyone else in your household affected?* _____
_____
_____

Interviewer: *Did you/they have any underlying health conditions? [**Prompt:** For example diabetes, heart condition, respiratory, asthma, etc.]* _____
_____
_____
_____

Interviewer: *Did you/they get a letter from the NHS to say you/they should stay at home? [**Prompt:** If appropriate ask them what the condition/illness/disease it was.]*
_____
_____

Interviewer: *Did you/they get treatment for coronavirus from the NHS? What kind of support did you get? How was the treatment?* _____

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_____

_____

_____

_____

Interviewer: *After you/they recovered from coronavirus, did you have any lasting illness from coronavirus?* _____

_____

_____

PART 3   Employment situation

ℹ *This section asks about your employment situation before the lockdown and during the lockdown.*

Interviewer: *What was your employment situation before the lockdown? [**Prompt:** Were you self-employed, retired, carer, zero hours contract, etc.].* _____

_____

_____

Interviewer: *Did you have to work outside the home during lockdown? Were you an essential worker?* _____

_____

_____

If the interviewee did not work outside the home during lockdown you can skip the questions in part four.

PART 4   Working during coronavirus lockdown

ℹ *The section is relevant only for those who worked outside the home as an essential worker, which considers how BAMER people travelled to work, choices about attending work, feeling safe at work and disparity in treatment at work and levels of risk.*

Interviewer: *How are you travelling to work? How did you to travel to work before the lockdown?* _____

_____

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Interviewer: *Do you feel safe at work? Do you think you were expected to take higher levels of risk than your white colleagues?* _____

_____

_____

_____

What PPE did your employer provide? Did your employer carry out a coronavirus risk assessment? _____

_____

_____

Interviewer: *Did you get the PPE (personal protection equipment) you needed?*

_____

_____

PART 5   Information and concerns

The fifth part explores how BAMER people access health information, preferred communication styles, how information and messages are consumed, impact of the lockdown and sources of advice that might better support them.

Interviewer: *Where did you get your information about coronavirus? [**Prompts:** Government briefing, social media, WhatsApp groups, family, council, community/ voluntary groups, religious groups, newspapers, tv, radio, etc.]* _____

_____

_____

Interviewer: *How would you likex to have received information from the NHS? [**Prompts: Would you like clearer information? Plain language, pictorial, Easy Read, in another language other than English, website, WhatsApp messages, texts, emails, leaflets, letters, billboards, helpline, etc.**]*_____

_____

_____

Interviewer: *What are the main symptoms of the coronavirus?* _____

_____

_____

_____

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Then confirm to the person through the NHS definition what the main symptoms of coronavirus are.

Interviewer: Do you and your household feel you are taking more risks than you would like to? Tell me more about that? _____

_____

_____

_____

_____**Interviewer:** *What would you do if you or a member of your household got sick from the coronavirus?* **[Prompts:** *Would you visit/speak to your GP, go to the pharmacy, call 111, go to the hospital, call friends and family for help, go to a traditional healer, contact the council, etc.]*
_____

_____

_____

_____

_____

Interviewer: How have you felt since the lockdown has started? Have you any concerns about the coronavirus? **[Prompts:** *Have you felt positive, negative or had mixed feelings about it? Have you felt happy to be in your homes or has it been difficult? Has is been stressful or relaxed? How have your household found it? Did you feel alone or scared? Did you have a routine? Did you feel you had to do more to do in the house, did everyone in the house work together to get all the work done?]* _____

_____

_____

Interviewer: What sort of things would have helped you/would help you during this coronavirus pandemic? **[Prompts:** *Would you have liked more information about keeping safe for the coronavirus, learning how to get advice on issues such as: libraries, keeping family safe at home, keeping fit, IT lessons, ESOL lessons, help with bills and benefits, racist abuse, someone to talk to.]* _____

_____

_____

Interviewer: How are you keeping yourself well? **[Prompts:** *Exercise, talking to friends and family on the phone, on Zoom/WhatsApp, etc., spending time on your hobbies, doing things you like to do. Is it difficult to keep yourself well? What would help you?]*
_____

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_____

Interviewer: *What can the NHS do to support you?* _____

_____

_____

ℹ️ *Ending the interview*

Thank the interviewee for their time and participation and let them know that you value their contribution.

Monitoring question

Please fill in the equalities monitoring section below, only complete what is reasonable and appropriate and leave blank any unanswered questions.

Next step

Next steps are explained at the end of document.

11.1   Valerie Mainstone:

Dame Marianne Griffiths, CEO of West Sussex Hospitals Trust and of Brighton Sussex Universities Hospital Trust, now wishes to merge them into a single entity. Meanwhile, Sir Simon Stevens, CEO of NHS England "hopes" that there will be only one CCG corresponding to each Integrated Care System by April 2020. Does the HOSC share my concern that these proposed mergers will be the death knell of local decision-making, and result in a democratic deficit, whereby Brighton & Hove GPs currently serving on our CCG, and Brighton & Hove Councillors currently serving on our HWB and HOSC, will find it very hard to represent our local interests on enormous regional bodies?

11.2   Chris Tredgold:

'Care Home residents have been the most severely affected by Covid-19 - accounting for over 40% of England's high death rate.
Age and undiagnosed infected patients discharged from hospital have been causes of this - but so have a lack of testing and adequate PPE.
Testing is at last planned - weekly for the staff, monthly for the residents.
Homes and Local authorities need the results quickly.
How will the HOSC ensure that all staff and residents in Care Homes receive clear test results and that all staff have access to adequate PPE?'

HEALTH OVERVIEW & SCRUTINY COMMITTEE	Agenda Item 13
	Brighton & Hove City Council

Subject:		**Covid: Local Health & Care Stem Responses and Planning**
Date of Meeting:		**14 October 2020**
Report of:		**Executive Lead, Strategy, Governance & Law**
Contact Officer:	**Name:**	**[Giles Rossington Tel: 01273 295514**
	Email:	**Giles.rossington@brighton-hove.gov.uk**
Ward(s) affected:		**All [If not All, insert affected wards]**

FOR GENERAL RELEASE

1.   PURPOSE OF REPORT AND POLICY CONTEXT

1.1   This report sets out local health and care system responses to the Covid crisis and outlines plans for system restoration and recovery.

1.2   Slides detailing response and recovery actions have been provided by Brighton & Hove CCG and are included as **Appendix 1** to this report.

2.   RECOMMENDATIONS:

2.1   That members note the information provided on local health and care system actions and planning in relation to the Covid 19 crisis.

3.   CONTEXT/ BACKGROUND INFORMATION

3.1   During the first wave of the Covid crisis, local health & care system leaders provided regular updates on their actions to the Council's Health & Wellbeing Board (HWB) and to the Health Overview & Scrutiny Committee (HOSC), either at scheduled committee meetings or via briefings to the committee Chairs etc.

3.2   However, the fast-changing nature of the Covid outbreak and the demands that managing the outbreak placed on senior managers and clinicians across health and care services, meant that engagement with local HOSCs was necessarily limited. This report offers members an opportunity to explore local health and care system actions in response to the Covid emergency, as well as system planning to restore normal services and to prepare for a second wave of infections.

3.3   Specifically, the HOSC Chair has asked system leaders to provide information on:

- Substantial changes to NHS services made under urgency powers (i.e. changes that would normally have required NHS bodies to consult with local HOSC(s) at an early stage of planning).

- System plans to restore services to normality and to address any backlog in terms of treatment where services were suspended/limited during the Covid outbreak. For example, the NHS suspended a range of elective procedures to enable acute hospitals to focus on Covid treatment. Of particular concern here are areas where local performance has historically been weak: e.g. in cancer diagnosis and treatment, and in reaching the national NHS target of a maximum 18 week wait between referral and treatment for non-urgent conditions (the RTT target).

- Instances where the system is planning to make temporary changes permanent where those changes have delivered real benefits to service users – e.g. the increased use of digital/remote consultations. HOSC members may wish to focus on the benefits to patients of 'locking-in' some of these temporary changes; but also how services will ensure that some users do not experience worse care through these changes, and particularly what safeguards are in place to ensure that changes do not exacerbate existing health inequalities.

4. ANALYSIS & CONSIDERATION OF ANY ALTERNATIVE OPTIONS

4.1 Not relevant to this report to note.

5. COMMUNITY ENGAGEMENT & CONSULTATION

5.1 No formal engagement regarding this report to note.

6. CONCLUSION

6.1 HOSC members are asked to note the information provided by health & care system leaders on actions and planning with regard to the Covid emergency.

7. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

7.1 None for this report to note

Legal Implications:

7.2 There are no legal implications to this report to note.

Lawyer Consulted: *Elizabeth Culbert*   *Date: dd/mm/yy*

Equalities Implications:

7.3 Members may wish to explore the equalities implications of actions taken in response to the Covid emergency and of plans to restore and recover the system. Of particular interest may be impacts on BAME communities; and the mitigations in place to ensure that a greater emphasis on remote appointments/consultations do not adversely impact on protected groups which are more likely to experience digital exclusion (e.g. older people).

Sustainability Implications:

7.4 Moves to more remote working may have a positive impact on carbon emissions by reducing patient journeys.

Brexit Implications:

7.5 None identified. However, members may wish to explore how Brexit risks have been evaluated in terms of system planning for a second wave of Covid infections given that any winter second wave is likely to coincide with the end of the transition period.

Any Other Significant Implications:

None identified

SUPPORTING DOCUMENTATION

Appendices:

1. Information provided by Brighton & Hove CCG

Background Documents
None

Brighton and Hove HOSC
COVID-19 update

October 2020

Introduction

- We have worked collaboratively across health and social care partners to manage our response to the pandemic.

- This approach has delivered significant benefit for the population of Brighton and Hove – deaths per 100,000 in the county were significantly lower then the average across England.

- These slides set out:-

  1. An overview of the response in Brighton and Hove, and across Sussex, including any changes to services during this period;
  2. System plans to restore services effectively; and
  3. Planning for the future, including reviewing changes to services and implications for inequalities and how we are addressing these as part of recovery plans.

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Our response to COVID-19

Our response to the COVID-19-19 pandemic in Brighton and Hove

- We have worked incredibly collaboratively across health and social care partners to manage our response to the pandemic in Brighton and Hove – and across Sussex as a system.

- This approach has delivered significant benefit for the population of Brighton and Hove – deaths per 100,000 in the county were significantly lower then the average across England.

- The whole system adapted its governance in March to respond to the emergency response across Sussex.

- In Brighton and Hove, there were daily OPEX calls to manage the local system operational response, with escalation of risks to weekly Senior Responsible Officer calls, and monthly wider senior leadership calls to support system agreement and coordination of response plans.

- This covered hospital discharge pathways, surge capacity planning, agreeing and securing additional bed capacity; mutual aid for PPE, care home resilience plan and mutual aid to nursing and residential care.

Changes to services

- During the COVID-19 response there have been temporary changes made to the way some health services worked and how patients could access care and support;

- In the majority, these changes involved providing phone, digital and online access and appointments to patients apart from where face to face was clinically necessary;

- This enabled services to continue to provide care and support whilst ensuring the safety of patients and of staff;

- This approach was adopted in primary care (GP practices), secondary care and mental health;

- There are no formal substantive changes to services in Brighton and Hove that have been made during the COVID-19 response;

- The CCG is now engaging with the local population, stakeholders and partners to understand people's experiences of health and care services during the pandemic response, to help inform and shape plans as we consider how services restore and longer term ways of working.

Lessons learnt to date

- A debrief process took place in July across the ICS following the standard model used by the Sussex Local Resilience Forum. The process sought to identify items of good practice, areas for improvement and recommendations to be made.

- The key areas for improvement taken forward in current work include:

1. **Preparations and Expectation**
    - Need for preparedness to resource an incident of this long standing nature and across more than one geography
2. **Governance and Decision Making**
    - Need for plans to stand up response more quickly to full level of response
    - Variation in approaches across CCG/LA areas
3. **Communications**
    - Clear need for proactive comms at all times, especially around what is available
4. **Information Flows**
    - Volume of information requests/sitreps was significant
5. **Partnership working and coordination**
    - Not all NHS providers and partners using the same platform
6. **PPE**
    - Need for detailed planning and preparation for scenarios requiring PPE at this level

Key areas identified have informed the system's continuous planning for managing the Sussex response to COVID-19-19 and the system's response to the Phase 3 letter.

System plans to restore health and care services

Summary

Phase 3 letter for the NHS response to COVID-19-19 was released by NHS England and Improvement on 31 July 2020.

- NHS emergency incident level moved from Level 4 (national) to Level 3 (regional) with effect from 1 August.
- Focus on priority areas:

  - ➤ **Accelerating the return to near-normal levels of non-COVID-19 health services**, making full use of the capacity available in the 'window of opportunity' between now and winter.
  - ➤ **Preparation for winter demand pressures**, alongside continuing vigilance in the light of further probable COVID-19 spikes locally and possibly nationally.
  - ➤ Doing the above in a way that takes account of lessons learned during the first COVID-19 peak; locks in beneficial changes; and explicitly **tackles fundamental challenges including support for our staff, and action on inequalities and prevention.**
  - ➤ **Further system development**, including leadership, governance, and commissioning.

- Sussex Health and Care Partnership submitted the system's local plans to NHS England by 21st September.

Approach to Phase Three planning

A Consistent systematic approach overseen by the **SHCP Partnership Executive**

B Plans developed under the auspices of the **Sussex Collaborative Networks**

Understanding of drivers and root cause of gaps:

a. **Demand and capacity mismatch:** using the Sussex Model
b. **Workforce**: vacancy, shielding, redeployment
c. **Productivity**: reduced productivity due to national and local policies
d. Recognising System risks and mitigations
e. Patient Feedback and experience

Draft Plan developed and signed off via Collaborative Networks

1   **2**   **3**   **4**

Detailed gap analysis identifying the gap between current performance, Phase Three requirement and the existing Sussex plan (submitted as part of pre-planning in July 2020).

Bridging the gap:

a. Review of existing plans to ensure actions are aligned to the root causes, maximising the ambition and delivery;
b. Learning from others; Adapt and Adopt
c. Clinical Leadership and shaping our system to meet the challenge

Changes to services

A summary of changes made during COVID-19 response and current position is as follows:

Primary care provided online and phone appointments, and only face to face where clinically necessary.	GP practices are now open for patients, and are providing face to face appointments for those who need them. Triage processes are still in place and patients will be encouraged to use phone and online appointments where appropriate.
Locally Commissioned Services were suspended in primary care.	The CCG is working with GP practices to restore LCS services across Brighton and Hove where it can be done safely for patients and staff.
Improved Access was suspended.	Evening and weekend appointments are now being restarted across Sussex.
Elective procedures were suspended to enable acute hospitals to focus on COVID-19 treatment.	Elective and non elective services are resuming, with all patients currently waiting for treatment having had their cases clinically assessed to ensure appointments are being clinically prioritised.
Memory Assessment Services were suspended in line with national guidance along with some Locally Commissioned Services.	Services have restarted and plans are in place to support agreed recovery trajectory across Sussex within 12 months.
Cancer screening services were suspended	Return of cancer screening services across Sussex.
Any Qualified Provider (AQP): many services scaled down or suspended	Services restarted
Fertility services suspended	Services restored with appropriate safety measures

System plans to restore services (1/6)

Urgent and emergency services

- All services have been maintained throughout COVID-19-19 pandemic for Brighton and Hove residents.
- There has been substantial adaptation of facilities to accommodate infection prevention and control measures.
- Significant reduction in demand for services from April–June beginning to reverse and activity is expected to return to pre-COVID levels.
- Week ending 9 August: 4 hour performance was 92.0% across Sussex. An increase of 5% compared to the same week last year (87.0%). In the same week there were 3,513 emergency admissions across Sussex. A decrease of 213 (-5.7%) compared to the same week last year (3,726).

Actions to support restoration

- The Clinical Assessment Service as part of NHS 111 went live on 1 October.
- Sussex-wide Service Finder rolled out providing access to the Directory of Services to ambulance crews allowing them to identify appropriate services for referral.
- GP oversight role established in NHS111, supported by video consultation technology, to increase 'consult and complete' outcomes.
- Sussex-wide communications and engagement campaign to promote NHS111 and online as first point of contact.
- ESHT testing NHS 111 First from mid October; BSUH and WSHFT go live in December.

System plans to restore services (2/6)

Elective, diagnostic and Cancer services

- Across Sussex activity is lower than pre COVID-19 levels:
  - Outpatient first appointments at 66% (72% - plan) and follow ups at 82% (71% - plan).
  - Day case at 52% (43%) and elective admission at 49% (50%).
  - The system has restored CT and MRI services to pre-COVID-19 levels and will maintain this position for the rest of the year.
- The system has seen an increase in cancer referrals to pre-COVID-19 levels and plans to meet this level of demand throughout the remainder of the year.
- There is an increase in patients waiting over 52 weeks.

Actions to support restoration

- Rapid progress made in roll out of virtual consultations and will become the default position:
  - 45% of first outpatient appointments in Sussex in August were virtual compared to 5% pre-COVID-19-19 lockdown measure.
- BSUH is risk stratifying patient lists working to local clinical prioritisation based on the Royal College of Surgeons guidelines
- Cancer long waiters – clinical harm reviews to determine level of harm (physical and psychological) for those impacted by a long wait and understand impact on health outcome and patient experience.
- Sussex Cancer Board has approved proposals to work collaboratively to address variation and health inequalities and funding proposals to improve cancer outcomes.
- Formation of Clinically led Sussex Outpatients, Theatre, Diagnostics and Endoscopy Working Groups with a remit to further develop demand assumptions, adopt and adapt innovative solutions, ensure access to additional diagnostic capacity and develop longer term plans.
- Continue working with Healthwatch on patient and public comms
- Continued use of Independent sector capacity.

Working in partnership across Sussex

System plans to restore services (3/6)

Mental Health

- Crisis services continue to support increasing demand.

- Mental Health Collaborative have implemented plans to improve flow, reduce DToC and increase bedded capacity across Adult services

- Enhanced Mental Health Line to provide 24/7 support to patients, carers, and Health & Social care staff across Sussex.

- Urgent care pathway enhanced to cover 24/7 and providing alternatives to A&E through the establishment of Urgent Care Lounges/Havens across Sussex.

- Increased use of digital solutions as safe alternative to face to face interventions.

- Enhanced psychological support for all NHS staff who need it is now in place and psychological provider services have worked with each acute trust to ensure support is being consistently provided.

- Referrals to IAPT are steadily increasing towards pre-COVID-19 levels and a system wide recovery plan has been developed to describe the recovery trajectory back to agreed planned activity.

- Recruitment is underway to an expanded CYP Eating Disorder Access service.

- Dementia Diagnosis Rates - Memory Assessment Services were suspended in line with national guidance along with some Locally Commissioned Services, and some staff redeployed to front line services. Plans in place to support agreed recovery trajectory in each of the 3 Sussex 'places' within 12 months.

System plans to restore services (4/6)

Primary care

- There is a focused programme of work to support primary care in Brighton and Hove, and across Sussex more widely, to restore services back for the local population. This includes monitoring and managing capacity and demand.

- **Access to services:**
  - GP practices have re-started to see patients face-to-face, following a clinical triage process.
  - Telephone and digital appointments do continue to be routinely offered where possible but face to face appointments are available for those who clinically need them.
  - Patients who are COVID-19 positive or symptomatic are now mostly zoned in practices, with a small number of Hot Sites remaining.
  - Clinical guidance is being coordinated to ensure the most appropriate support for high risk patients as services restore.
  - During the pandemic Improved Access appointments were repurposed to support Hot Sites. As part of the restoration and recovery process these are now returning to previous use with patients able to access weekend and evening appointments.
  - The new 111 Clinical Assessment Service went live on 1 October 2020. As part of its introduction, there is a wider range of health professionals available as part of the 111 service so more patients should be able to receive help and advice on the cal. There will also be the ability to book a set number of patients into a telephone appointment with their practice as this is rolled out.

System plans to restore services (5/6)

Primary care (continued)

- **Annual Health Checks (LTC):**
  - At the start of the pandemic the CCG suspended the requirement to deliver a number of services in order to free up capacity to manage the impact on patients and practices. GPs are now being encouraged to restart these services where appropriate and safe to do so. A restoration and recovery group meets fortnightly to manage the reinstatement of Locally Commissioned Services, which are put in place to provide additional support often for patients with Long Term Conditions, reviewing each specification to ensure it remains fit for purpose given the continued need for social distancing etc. Services for patients with Diabetes, COPD, Cardiac problems, and those in Care Homes have been prioritised.

- **Annual Health Checks (LD):**
  - There has been a specific Sussex-wide focus concerning Learning Disability (LD) services to improve uptake and access, particularly annual health checks.
  - This includes an expression of interest to become a Learning Disabilities Annual Health Check exemplar. A proposal for stopping over medication in people with LD being developed (STOMP).

- **BAME residents:**
  - A BAME Locally Commissioned Service (LCS) has been launched to provide additional healthcare to support BAME residents who are at higher risk of complications resulting from COVID-19; 98% of practices have signed up across Sussex.
  - This includes all practices writing to their BAME patients to provide clear information on how to stay safe and protect themselves and those around them (information translated as appropriate).

Maternity

- Core cervices have been maintained throughout
- Home birthing services resumed on 22 June.

Stroke and Cardiovascular disease services

- Stroke services have continued throughout with Thrombectomy pathways continuing into RSCH and Southampton.
- Cardiac, Heart Attacks, PCW, PPCI, Urgent Arrythmia services, severe heart failure/valve disease services are fully functioning.

Clinically Effective Commissioning

- In response to COVID-19 efforts in March and April 2020, the CCGs had decided to temporarily suspend the next stage development of the Sussex Clinically Effective Commissioning programme, which would have seen the commissioning of a third tranche of policies.
- Given the continued focus on recovery and restoration of NHS services, and the need for additional capacity that the introduction of additional clinical policies would place upon our acute and community providers, the CCGs have taken the view that the CEC programme will remain suspended until the end of the financial year, and a further decision will be made as to the appropriateness of restarting it.
- The only exception to this, is the development of a policy on fertility which is necessary to align all Sussex CCGs to NICE guidance.

COVID-19 testing

Pillar	Owner	Testing for	Locations	Booked through
Pillar 1	NHS pathology labs	• Patients • Staff (if spare capacity)	NHS Trusts	Internal NHS systems
Pillar 2	DHSC and commercial partners	• Public • Key workers • Care home residents and staff	Brighton, Gatwick, Tangmere, Bexhill, mobile testing units, home testing kits, care home testing kits	National booking portal
Pillars 3, 4 and 5 cover research studies including antibody testing and new testing methods				

- The national COVID-19 testing system's laboratories are currently facing very high demand.
- COVID-19 test are currently available for people at East Brighton Park Tennis Courts, Gatwick, Bexhill and Tangmere.
- The latest guidance is that you should only apply for a COVID-19 test if you have symptoms – a new continuous cough, a high temperature or a loss or change to your sense of smell or taste. You should isolate for ten days or until a negative test result is received, only leaving home to get tested. Anyone in your household who does not have symptoms should isolate for 14 days.
- Tests can be booked at www.gov.uk/get-coronavirus-test or by calling 119.
- As a local system, the NHS, public health and local authorities are working together to support DHSC to find additional testing sites. We are in regular discussions and we are putting more key worker (NHS and council staff) tests through our local in-house laboratories to enable the general population to have as much access to the national laboratory capacity as possible.

System plans for the future

Planning for the future

As services restore, system wide plans for recovery are also being progressed. This means longer term aspirations for health and care across Brighton and Hove are being scoped, including:

- **Digital use** – work is underway to explore how use of technology can support an increase in virtual appointments, especially in outpatients. This will need to take account of public and patient engagement on digital use, and any groups or communities who may find it as easy to use technology in these circumstances. Work with Healthwatch has already taken place to gain insight on attitudes, behaviours and barriers to digital use to help inform this work;

- **Triage in GP practices** – to work with GP practices as they shape their processes to support patients, such as the clinical triage process to understand a person's needs before offering an appointment, whether that be online, on the phone or face to face;

- **Support for patients post discharge -** wellbeing checks pilot scheme in Brighton and Hove carried out with Healthwatch (overseen by CCG and LA) being evaluated and sustainability explored.

Any consideration of service change would follow clear governance and agreed processes, including HOSC.

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Impact on inequalities

- COVID-19 has exposed some health and wider inequalities. For example men, older people, those with existing health conditions, ethnic minority communities, low skilled workers and people living in deprived communities are all at a greater risk of infection, serious illness and of dying from COVID-19.

- As services restore, and we look at longer term planning, there is a clear focus on protecting the most vulnerable from COVID-19 and restoring services inclusively so they are used by those in the greatest need.

- The CCG has collaborated with partners to rapidly support the most vulnerable in our communities. This work includes:
    - Implementing enhanced access to primary care for accommodated rough sleepers and asylum seekers and expanded multi-agency safeguarding services.
    - Ensuring patients being discharged from hospital are well supported and connected to relevant local services.
    - Supporting the establishment and further development of Community Hubs to help people access information / advice, medicines, food and local support services.
    - Ensuring all Care Homes have been able to access PPE, staff training, health protection support and advice and access to testing for residents and staff.

Impact on inequalities (cont)

- BAME COVID-19 Disparity Programme established across the Sussex system to protect BAME staff and communities, which includes:

  - All GP practices contracted to provide holistic reviews for patients identified taking into account lifestyle factors that contribute to the higher risk of COVID-19 (LCS).
  - Implemented risk assessments for all NHS and care staff from specific BAME populations groups.
  - A programme of community engagement in Brighton, Crawley and Hastings, which have a higher BAME population density, and engagement across other geographic areas. Phase 1 complete and reported, phase 2 to commence.

Hearing from our population

We have launched the **Big Health and Care (Socially Distanced) Conversation**: a system wide public involvement programme to hear experiences of access and use of health and care services during COVID-19:

- Sussex NHS Commissioners/Healthwatch across Sussex have sought the views of people and communities through two online surveys and interviews to understand how people accessed health and care services during the initial crisis period, challenges and public behaviour (with a focus on digital access covering GP services, A&E, mental health services):
  - The final report has been produced, and is a helping shape restoration and recovery plans related to digital and non digital access;
  - A similar number of responses were received from Brighton and Hove, East Sussex, and West Sussex (less than a 4% difference across the three areas).
- **#LetsTalkSussex**; themed online conversations to draw in feedback – topics so far include GP services, mental wellbeing, carers, dentistry.
- Healthwatch carrying out further **engagement on care homes** (with carers/residents);
- **Hospital discharge engagement** underway- phase 1 complete, phase 2 being planned;
- "**The Big Debate**" – narrative and deliberative engagement on key topics, including the impact of delayed care, and self care/self support
- Work with NHS and Local Authority partners to scope out **common topics and joint work and triangulate intelligence** – including mental wellbeing, access to A&E, information provision
- A grant programme for **inclusion engagement** across Sussex was launched on 07 September and expressions of interest are now being evaluated;
- Pan Sussex "**provider Community Engagement**" network established, including BHCC and BSUH;
- Brighton and Hove **Communications and Engagement Network** established
- Pan Sussex **Partnership Forum** established, membership comprising VCS and Healthwatch, communications and engagement leads across system

Stay up to date with COVID-19 advice in Brighton and Hove

See the latest alert level for the city, public health information and latest update on services:
https://www.brighton-hove.gov.uk/coronavirus-covid-19

Join the Big Health and Care (Socially Distanced) Conversation:
https://www.seshealthandcare.org.uk/priority/engaging-with-our-people/

HEALTH OVERVIEW & SCRUTINY COMMITTEE	Agenda Item
	Brighton & Hove City Council

Subject:		**Sussex Health and Care Partnership Winter Plan 2020-21 Update**
Date of Meeting:		**14 October 2020**
Report of:		**Izzy Davis-Fernandez, Head of Resilience, Sussex CCGs**
Contact Officer:	**Name:**	**Leila Morley** Tel: 07775412510
	Email:	**Leila.morley@nhs.net**
Ward(s) affected: All		**(All Wards); Yes**

FOR GENERAL RELEASE

1.   PURPOSE OF REPORT AND POLICY CONTEXT

1.1   The purpose of this paper is to provide the Brighton and Hove Health Overview and Scrutiny Committee with an update on progress to date in relation to winter planning, outline next steps and timelines.

2.   RECOMMENDATIONS:

2.1   The Brighton and Hove Health Overview and Scrutiny Committee are asked to review and comment on the Sussex Health and Care Partnership Winter Plan 2020-21 Update.

3.   CONTEXT/ BACKGROUND INFORMATION

3.1   The overall purpose of the winter plan is to ensure that the system is able to effectively manage the capacity and demand pressures anticipated during the Winter period. The Winter planning period covers the period October 2020 to 31 March 2021. The plan should ensure that the local systems remain resilient and are able to manage demand surge effectively, maintain patient safety and support delivery of the relevant business plan objectives and locally agreed system improvements during this period.

3.2   For 2020/21, the planning process has also considered the impact and learning from the current Covid-19 outbreak as well as plan for further possible outbreaks. Core to the development of plans for 2020/21 are the following:

- Building upon learning from winter 2019/20

- Developing capacity and demand modelling which takes into account expected A&E activity, impact of the covid-19 pandemic (numbers of incidents as well as impact of national requirements)
- Reviewing system surge plans and escalation triggers

3.3 This year's winter plan has been developed through place based engagement with commissioners and providers through the Local A&E Delivery Board and working groups.

3.3 Winter plans have been reviewed through the system and ICS governance framework and an ICS Winter Oversight and Assurance Group has been established to enable this. A RAG rating assurance framework has been used to demonstrate delivery against overarching requirements and key deliverables. Winter plans will assured against the national Key Lines of Enquiry (KLoEs), in addition to assessment of placed based plans and the Sussex wide plans in relation to Communications, Flu, NHS 111 and NHS 999

3.3 The Sussex Health and Care Partnership Winter Plan 2020-21 has the following governance and assurance process in progress ahead of submission of the final plan to NHS England:

Committee / Board	Date	Status
Sussex Local A&E Delivery Boards	w/c 20 July 2020	Completed
CCG Brighton and Hove and East Sussex Local Management Team	04 August 2020	Completed
CCG West Sussex Local Management Team	05 August 2020	Completed
Sussex Local A&E Delivery Boards	w/c 17 August 2020	Completed
East Sussex Covid-19 Executive Group	28 August 2020	Completed
Integrated Care System Oversight and Assurance Group	04 September 2020	Completed
Brighton and Hove Health and Wellbeing Board	08 September 2020	Completed
CCG Joint Quality Committee	08 September 2020	Completed
Brighton and Hove Local A&E Delivery Board Working Group	10 September 2020	Completed
East Sussex Health Overview and Scrutiny Committee	10 September 2020	Completed
West Sussex Health and Adult Social Care Scrutiny Committee Task and Finish Group	11 September 2020	Completed

Sussex Local A&E Delivery Boards	w/c 14 September 2020	Completed
Brighton and Hove and East Sussex Local Management Team	15 September 2020	Completed
West Sussex Local Management Team	16 September 2020	Completed
East Sussex Health and Wellbeing Board	17 September 2020	Completed
West Sussex System Resilience Operational Group	22 September 2020	Completed
Brighton and Hove Local A&E Delivery Boards	24 September 2020	Completed
Integrated Care System Oversight and Assurance Group	25 September 2020	Completed
CCG Executive Management Team	28 September 2020	Completed
CCG Joint Finance and Performance Committee	30 September 2020	Completed
NHS England	**01 October 2020**	**Not due at time of writing**
Brighton and Hove CCG Governing Body	06 October 2020	Not due at time of writing
West Sussex CCG Governing Body	06 October 2020	Not due at time of writing
East Sussex CCG Governing Body	07 October 2020	Not due at time of writing
Integrated Care System Covid-19 Incident Management Team and Restoration Group	08 October 2020	Not due at time of writing
West Sussex Health and Wellbeing Board	08 October 2020	Not due at time of writing
Brighton and Hove Health Overview and Scrutiny Committee	14 October 2020	Not due at time of writing

4   ANALYSIS & CONSIDERATION OF ANY ALTERNATIVE OPTIONS

4.1   Not relevant to this report to note.

5   COMMUNITY ENGAGEMENT & CONSULTATION

5.1   The plan has been developed by the place based Local A&E Delivery Boards (LAEDBs) and working groups, which have representation from all local system health and social care providers and commissioners. Healthwatch colleagues are part of the LAEDBs and working groups and have shared learning and informed

the development of the plan. Sussex CCGs engagement team have produced a report from existing patient and public feedback on the new discharge from hospital process, key learning and feedback from this report has been fed into the development of the winter plans.

6   CONCLUSION

6.1   The purpose of this paper is to provide the Brighton and Hove Health Overview and Scrutiny Committee with an update on progress to date in relation to winter planning, outline next steps and timelines. The Brighton and Hove Health Overview and Scrutiny Committee are asked to review and comment on the Sussex Health and Care Partnership Winter Plan 2020-21 Update.

7   FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

7.1   A commissioning stock-take exercise looking at quality and value for money reviewed the additional capacity put in place during the Covid-19 response and has informed the winter plans in terms of actions recommended to continue as part of the arrangements to maintain delivery of the national Hospital Discharge requirements. The winter plans are linked to the work underway in relation to the draft system financial plans required in October.

Finance Officer Consulted: Name   *Date: dd/mm/yy*

Legal Implications:

7.2   Planning for the winter period is a national requirement for local preparation for additional demands and pressure on the health and social care system expected during the winter period (October 2020 to 31 March 2021).

Lawyer Consulted: Name   *Date: dd/mm/yy*

Equalities Implications:

7.3   The aims of effective collaborative winter plan arrangements are to ensure that local health and care systems are able to continue to deliver the totality of services that have been developed to meet the needs of the local population which would be in line with agreed local and national strategies and priorities. An Equality Impact Assessment is not appropriate for this paper. Where services are further developed to support delivery during the winter period EIAs will be undertaken.

Sustainability Implications:

7.4   None identified

Any Other Significant Implications:

7.5   None identified

SUPPORTING DOCUMENTATION

Appendices:

1.   Sussex Health and Care Partnership Winter Plan 2020-21 Update

Documents in Members' Rooms
None

Background Documents
None

Brighton & Hove HOSC

Winter Plan Update

14 October 2020

Summary of winter planning

- Winter plans have been developed by Local A&E Deliver Boards (LAEDBs) with input from partners across each system; local authority, providers and commissioners.
- Three place-based winter plans have been produced as in previous years.
- The overall purpose of the Winter plan is to ensure that the system is able to effectively manage the capacity and demand pressures anticipated during the Winter period (October 2020 to 31 March 2021). Ensuring local systems are able to manage demand surge effectively, maintain patient safety and support delivery of the relevant business plan objectives and locally agreed system improvements during this period.
- For 2020/21, the planning process has also considered the impact and learning from the current Covid-19 outbreak as well as plan for further possible outbreaks. As such, the capacity and demand modelling, surge escalation triggers and overall response will require review and ongoing refinement as further learning emerges over coming weeks and months.
- An ICS Winter Oversight and Assurance Group has been established and agreed governance for winter is in place. The plan will be considered for assurance by the Brighton and Hove CCG Governing Body in October and individual providers will assure their own plans though their respective boards.
- Based on current pressures and key winter risks, the high-level strategic priorities for the system and underpinning the winter plan include:

  - A single, Sussex-wide robust escalation framework aligned to Covid-19 Early Warning Indicators and embedded into SHREWD
  - Further efficiency and sustainability of MRD and long length of stay (LLOS) gains to maintain system resilience
  - Continuation of both in hospital and out of hospital models of care, including additional capacity to address the identified bed gap
  - Strengthened Mental Health escalation process and system-wide response to mitigate increase in demand

Objectives of winter planning

The objectives of the Winter plan are:

- To maintain patient safety at all times;
- To prepare for and respond to periods of increased demand, including any future increases in Covid-19 infections;
- To ensure that acute hospital bed occupancy is maintained at a level that ensures that patients who require admission to a hospital bed are able to be admitted in a timely way, thereby avoiding the risk of overcrowding in A&E and delays to ambulances being able to handover patients and respond to 999 calls;
- To ensure that community health services are maximised, e.g. improving length of stay and utilisation and increasing the number of patients who can be safely discharged home in a timely manner with care support. Effective use of community services during the winter period will support timely discharge from hospital and avoidance of unnecessary admission to an acute hospital bed;
- To avoid ambulance delays of over 30 minutes;
- To support delivery of the agreed local system performance trajectory in respect for the 4 hour A&E standard, the 18 week referral to treatment standard (in line with Covid-19 restoration and recovery plans) and Cancer waiting times standards;
- To continue to deliver a reduction in long length of stay patients by March 2021;
- To proactively prevent and manage infection control outbreaks or issues such as norovirus and influenza – including the influenza vaccination programme

Local and national Covid-19 surge planning

The Covid-19 Phase 3 letter released on 31 July 2020, outlines the expectation for preparation for winter demand pressures, alongside continuing vigilance in the light of further probable Covid-19 spikes locally and possibly nationally. Including:

- Continue to follow good Covid-19 related practice to enable patients to access services safely and protect staff, whilst also preparing for localised Covid-19 outbreaks or a wider national wave
- Prepare for winter, including:
  - Sustaining current NHS staffing, beds and capacity, including use of independent sector capacity, Nightingale hospitals, and support to quickly and safely discharge patients from NHS hospitals through to March 2021.
  - Deliver a very significantly expanded seasonal flu vaccination programme
  - Expanding the 111 First offer
  - Maximise the use of 'Hear and Treat' and 'See and Treat' pathways for 999
  - Continue to make full use of the NHS Volunteer Responders scheme
  - Continuing to work with local authorities - ensure that those medically fit for discharge are not delayed from being able to go home as soon as it is safe for them to do so

In addition to these requirements, work is in progress across Sussex to ensure alignment of escalation frameworks across LAEDB resilience and surge arrangements with escalation based on early warning indicators related to Covid-19 incidence. This will enable a pre-emptive, robust and timely response to ensuring service provision meets the needs of local people.

Critical Milestones

Milestone RAG Key
- Planned work
- Complete
- At risk
- Overdue

May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March

Capacity & demand Development

Modelling complete

Stress testing initial session

Stress testing 2nd session

Winter plan in operation (including Christmas, New Year, cold weather, and Feb half term plans)

Review winter 19/20 & Easter lessons learnt

Review system escalation plans and triggers

Escalation plans and triggers complete*

Updates to SHREWD dashboards

Continue to review capacity & demand against actuals

Lessons learnt review

Review Covid-19 initial lessons learnt

Ongoing review of plan at LAEDBs

Stocktake papers to LAEDB, LMT, & F&P

Winter comms plan developed

Winter comms in operation

Template plan developed

Draft plan reviewed by LAEDBs

Final plan governance and sign-off

NHSE submission

LAEDBs WSx 16th BH 18th ESx 19th

LAEDBs WSx 21st BH 23rd ESx 24th

LAEDBs WSx 18th BH 20th ESx 21st

LAEDBs WSx 15th ESx 18th BH 24th

LAEDBs WSx 20th BH 22nd ESx 23rd

LAEDBs WSx 20th BH 22nd ESx 23rd

LAEDBs WSx 15th BH TBC ESx TBC

LAEDBs WSx 19th BH TBC ESx TBC

LAEDBs WSx 19th BH TBC ESx TBC

LAEDBs WSx 16th BH TBC ESx TBC

Assurance Process

- Winter plans will be reviewed through the system and Integrated Care System (ICS) governance framework and an ICS Winter Oversight and Assurance Group has been established to enable this

- A Red Amber Green (RAG) rating assurance framework will be used to demonstrate delivery against overarching requirements and key deliverables

- Winter plans will assured against the national Key Lines of Enquiry (KLoE) set out below, in addition to assessment of placed based plans and the Sussex wide plans in relation to Communications, Flu, NHS 111 and NHS 999

NHSE/I Winter Operating Model

NHS Long Term Plan

Local Strategy / Operating Plans

Covid-19 / Surge Learning

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Winter Plan Key Risks and Mitigations

Identified Risk	Mitigations
Covid-19 related surge: There is a risk that there will be a second wave surge resulting in system fragility and potentially impacting on patient safety and delivery of restoration and recovery trajectories.	Demand and capacity planning has modelled reasonable scenarios and plans to close this gap identified. Covid-19 phase one schemes have been reviewed as part of the Covid-19 stocktake exercise and schemes recommended to continue to sustain community capacity. A Sussex Monitoring Group is established to develop early warning mechanism and local outbreak management plans.
Critical care capacity: There is a risk that critical care capacity will be insufficient to manage normal winter demand and a second wave Covid-19 surge and that this will impact on restoration trajectories.	A Critical Care system surge and capacity plan has been agreed. Monitoring and management of critical care capacity at system level to manage Covid-19 related surge. A Regional/Cross border Escalation Plan will be in place alongside access to SE Critical Care Surge hubs and commissioned critical care transfer resource. This includes work with Surrey and Frimley to agree how we will use critical care capacity to manage demand as it arises across the three ICS systems
Workforce: There is a risk to the resilience of the health and care workforce during the winter months. Existing workforce pressures are likely to exacerbated by requirements for shielding and self-isolation, staff resilience and increase levels of sickness absence.	Risks assessments for at risk staff completed across the system and workplace environments adapted to be Covid-19 secure where possible. The delivery of staff flu vaccination programme. Redeployment and PPE protocols established and in place to deal with surge periods. Sussex ICS mutual aid mechanisms in place.
Staff, key worker and Patient testing: There is a risk that NHS and non-NHS key workers will not be able to access testing, which will extend periods of staff absence related to Covid-19 or that patients will not be able to access timely testing.	A Sussex ICS Testing Prioritisation Framework has been developed. Pillar 1 capacity and demand modelling developed to inform the above. Re-establishment of provider in house staff testing capacity. Sussex Central Booking Hub to facilitate and prioritise access for key workers. Targeted deployment of mobile testing units

Working in partnership across Sussex

Winter Plan Key Risks and Mitigations

Identified Risk	Mitigations
Public Behaviour: There is a risk that patients may be reluctant to access face to face services during a Covid-19 surge and local lock down scenario potentially impacting on health outcomes and delivery of restoration trajectories	Extensive system wide communications and engagement plan and a single system access policy in development.
Residential and Care Home fragility: There is a risk of outbreaks and closures in residential and care home settings.	Care home enhanced support in place delivered by PCNs, medicines management team and community services. Care Home Support LCS in place for primary care support, prior to the introduction of the Enhanced Health in Care Homes DES scheme in October 2020. Care home fragility and issues are monitored managed and coordinated by a dedicated joint care home cell including provision of PPE. Stock take of care homes in progress to consider areas / homes where additional focus may be required.
Mental Health: There is a risk of increased Mental Health demand as a result of Covid-19. Unmet surge mental health activity will impact on quality and patient experience in addition to placing pressure on A&E impacting negatively on system flow	Detailed mental health demand and capacity planning has been completed. Increasing Mental Health workforce and reconfiguration of services to support the front door. Mental health escalation framework, triggers and actions to support resilience. A weekly Sussex ICS Mental Health Resilience group established.
Medically Ready for Discharge (MRD) delivery: There is a risk that the system will not sustain the discharge trajectories assumed in the modelling to protect acute bed capacity.	A community-led Executive MRD Task and Finish Group has been established to oversee the development and delivery of MRD improvement plans. Modelling and work-up of proposals to secure additional community capacity to support discharge is underway, relating to "Home First" discharges and bedded community capacity.
NHS111 First: There is a risk that the funds allocated to support rollout may be insufficient to enhance the NHS111-CAS to the degree required to deliver targeted benefits	Proceed with ESHT as fast follower at pace; share lessons learnt across other Trusts in parallel; confirm NHS111 capacity requirements following full service mobilisation; commissioning group established to manage pan-Sussex elements and contractual levers; collaboration across systems to provide a collective response

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Winter plan – next steps

Action required	By When	Status
Winter plan stocktake paper to LAEDBs, LMTs, and F&Ps	May – June 2020	Completed
System development of Winter plan	May – August 2020	Completed
Place based stress testing of initial draft plan	August 2020	Completed
Sussex wide stress testing of revised plan	September 2020	Completed
Review and sign-off final plan	September 2020	In progress at time of writing
NHSE submission	01 October 2020	Not due at time of writing
Monitoring of plans and actuals against planning assumptions	October 2020 – February 2021	Not due
Monthly Winter plan progress report and review at LAEDBs	October 2020 – February 2021	Not due
Detailed operational plan for Christmas and New Year confirmed	November 2020	Not due
Winter lessons learnt stocktake	March 2021	Not due

HEALTH OVERVIEW & SCRUTINY COMMITTEE	Agenda Item 15
	Brighton & Hove City Council

Subject:		**Foundations For Our Future – the final Report from the Sussex Wide Children & Young Person's Emotional Health & Wellbeing Service Review**
Date of Meeting:		**14 October 2020**
Report of:		**CCG Managing Director**
Contact Officer:	**Name:**	**Giles Rossington** **Tel: 01273 295514**
	Email:	**Giles.rossington@brighton-hove.gov.uk**
Ward(s) affected:		**All**

FOR GENERAL RELEASE

1.   PURPOSE OF REPORT AND POLICY CONTEXT

1.1   The Foundations For Our Future (Appendix 1) is the independently authored report from the **Sussex Wide Children & Young Person's Emotional Health & Wellbeing Service Review** which was jointly commissioned by Sussex Clinical Commissioning Groups (CCGs), the three local authorities in Sussex and Sussex Partnership NHS Foundation Trust (SPFT). The Review was independently chaired throughout its duration.

1.2   The review was presented to Brighton & Hove Health & Wellbeing Board (HWB) in July 2020, where the review recommendations was agreed. The review was also reported to BHCC Children, Young People & Skills Committee (CYPS) in September 2020. CYPS will maintain oversight of the local implementation of the review recommendations.

1.3   The review is presented to HOSC for information and to inform HOSC work-streams relating to the emotional health & wellbeing of children and young people.

2.   RECOMMENDATIONS:

2.1   That members note the contents and recommendations of the 'Foundations For Our Future' review of Children & Young People Emotional Health & Wellbeing Services (see **Appendix 1**).

3.   CONTEXT/ BACKGROUND INFORMATION

3.1   Across Sussex, NHS and local authority partners had increasingly become aware that the experience of children and young people, and their families land carers, who needed emotional and wellbeing support required improvement.

3.2   To better understand; the obstacles to access and to treatment; what needed to

improve; and what worked well in the current system, the Sussex Wide Children & Young Person's Emotional Health & Wellbeing Service Review was jointly commissioned by Sussex CCGs, the three local authorities in Sussex and Sussex Partnership NHS Foundation Trust (SPFT). The Review focused on obtaining an in depth understanding of the emotional health and wellbeing services and support on offer to children and young people, aged 0 -18, and their families in Sussex. The Review was established in January 2019 and the final report – **Foundations For Our Future** will be the published document from the review, coming at a time of unprecedented focus on children and young people's mental health both locally and nationally.

3.3 The partners to the Review, requested that it should result in ambitious recommendations for action.

3.4 The Review was conducted to provide an in-depth and up-to-date picture of the services and support available to children and young people and was a listening and analytical exercise aimed at gathering a wide scope of information and feedback, from quantitative data to qualitative insights. The Review was not a formal public consultation and the communications approach developed was designed to support and promote targeted and meaningful stakeholder engagement work, making every effort to be as inclusive and wide-reaching as possible within the timescales and available resources. The scope of the Review was wide, taking a broader view of the services and support available and offered an opportunity to step back and consider not only what is provided currently but also, what might be offered in future and how organisations across Sussex can improve that offer, through working collaboratively or by making changes to their own structures, systems or practices.

3.5 Oversight - A complete list of those local senior leaders providing oversight can be found in the full Report at Appendix 2. The Oversight Group (OSG) was chaired by Adam Doyle, Chief Executive Officer of the Clinical Commissioning Groups in Sussex and the Senior Responsible Officer for the Sussex Health and Care Partnership.

3.6 Review Panel - The OSG was supported by an independently chaired Review Panel (RP) and a review team. The RP included; clinical leaders (both local and regional), commissioners, experts by experience, engagement representatives, the voluntary sector, schools and colleges representatives, Special Educational Needs and Disabilities (SEND) leaders, quality & safety leads and Public Health, all of whom possessed a depth of knowledge of children and young people's experiences and perspectives, as well as issues relating to emotional health and wellbeing and children and young people's mental health. Steve Appleton[1] was commissioned as the independent chair of the RP and is the author of the final report. The RP was accountable to local organisations through the OSG.

3.7 Terms of Reference - The Review process was governed by a Terms of Reference (ToR). The full details are providing in appendix 1 but in summary included engagement levels of service users, effectiveness of pathways, quality and timeliness of services, evidence of outcomes and a range of areas to inform future commissioning.

3.8 Key Lines of Enquiry (KLOE) - The ToR were defined into a concise set of KLOE which enabled the RP to focus and consider a series of questions that informed the final

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[1] http://www.contactconsulting.co.uk/

report and its recommendations. The KLOE can be summarised under the following headings;

- **Access to services**: how easy is it to get a service and what could we do better?
- **Capacity**: how long do people wait to be seen, why is this and what can we do about it?
- **Safety of current services**: how are children kept safe when accessing services?
- **Funding and commissioning**: what are the available resources locally?
- **The experience of children, young people and their families**: what knowledge do our communities have of services and do they think their experiences are being heard?
- **Effectiveness**: do the current pathways deliver the care and support we need?
- **Relationships and partnership**: how well do services work together?

3.9   Over the duration of the Review, more than 40 engagement events were attended and just under 1500 individual voices were heard through online surveys, open space events, visits to services and focus groups. Over 700 people responded to the five online surveys alone, with one in four Sussex GPs responding to their specific survey. This feedback contributed to the findings of the Report and the themes and recommendations that inform implementation.

3.10   The Oversight Group developed a Concordat Agreement as the partnership framework to act upon the recommendations and to implement change across the health and social care system.

3.11   The review has been reported to and its recommendations accepted by Sussex CCGs, Sussex Partnership Trust and Sussex HWBs.

4.   ANALYSIS & CONSIDERATION OF ANY ALTERNATIVE OPTIONS

4.1   Not relevant to this report for information.

5.   COMMUNITY ENGAGEMENT & CONSULTATION

5.1   The review includes information on community engagement.

6.   CONCLUSION

6.1   HOSC members are asked to note this review. Members may wish to draw on this review when developing a HOSC work plan, although CYPS will be the main council committee monitoring the local implementation of the review recommendations.

7.   FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

7.1   Not relevant to this report for information.

Finance Officer Consulted: Name   Date: dd/mm/yy

Legal Implications:

7.2   Not relevant to this report for information.

Lawyer Consulted: Name   Date: dd/mm/yy

Equalities Implications:

7.3   This is addressed in the body of the review (Appendix 1)

Sustainability Implications:

7.4   This is addressed in the body of the review (Appendix 1)

Brexit Implications:

7.5   None identified at this stage.

Any Other Significant Implications:

None identified

SUPPORTING DOCUMENTATION

Appendices:

1.   The Foundations For Our Future Review

Background Documents
None

SUSSEX-WIDE REVIEW OF

EMOTIONAL HEALTH AND WELLBEING SUPPORT

for children and young people

Foundations For Our Future

Report of the Sussex-wide review of Emotional Health and Wellbeing Support for Children and Young People

V5

May 2020

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Independent Chair's Foreword

Foundations For Our Future is the culmination of twelve months' work and marks the conclusion of a thorough process of review of young people's emotional health and wellbeing services that has taken place across Sussex. This review comes at a time of unprecedented focus on children and young people's mental health more broadly, at local level as well as nationally and internationally.

Leaders in the local NHS Clinical Commissioning Groups, the NHS mental health provider Trust and the three local authorities commissioned this review. Collectively, they believed that services and experiences were not as they'd want them to be for young people, their families and carers and therefore, felt that the time was right; to understand, plan for and respond to what could be improved as well as being given ambitious recommendations for action. They provided a strong mandate and were determined that this review should deliver clear findings, however challenging they might be.

In conducting this review, my Review Panel colleagues and I have sought to focus on the issues of most importance to children and young people, their families and carers. We have gathered a wealth of evidence and information, including the views of children and young people, as well as professional opinion and expertise. We have used these to inform our findings and recommendations.

I want to thank all those people who took the time to contribute to the review. Your input was invaluable. We have listened and we have learned – we hope that our report and recommendations resonate with you.

We recognise that this report cannot address all the deficits in relation to emotional health and wellbeing services. However, we believe that the report provides the opportunity for focusing on the immediate priorities as well as longer-term ambitions.

The importance of improving emotional health and wellbeing services for children and young people is undeniable, as more and more of them experience emotional distress and mental health problems. We must make every effort to ensure that children and young people experiencing these difficulties can access the support that gives them the best chance of living happier, healthier lives.

This report provides a foundation for understanding what works well and what we need to do better and the recommendations provide the Sussex Partnership NHS Foundation Trust, the Clinical Commissioning Groups, the three local authorities and the third sector with a plan of how to make improvements that will

benefit children and young people in Sussex. I urge the local partners to act swiftly on the recommendations we have made. That is my challenge to them.

Steve Appleton
Independent Chair

February 2020

Foreword from the Review Panel Members

The most senior leaders in the NHS and in local authorities locally gave us the mandate to engage with Sussex communities and talk with them about their experiences of accessing, receiving and delivering emotional health and wellbeing support to children and young people.

We travelled across Sussex and on that journey, we heard from 1,500 voices who told us about their experiences.

We met with young people leaving care, young mums worried about their own emotional health and the impact on their children: we met with school pupils and college students who told us about their challenges and asked us for ways in which they could support themselves and their friends. We also heard about the specific emotional health and wellbeing issues experienced by children with special educational needs and disabilities, including those with autism.

Across Sussex we saw positive examples of: parenting, caring and family support; resources developed by young people for schools and parents and carers; and multi-agency working in schools and colleges taking universal, preventative and targeted approaches to supporting children and young people's emotional health and wellbeing. We met with grandparents who were supporting their grandchildren because their parents had their own mental health needs. Local services opened their doors to us and talked with us about the challenges and the pressures services faced. When people said 'you really should speak with so and so', we took time to make contact and do that very thing.

We heard difficult stories: from families and children waiting for appointments, from children and young people uncertain of where to turn, from GPs frustrated by their experience of trying to help, from school and college staff stretching their resources to meet their students' needs and from front line staff and managers trying to deliver the best care possible.

We were humbled and heartened by people's willingness to meet with us and tell their stories so readily and who invested their time and energy in doing so. We have strived to ensure that this report reflects those stories loudly and clearly.

Without exception, everyone we met showed a passion, a fierce commitment and a will to improve help and support for emotional health and wellbeing for the county's children and young people and their families and carers.
We have brought those voices together through this report and enabled people to tell their own story.

Alongside this narrative from our communities, we have gathered data and reviewed all of the current local strategies and plans for children and young people's emotional health and wellbeing. We saw many examples of good

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practice on our road trip and we have captured them here to help inform the narrative. This huge wealth of information has informed the report and supports the recommendations we have made.

The senior leaders challenged us to be bold in our recommendations; and we hope we have met that challenge by providing the foundations for change in this report.

Review Panel Members

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A response to the review from the Chair of the Oversight Group

When the partner organisations that commissioned this review set out on the journey over a year ago, we had already recognised that we needed to improve our emotional health and wellbeing services for children and young people in Sussex.

We knew that we needed to hear the voices of children; young people and their families and carers to better understand their experience of current services and to listen to the improvements they wanted us to make, so that we could act upon them. This united desire and ambition for our population about the improvements we will achieve, sits at the heart of this review process.

This review has been far-reaching and we have listened to the voices of hundreds of children, young people, their parents and carers as well as the views of professionals working in healthcare, social care and education. I thank all of those people for taking the time to tell us about their experiences of what works well here in Sussex, what needs to improve and how we might work together to achieve these changes.

Of the many things we heard, one of the most important for me is that the needs of children, young people and their families and carers must be at the centre of emotional health and wellbeing interventions and services that are responsive and that focus on building resilience. I, along with my partners in this review, am committed to doing everything feasible and possible to nurture the potential of our children and young people, especially those most vulnerable.

As Chair of the Oversight Group, responsible for the governance of this review process, I would like to take this opportunity to acknowledge and thank both Steve Appleton as the Independent Chair of the Review and the Review Panel members for all their hard work in bringing those voices together with a range of other evidence to underpin the findings in this report.

I am pleased that the review has identified the dedicated and hard work of people working in services to support children and young peoples' emotional health and wellbeing, together with examples of good practice taking place in Sussex. That does not however detract from the more difficult messages that there is much work to be done to improve the experiences and outcomes of children, young people and their families. On that basis, the partners to this review welcome its findings and recommendations and we are committed to driving those recommendations through to implementation.

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Adam Doyle

Chief Executive Officer of the Clinical Commissioning Groups in Sussex and the Senior Responsible Officer for the Sussex Health and Care Partnership

Chair of the Oversight Group, Sussex-wide Children & Young Persons' Emotional Health & Wellbeing Services Review

Samantha Allen
Chief Executive Officer
Sussex Partnership NHS
Foundation Trust

Karen Breen
Deputy Chief Executive Officer and Chief Operating Officer
Sussex Clinical Commissioning Groups

AnnMarie Dodds
Director of Children's Services
West Sussex County Council

Stuart Gallimore
Director of Children's Services
East Sussex County Council

Pinaki Ghoshal
Director of Children's Services
Brighton & Hove City Council

Building the Foundations: A concordat for action

As the partners that commissioned the review of children and young peoples' emotional health and wellbeing services in Sussex, we accept the challenge that the report has set out for us, both in its findings and its recommendations.

We are determined that the recommendations are translated into demonstrable actions, so that children, young people and their families reap the benefits of the work we now commit to undertake.

To ensure that all the partners play their part, we have developed this concordat for action. It means that the Clinical Commissioning Groups, Brighton & Hove City Council, East Sussex County Council, West Sussex County Council and Sussex Partnership NHS Foundation Trust are all equally committed to working together in a collaborative way to deliver the actions needed.

This is a significant statement of commitment to a common purpose that has been shared, agreed and signed by the senior leaders of each of the partnership organisations that commissioned the review.

The following statements describe that nature of that commitment:

We accept the recommendations and will work together in partnership to implement them. In doing so, we are collectively committed to the improvement of services to support the children and young people who experience poor emotional health and wellbeing in Sussex.

We will develop a clear and prioritised action plan to implement the recommendations. It will contain agreed timescales for the achievement of each of the recommendations and we will work together to regularly monitor our progress and hold each other to account for delivery. We will also ensure independent review of our progress over the period of implementation.

As senior leaders, we will set the standard in the way we work together. We will do so honestly and transparently and we will ensure effective collaboration at all levels of our respective organisations. We will actively support those working to deliver each of the recommendations and practically assist them to overcome any obstacles to achieving them.

We will work closely and constructively with our communities and our other partners in Sussex in the delivery of the recommendations. In particular, we will call upon our colleagues in the voluntary and third sector to commit to work with us and support us, on this journey of improvement.

We will give a strong voice to children, young people and their families. We will listen to them and continue to draw upon their experiences to guide our work to ensure a co-productive approach to improvement.

By signing this concordat, we as leaders are committing ourselves and our organisations to this work, to do it collaboratively and to improve the emotional health and wellbeing of children and young people in Sussex.

Signed:

Samantha Allen
Chief Executive Officer
Sussex Partnership NHS
Foundation Trust

Adam Doyle
Chief Executive Officer of the
Clinical Commissioning Groups in
Sussex and the Senior
Responsible Officer for the Sussex
Health and Care Partnership

Geoff Raw
Chief Executive
Brighton & Hove City Council

Becky Shaw
Chief Executive, East and West
Sussex County Councils

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Executive summary

The Sussex Clinical Commissioning Groups, Sussex Partnership NHS Foundation Trust and the three local authorities in Sussex commissioned this review because they were aware that the experience of children and young people, their families and carers who need emotional and wellbeing support requires improvement.

During the review, we heard the views of children, young people and their families. We also heard from professionals working across Sussex. We conducted a wide-ranging engagement process, including service visits, focus groups, listening events and online surveys and heard from 1,500 people. We also gathered and analysed data and information about current services, quality, performance and financial investment.

What you read in this report is what we heard about people's experiences, their expectations and their own ideas about some of the potential solutions that could bring about improvement. We have drawn upon the things we heard along with the other evidence we reviewed to inform our findings and recommendations.

We considered the following key areas:

- Access to services: how easy is it to get a service and what could we do better?
- Capacity: how long do people wait to be seen, why is this and what can we do about it?
- Safety of current services: how are children kept safe when accessing services?
- Funding and commissioning: what are the available resources locally?
- The experience of children, young people and their families: what knowledge do our communities have of services, and do they think their experiences are being heard?
- Effectiveness: do the current pathways deliver the care and support we need?
- Relationships and partnership – how well do services work together?

By scrutinising these areas, we have identified a number of key themes and findings:

- The response to the challenges and recommendations set out in this report require a whole system response. This means that the partner organisations must work together closely in a spirit of openness, constructive challenge and positive ambition to deliver the changes needed.
- Access to services can be difficult and the current pattern of provision is complex and hard to navigate, with many different providers. There is a lack

of knowledge about the wider range of emotional health and wellbeing services in Sussex and an over reliance on referral to specialist mental health services, leading to higher demand.

- The range and development of upstream services and supports, through public and population health approaches, promotion, prevention and universal services, along with early help need to be expanded further to create a more effective pathway. Opportunities for open access to help and support, need to be created as part of the development of a new model of provision.

- Referral criteria and thresholds (entry standards) for services are not well articulated and are not clear to either professionals or the public. Sometimes, services appear to work in isolation from one another and are not joined up.

- Children and young people often experience waits for assessment and the provision of services. This is the case in both statutory and third sector services. In specialist mental health services, waiting times for assessment have doubled in the last two years and although waiting times for treatment are falling, there is more to be done to improve access and response.

- In common with many other parts of the South East, Sussex faces a workforce challenge, both in recruitment and in retention, but also in the professional and skill mix.

- Distribution of current levels of investment does not take account of the levels of need across Sussex. Additionally, the level of investment made in children and young people's emotional health and wellbeing from local authorities does not have sufficient clarity. There are known reasons for this, but a clearer understanding of the level of investment made is required. Making planned investment in prevention, promotion, self-care and resilience, and schools based support as well as specialist services will, if done over time, achieve more balance and a model that is preventative and enables early intervention.

- There needs to be a better understanding of the range of services and interventions that should be available across the pathway and the levels of investment needed to be sustainable. As part of a process to achieve the change, a system wide approach is needed to review what is needed, accompanied by a rapid process of specialist services modernisation.

- We saw no direct evidence during the review to demonstrate that specialist or other services are not safe. However, the data in Sussex shows that the number of children and young people admitted to hospital due to self-harm is higher than both the region and England average. We cannot evidence whether what we have seen and heard has directly contributed to this

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position, but there is a need to positively address, monitor and respond to the current trends.

- Commissioning of services is not consistent across Sussex and suffers from a lack of co-ordinated leadership, capability and capacity. Existing organisational structures mean that it has been hard to establish clear lines of responsibility. This has also hampered the connectivity between emotional health and wellbeing and the physical health needs of children and young people. There is no over-arching strategic vision for emotional health and wellbeing services or description of the need to integrate physical health and emotional health services across Sussex. There is a need for clear leadership and capability to drive transformation and integration.

- Commissioning is not outcomes led and at present, it is difficult to determine the range of delivery outcomes, both positive and negative in relation to children and young people's emotional health and wellbeing.

- Schools and colleges do have, and should continue to have, a central role in relation to children and young people's emotional health and wellbeing. However, at present, they are not uniformly equipped to do this, nor is it clear that they are sufficiently resourced. School leaders clearly see and understand the issues relating to emotional health and wellbeing. They want to respond to it, and to do so with urgency. They agree it is part of what they should do. What they need is the help, resources and support to do it in the best way possible.

- The opportunities to engage children, young people and their families and carers and draw on their experiences and views have not yet brought about change they seek. The voice of children and young people is not being heard or used as effectively as it could be. The mechanisms for engaging them in a meaningful process of listening and responding, has not yet been demonstrated or featured in co-design and co-development.

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The current pathway and service model for emotional health and wellbeing in Sussex does not appear to be effective and would benefit from radical transformation. This is the case for the whole pathway, from upstream services, prevention, promotion and early help as well as in relation to specialist mental health services. The findings and recommendations of this review provide an opportunity to do this.

Our 20 recommendations pay particular attention on how best to address these findings. They focus on the following key actions:

- Radical redesign of the service model with a particular focus on creating a more effective pathway, improving access and achieving better outcomes
- Ensuring focussed investment on priorities and outcomes demonstrated across the provider pathway. Where the investment is largest, the challenge will be bigger
- Establishing more effective partnership working across Sussex both in commissioning and in the provision of services
- Hearing and responding to the voice of children and young people and ensuring improved co-production and co-design
- Ensuring that commissioning is more co-ordinated, strategic and has the capacity, capability and leadership to drive improvement
- Developing a strategic outcomes framework that enables a full and accurate understanding of the return on investment
- Simplifying the map of provision so that children, young people and their families can find help more easily and more quickly
- Making sure that levels of investment reflect local need
- Improving accuracy and availability of data
- Addressing the workforce challenge.

This review and its recommendations provide the opportunity for the partners to focus on the improvements and changes that are needed. We believe that the report lays the foundations for the future, a future in which the emotional health and wellbeing needs of children and young people in Sussex are responded to more effectively.

We would like to acknowledge the commitment of all those who took part in the review, and who are involved in delivering and improving services. The review would not have been possible without the time, expertise and knowledge of the partner organisations and their staff, children, young people and their families.

Introduction

In conducting this review, the Review Panel has taken account of the current picture in relation to the emotional health and wellbeing of children and young people, the issue of mental health problems and the policy context that addresses the challenge of responding to the needs of those children and young people.

For the purposes of this review, we offer the following definition of what is meant by emotional health and wellbeing or good mental health. Positive mental health or good mental health is the state of wellbeing. Mental ill health is therefore the absence of emotional and or mental wellbeing. A useful definition of emotional wellbeing is offered by the Mental Health Foundation as: 'A positive sense of wellbeing enables an individual to be able to function in society and meet the demands of everyday life; people in good mental health have the ability to recover effectively from illness, change or misfortune.'[1]

The World Health Organisation (WHO) describes emotional health and wellbeing as 'the state of being in which every individual realises his or her own potential, can cope with the normal stresses of life, can live, work or study productively and fruitfully, and is able to make a contribution to her or his community'[2].

In the absence of a single, defined view, we believe that these two observations, when taken together, provide a useful and workable description of emotional health and wellbeing.

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[1] Mental Health Foundation quoted by Imperial College Healthcare
http://www.imperialhealthatwork.co.uk/services/wellbeing/mental-emotional-wellbeing
[2] WHO in Being Mindful of mental health Local Government Association June 2017
https://www.local.gov.uk/sites/default/files/documents/22.6_Being%20mindful%20of%20mental%20health_08_revised_web.pdf

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The context

In 2015, the coalition government published Future in Mind[3], a report of the work of the Children and Young People's Mental Health Taskforce. Future in Mind outlines a series of aims for transforming the design and delivery of the mental health offer for children and young people in any locality. It describes a step change in how care is delivered, moving away from a system defined in terms of the services organisations provide (the tiered model) towards one built around the needs of children, young people and their families, to ensure they have easy access to the right support from the right service at the right time. It described a five-year ambition to create a system that brought together the potential of the NHS, schools, social care the third sector, the internet, parents and of course children and young people, to improve mental health, wellbeing and service provision.

As the end of that five-year period approaches, this Sussex-wide review has taken into account the work that Future in Mind has stimulated, together with more recent policy development including the Five Year Forward View for Mental Health (FYFVMH)[4] and the NHS Long Term Plan[5]. However, there remains more to do.

We know that nationally, 70% of children and young people who experience a mental health problem have not had appropriate support at an early enough age.[6] Reporting of emotional and wellbeing problems has become increasingly common. Between 2004 and 2017, the percentage of five to 15 year olds who reported experiencing such problems grew from 3.9% to 5.8%.[7]

In the UK, 5% of children aged five to 15 reported being relatively unhappy. Wellbeing has been shown to decline as children and young people get older, particularly through adolescence, with girls more likely to report a reduced feeling of wellbeing than boys do. As a group, 13-15 year olds report lower life satisfaction than those who are younger.[8]

Children from low-income families are four times more likely to experience mental health problems compared to children from higher-income families.[9] Among LGBTQ+[10] young people, seven out of 10 girls and six out of 10 boys describe experiencing suicidal thoughts. These children and young people are around three times as likely as others to have made a suicide attempt.[11]

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[3] Future in Mind, Promoting, protecting and improving our children and young people's mental health and wellbeing, NHSE 2015

[4] Five Year Forward View for Mental Health, NHSE Taskforce, 2016

[5] NHSE, 2019

[6] Children and Young People Mental Health Foundation accessed December 2019 https://www.mentalhealth.org.uk/a-to-z/c/children-and-young-people

[7] Mental health of children and young people in England 2018

[8] State of the Nation 2019: Children and Young People's Wellbeing Department for Education October 2019

[9] Children and young people's mental health: The facts Centre for Mental Health 2018

[10] LGBTQ+ is used to represent those people who are lesbian, gay, bisexual, transgender, questioning and "plus," which represents other sexual identities including pansexual, asexual and omnisexual

[11] Children and young people's mental health: The facts Centre for Mental Health 2018

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In 2017, one in eight young people aged between five and 19 in England had a mental health disorder[12]. The World Health Organisation (WHO) describes mental health disorders as comprising a broad range of problems, with different symptoms. However, they are generally characterised by some combination of abnormal thoughts, emotions, behaviour and relationships with others. They can include depression, anxiety disorders and psychosis.[13]

In pre-school children (those under the age of five), the national prevalence of mental health disorders is one in 18, with boys 50% more likely to have a disorder than girls.[14] Of the more than 11,000 14-year-olds surveyed in the Millennium Cohort Study in 2018, 16% reported they had self-harmed in 2017/18.[15] Based on these figures, it is suggested that nearly 110,000 children aged 14 may have self-harmed across the UK in the same 12-month period.[16] Young women in this age group were three times more likely to self-harm than young men.[17] An estimated 200 children a year lose their lives through completed suicide in the UK.[18]

It is estimated that one in ten children and young people have a diagnosable mental disorder, the equivalent of three pupils in every classroom across the country.[19]

In England, the demand for specialist child and adolescent mental health services (SPFT specialist services) is rising, with record levels of referrals being reported.[20] Demand continues to exceed supply with increasing numbers of young people on waiting lists to access SPFT specialist services and waiting times longer than previous years.[21]

The emotional health and wellbeing of children and young people is crucial, it is as important as their physical health. It is accepted that until recently, there has been insufficient focus on this area of children and young people's development. However, the past few years have brought a renewed and much needed focus both in terms of policy and in terms of development.

Building on previous policy, the Five Year Forward View for Mental Health (in England)[22] and the NHS Long Term Plan now sets out a commitment that funding for children and young people's mental health services will grow faster

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[12] Mental health of children and young people in England, ONS
https://files.digital.nhs.uk/A6/EA7D58/MHCYP%202017%20Summary.pdf
[13] World Health Organisation definition https://www.who.int/mental_health/management/en/
[14] Mental health of children and young people in England, 2018
[15] Millennium Cohort Study https://cls.ucl.ac.uk/cls-studies/millennium-cohort-study/
[16] The Good Childhood Report Children's Society, 2018
[17] Brooks et al 2015 in Children and young people's mental health: The facts, Centre for Mental Health, 2018
18 Burton, M. Practice Nursing Vol. 30, No. 5
[19] Supporting mental health in schools and colleges Department for Education/NatCEN Social Research and National Children's Bureau, August 2017
[20] Children's mental health services: the data behind the headlines Centre for Mental Health October 2019
[21] CAMHS benchmarking findings NHS Benchmarking Network, October 2019
[22] NHSE, 2016

than both overall NHS funding and total mental health spending. This means that children and young people's mental health services will for the first time grow as a proportion of all mental health services, which will themselves also be growing faster than the NHS overall. Over the next five years, the NHS will continue to invest in expanding access to community-based mental health services to meet the needs of more children and young people.

This investment and the expansion of NHS services is to be welcomed but it should not detract from the low base from which these developments start. Even with these improvements, the increase in access to specialist mental health services only aims to ensure that nationally, at least 34% of children and young people with a diagnosable mental health condition should receive treatment from an NHS-funded community mental health service in 2019/20 and 35% by end of 2020/21[23].

The developments described in the NHS Long Term Plan focus on the specialist mental health needs of children and young people. They do not comment on wider emotional health and wellbeing needs. Nor do they seek to address the ways in which support can be provided that can help to prevent the development of poor emotional health and wellbeing, either with children and young people directly, or through support provided by schools, colleges and the voluntary sector, or the supports needed by parents and carers. That blueprint for a local offer for children and young people with emotional health and wellbeing support needs, is detailed in Future in Mind and responds to the systemic challenges that any locality will face in embedding this. Furthermore, the NHS Mental Health Implementation Plan 2019/20 – 2023/24[24] commits us to ensuring that children and young people's mental health plans align with those for children and young people with learning disability, autism, special educational needs and disability (SEND), children and young people's services, and health and justice by 2023/24.

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[23] NHS mental health dashboard https://www.england.nhs.uk/mental-health/taskforce/imp/mh-dashboard/
[24] NHSE, 2019

We know that half of all mental ill health starts by the age of 15 and 75% by the age of 18.[25] Effective early intervention is known to work in preventing problems occurring, or to address them directly when they do, before problems get worse. It also helps to foster a wide set of personal strengths and skills that prepare a child for adult life.[26] It can reduce the risk factors and increase the protective factors in a child's life. This is one example of the benefits of a broader approach that is less firmly rooted in more traditional models of support and that addresses not only mental ill health but which also focuses more on emotional health and wellbeing.

The challenge is clear. Improving emotional health and wellbeing is vital to ensuring happy, healthy, thriving children and young people. It is in this context that this review has been undertaken.

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25 Department of Health, Department for Children S and F. Healthy lives, brighter futures 2009 http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/285374a.pdf and Davies SC. Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence 2014.
26 Early Intervention Foundation https://www.eif.org.uk/why-it-matters/what-is-early-intervention

Section One

The Review Process, Approach and Governance

Why this review has been undertaken

Across Sussex, NHS and local authority partners have increasingly become aware that the experience of children and young people, their families and carers who need emotional and wellbeing support requires improvement.

As is the case across the country, our local services continue to experience significant demand, for example, across the UK, there were 3,658 referrals received per 100,000 population (age 0-18) in 2018/19. This was the highest level of demand ever reported over the eight years that the NHS Benchmarking Network has collected data. Locally, Sussex Partnership NHS Foundation Trust (SPFT) received 3,359 referrals per 100,000 population in 2018/19.

Those working in health, social care, education and the third sector across Sussex work hard to try to ensure that children, young people and their families get the help they need. However, the experience of those children, young people and their families has been variable, with too many of them saying that the current system has not been working as well as it should, and has not responded to them as quickly as they would like or that they have not been offered the choices they felt they needed.

Experiencing poor emotional health and wellbeing or mental health problems is distressing enough but this is further compounded when the help needed cannot be accessed easily. This is something that NHS and local authority partners collectively agreed needed to change.

It is on that basis that the Sussex Clinical Commissioning Groups (CCGs), the three local authorities (East Sussex and West Sussex County Councils and Brighton & Hove City Council) and SPFT agreed that an independently chaired review should be undertaken.

The scope of the review

The scope of the review has been wide, and most importantly, although including specialist mental health services it has taken a broader view of the services and support available. It has not been a review of SPFT specialist services or any other services specifically, neither has it been a consultation exercise. It has been an opportunity to take a step back and consider not only what is offered currently, but also what can be offered in future and how organisations across Sussex can improve that offer through working collaboratively or by making changes to their own structures, systems or practices.

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The review focused on children and young people from the age of 0-18 and those in transition to adulthood who require emotional health and wellbeing support. Other service areas such as learning disabilities, Special Educational Needs and Disabilities (SEND) and community paediatrics (physical health) were included as part of the review.

The review took into account, and learnt from local, regional and national best practice.

Governance of the review

The Review Panel was independently chaired, and was supported by a project team who assisted in evidence gathering, logistics and support. The Independent Chair, on behalf of the Review Panel, reported to an Oversight Group. The Chief Executive Officer of the CCGs in Sussex and the Senior Responsible Officer for the Sussex Health and Care Partnership chaired the Oversight Group.

The Review Panel

The Review Panel was composed of a diverse range of people, all of whom possessed a depth of knowledge of children and young people's experiences and perspectives, as well as issues relating to emotional health and wellbeing and children and young people's mental health.

Detailed work was undertaken to form the Review Panel. This involved a process of seeking expressions of interest, then, matching the skills and expertise of those putting themselves forward against a range of agreed criteria agreed by the Independent Chair and the project lead.

The panel composition is set out below to demonstrate the breadth of representation.

- Two commissioners, one from a CCG and one who has dual responsibility across a CCG and a local authority
- The Clinical Director for children and young people's services from SPFT
- The Director of a third sector provider organisation
- Two Public Health consultants (one left the panel in August 2019 and another joined)
- A parent/carer expert by experience
- A children and young people's representative, who also had a focus on engagement
- A local authority Equality and Participation Manager
- A local authority Assistant Director of Health and Special Educational Needs and Disability

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- The Clinical Lead for the South East Clinical Network (on the panel until August 2019
- A local authority Head of Targeted Youth Support and Youth Justice
- A General Practitioner who is also a CCG Chief of Clinical Quality and Performance
- Three head teachers from schools and academies and one assistant Principal of a sixth form college.

The full list of Review Panel members with their names and titles can be found at Appendix One.

The Oversight Group

An Oversight Group, made up of local health and care leaders who commissioned the review, supported the Review Panel, making sure, it conducted its work in a robust and inclusive way and was on track to deliver a report with clear recommendations.

More detail about the Oversight Group, its membership and role can be found at Appendix Two.

Terms of Reference

The commissioning partners in the NHS and the three local authorities set the Terms of Reference (ToR) for the review. These were subsequently discussed and agreed by the Review Panel and approved by the Oversight Group. They set out a series of questions that the Review Panel was mandated to consider as part of the review.

The full Terms of Reference can be found in Appendix Three.

The Key Lines of Enquiry

Given the scope of the review and the breadth of the Terms of Reference, Key Lines of Enquiry (KLOE) were developed with the aim of providing particular focus on specific issues that could help to address the Terms of Reference, respond to the scope of the review and assist in focusing the evidence gathering and the eventual findings.

The KLOE were agreed by the Review Panel and endorsed by the Oversight Group and included, in summary:

- Access to services: how easy is it to get a service and what could we do better?

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- Capacity: how long do people wait to be seen, why is this and what can we do about it?
- Safety of current services: how are children kept safe when accessing services?
- Funding and commissioning: what are the available resources locally?
- The experience of children, young people and their families: what knowledge do our communities have of services, and do they think their experiences are being heard?
- Effectiveness – do the current pathways deliver the care and support we need?
- Relationships and partnership – how well do services work together?

The full detail of the KLOE and details of the areas examined under each heading can be found at Appendix Four.

How the review has been conducted

The review was conducted using a mixed methodology approach using both qualitative and quantitative evidence gathering. This included:

- A desk-based service mapping exercise to establish, as far as was possible, the number and type of emotional health and wellbeing services provided in Sussex and which organisations delivered those.

- A desk-based information gathering process that sought data relating to current demand, performance and quality. Financial information on budgets and spending was also sought. The Review Panel commissioned the NHS Benchmarking Network (NHSBN) to help gather and then analyse this information. NHSBN produced a report for the Review Panel, which has been used to inform our findings and recommendations. Summary data and evidence from the NHSBN report is included in this report. The full NHSBN report is available as a companion piece to this report.

- A review of published literature and grey literature (grey literature is research that is either unpublished or has been published in non-commercial form), research evidence, current national policy and local plans and strategies relating to children and young people's emotional health and wellbeing and mental health.

A key part of the review was the delivery of a wide-ranging engagement process that gathered and described the experiences of children, young people, their parents and carers. The process had six components:

- Five listening events, held across Sussex, using the Open Space model. Open Space is a technique for engaging with the community where

participants create and manage the agenda and discussion themselves. This method has the central aim of ensuring that participants decide the areas of discussion that are important to them and then come up with potential solutions. These meetings stimulated discussions with members of the public and with local professionals about their experiences of emotional health and wellbeing services and support for children and young people; what works well, where there may be gaps in the system, and where and how improvements could be made.

- A series of focus groups, held across Sussex, to discuss a range of issues in more detail. These focus groups included parent and carer representatives as well as professionals working in the NHS, local authorities and the third sector.

- A series of visits to services in Sussex. These visits were designed to provide insights into the locations and environments where services are provided and hear directly from those working in the sector.

- Direct engagement events where Review Panel members undertook face-to-face meetings and event attendance with a number of different organisations, groups and networks.

- The development, publishing and analysis of a series of online surveys, each focused on a specific group including children and young people, their parents and carers, schools and General Practitioners (GPs).

- Direct feedback was also invited from members of the public, children and young people and professionals. This was submitted in a number of ways, usually from individuals, through a dedicated email address, online or by letter. Organisations, including Healthwatch and those in the third sector also provided feedback and evidence in the form of structured reports that were considered during the review.

Section Two

Population and epidemiology

Sussex is in the South East region of England and consists of three local authorities: West Sussex, East Sussex and Brighton & Hove. At the time of writing, there are seven NHS Clinical Commissioning Groups in Sussex. The main provider of specialist mental health services for children and young people for the NHS is Sussex Partnership NHS Trust (SPFT), which covers the three local authority areas. This data profile of Sussex is in two parts, the first focussing upon population, whilst the second section looks at issues related to health and wellbeing.

The population data used within this profile has been sourced from the Fingertips Public Health profiles website (https://fingertips.phe.org.uk/) and is based on figures from 2018. We have looked at each of the three local authority areas individually before drawing this together to show the picture for Sussex as a whole.

The population figures here are for the resident population. The review notes that there are a number of colleges and universities in Sussex, attracting a significant student population who may temporarily reside in Sussex. Subsequent work may need to be undertaken to look at the numbers within the student population as could add to the demands upon any services within the area.

West Sussex

In terms of population, West Sussex is the largest of the three local authority areas within Sussex with a total population (aged 0-90+) of 858,852. There are seven districts within the local authority, Adur, Arun, Chichester, Crawley, Horsham, Mid Sussex and Worthing. For the purpose of this profile, the focus is on the population of children and young people. The data sets we have used look at the age range of 0 - 19 years of age. Table One sets out the numbers of children and young people in West Sussex in five-year age cohorts and sets this against the total population to identify what percentage of the population they form.

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Table One: West Sussex population data (2018)

Age	Males	Females	Total	% of total Population
0-4 years	24,060	22,761	46,821	5.45
5-9 years	27,052	25,120	52,172	6.07
10-14 years	25,211	23,593	48,804	5.68
15-19 years	22,535	20,984	43,519	5.06
Total 0-19 years	**98,858**	**92,458**	**191,316**	**22.27**

Source:
https://fingertips.phe.org.uk/profile/healthprofiles/data#page/12/gid/3007000/pat/6/par/E12000008/ati/202/are/E10000032

Whilst West Sussex has the highest percentage of 0-19 years in relation to its overall population at 22.27%, (when compared to East Sussex and to Brighton & Hove), this is just below the national position for England where the proportion of the population between the ages of 0-19 years of age is 23.65%.

In each of the five-year age cohorts, the percentage of the total population is slightly below the national picture. Those aged 5 - 9 years of age account for the largest proportion at 6.07% or 52,172 children and young people.

There are a total of 191,316 children and young people aged between 0-19 years of age within the West Sussex local authority area. 98,858 of those are male whilst 92,458 are female.

East Sussex

East Sussex has five districts, Eastbourne, Hastings, Lewes, Rother and Wealden and a total population for all ages in the local authority of 554,590. Children and young people aged 0–19 years of age make up 21.19% or 117,559 of this overall population, which like West Sussex, is below that of the national picture.

As with West Sussex, East Sussex shows the largest proportion of children and young people to be found in the 5-9 years of age cohort. This accounts for 31,167 people or 5.61% of the population. Full details for East Sussex can be seen in Table Two.

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Table Two: East Sussex population data (2018)

Age	Males	Females	Total	% of total Population
0-4 years	13,921	13,185	27,106	4.88
5-9 years	16,146	15,021	31,167	5.61
10-14 years	15,836	14,645	30,481	5.49
15-19 years	14,837	13,968	28,805	5.19
Total 0-19 years	60,740	56,819	117,559	21.19

Source:
https://fingertips.phe.org.uk/profile/healthprofiles/data#page/12/gid/3007000/pat/6/par/E12000008/ati/202/are/E10000011

Brighton & Hove

Brighton & Hove is a unitary authority.

Table Three sets out the resident population for Brighton & Hove, which accounts for the smallest numbers compared to the other two local authority areas in Sussex. The total population within Brighton & Hove is 290,395 aged 0 - 90+ years of age. The total number of children and young people in Brighton & Hove aged 0-19 is 60,427. This equates to 20.80% of the total population.

When looking at the age cohorts individually the 15 - 19 year olds have the largest percentage of the total population at 6.11% or 17,765 people. This percentage is larger than the other two local authority areas and is also higher than the national picture for this age cohort, which stands at 5.53%. Table Three shows the full detail for Brighton & Hove.

Table Three: Brighton & Hove population data (2018)

Age	Males	Females	Total	% of total Population
0-4 years	7,047	6,694	13,741	4.73%
5-9 years	7,457	7,256	14,713	5.06%
10-14 years	7,314	6,894	14,208	4.89%
15-19 years	8,694	9,071	17,765	6.11%
Total 0-19 years	30,512	29,915	60,427	20.80%

Source:
https://fingertips.phe.org.uk/profile/healthprofiles/data#page/12/gid/3007000/pat/6/par/E12000008/ati/202/are/E06000043

Table Four of the population data shows the three local authorities of Sussex combined to give an overall picture. The total population in Sussex is 1,703,837. Within this overall population, females represent just over 51% of the population yet when looking at children and young people specifically males represent the larger proportion at nearly 52%.

Those aged 0-19 years of age represent 21.67% of the total population, which is slightly below the national picture. With 98,052 children and young people aged 5-9 years, this cohort is the largest percentage of the total population represented in Table 4 at 5.75%.

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Table Four: Combined Sussex population data (2018)

Age	Males	Females	Total	% of total Population
0-4 years	45,028	42,640	87,668	5.14
5-9 years	50,655	47,397	98,052	5.75
10-14 years	48,361	45,132	93,493	5.48
15-19 years	46,066	44,023	90,089	5.28
Total 0-19 years	**190,110**	**179,192**	**369,302**	**21.67**

The proportion of children and young people aged 0-19 and the sub-grouping of ages varies between the three local authority areas.

The following tables (tables five to eight) set out the current and forecast in growth or shrinkage in the 0-19 population. The caveat to these forecasts is twofold. Firstly, the projections are from the 2016-based sub-national population projections compiled by the Office for National Statistics (ONS). Their base figures for 2018 vary slightly from those in the Public Health England (PHE) Fingertips data, but not significantly. Secondly, they are predictions, and as such, there may be some variance in the actual percentage change in due course. It is important to understand these population projections for future investment discussions.

Table Five: West Sussex 0-19 population current and forecast (2018)

	2018	2019	2020	2025	2030	% Increase to 2035
0-4 years	46,900	46,800	46,600	46,400	46,000	-2%
5-9 years	52,100	52,200	52,100	50,500	50,200	-3%
10-14 years	48,900	50,300	51,900	54,400	52,700	8%
15-19 years	43,700	43,800	44,100	50,900	53,000	21%
Total 0-19 years	191,600	193,100	194,700	202,200	201,900	5%
0-19 years as % of total population	22.2%	22.2%	22.2%	22.2%	21.5%	

Table Six: East Sussex 0-19 population current and forecast (2018)

	2018	2019	2020	2025	2030	% Increase to 2035
0-4 years	27,500	27,500	27,500	27,600	27,500	0%
5-9 years	31,500	31,500	31,400	30,400	30,500	-3%
10-14 years	30,700	31,400	32,200	33,500	32,400	5%
15-19 years	28,800	28,700	28,800	32,400	33,500	16%
Total 0-19 years	118,500	119,100	119,900	123,900	123,900	4%
0-19 years as % of total population	21.2%	21.1%	21.1%	21.0%	20.2%	

Table Seven: Brighton & Hove 0-19 population current and forecast (2018)

	2018	2019	2020	2025	2030	% Increase to 2035
0-4 years	14,400	14,500	14,500	14,800	15,000	4%
5-9 years	14,800	14,600	14,500	14,000	14,300	-3%
10-14 years	14,200	14,400	14,700	14,700	14,200	0%
15-19 years	17,300	17,200	17,200	18,800	19,300	11%
Total 0-19 years	60,700	60,700	60,900	62,300	62,800	3%
0-19 years as % of total population	20.8%	20.6%	20.6%	20.5%	20.1%	

Table Eight shows the combined position across Sussex. The same caveats apply to the combined numbers and proportions as to those for each of the three local areas on their own. Notably, the combined picture shows that the proportion of 0-4 year olds and 5-9 years olds is forecast to decline over the next 10-15 years, albeit by a very small amount.

All other age groups are predicted to grow, with the 15-19 age group showing the largest increase, 18% over the next 10-15 years. The total population of 0–19 year olds across Sussex is forecast to increase by 8% by 2035.

Table Eight: Combined 0-19 age group forecast (2018)

	2018	2019	2020	2025	2030	% Increase to 2035
0-4 years	88,800	88,800	88,600	88,800	88,500	-1%
5-9 years	97,800	98,300	98,000	94,900	95,000	-3%
10-14 years	93,800	96,100	98,800	102,600	99,300	6%
15-19 years	89,800	89,700	90,100	102,100	105,800	18%
Total 0-19 years	370,200	372,900	375,500	388,400	388,600	5%
0-19 years as % of total population	21.6%	21.6%	21.6%	21.5%	20.9%	

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Health and Wellbeing

This section of the profile focuses upon specific areas of health and wellbeing within children and young people of Sussex. Data in these areas is limited in its scope and depth, and therefore offers only a limited but nonetheless helpful view of key nationally determined metrics.

Table Nine: Mental Health and Wellbeing in Sussex

	West Sussex	East Sussex	Brighton & Hove	England
Estimated prevalence of mental health disorders in children and young people - % of the population aged 5-16 years (2015)	8.4	8.8	8.4	9.2
Estimated prevalence of emotional disorders - % of the population aged 5-16 years (2015)	3.2	3.4	3.3	3.6
Estimated prevalence of conduct disorders - % of the population aged 5-16 years (2015)	4.7	5.3	5.0	5.6
Estimated prevalence of hyperkinetic disorders - % of the population aged 5-16 years (2015)	1.3	1.4	1.3	1.5
Prevalence of potential eating disorders among young people. Estimated number aged 16-24 years of age (2013)	10,038	7,069	6,185	Not recorded
Hospital admission as a result of self-harm in those aged 10-24 years per 100,000 (2017/2018)	535.9	527.4	548.6	421.2
Hospital admission as a result of self-harm in those aged 10-14 years per 100,000 (2017/2018)	205.6	298.8	231.7	210.4
Hospital admission as a result of self-harm in those aged 15-19 years per 100,000 (2017/2018)	795.2	774.5	926.8	648.6

Source: Fingertips Public Health Profile (Public Health England) data combined and presented by Contact Consulting (Oxford) Limited

Table Nine above presents data on a range of issues in relation to mental health and emotional wellbeing. It is taken directly from the national Fingertips website.[27] With regard to the mental health issues in the first four lines of the table, Sussex is just below the position for England as a whole, with East Sussex having the higher levels of prevalence within Sussex.

The rate of admission for self-harm in school aged children in Brighton & Hove doubled over the last ten years. There were 253 hospital admissions for self-

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[27] https://fingertips.phe.org.uk/profile-group/mental-health/profile/cypmh/data#page/0/gid/1938133090/pat/6/par/E12000008/ati/102/are/E06000043

harm (10-17-year olds in 2010/11) per 100,000 10-24 year olds in Brighton & Hove compared to 449 in 2018/19.[28] Young people aged 10-24 accounted for 39% of all admissions for self-harm in West Sussex and 80% of those admitted to hospital were female.[29]

Specifically in Sussex, hospital admissions as a result of self-harm are at a significantly higher rate per 100,000 people than England, with the highest rates being seen in the local authority area of Brighton & Hove where approximately one in five 14-16 year olds report that they have self-harmed.[30]

Table Ten: Education, Employment and Training in Sussex

	West Sussex	East Sussex	Brighton & Hove	England
School Pupils with social, emotional and mental health needs - % of school pupils with social, emotional and mental health needs (Primary School Age - 2018)	2.22	2.36	2.50	2.19
School Pupils with social, emotional and mental health needs - % of school pupils with social, emotional and mental health needs (Secondary School Age - 2018)	2.47	2.08	3.42	2.31
School Pupils with social, emotional and mental health needs - % of school pupils with social, emotional and mental health needs (Combined School Age - 2018)	3.01	2.52	2.47	2.39
Percentage of 16-17 year olds NOT in education, employment or training (NEET) or whose activity is not known. (2017)	9.8	4.9	4.5	6.0

Source: Fingertips Public Health Profile (Public Health England) data combined and presented by Contact Consulting (Oxford) Limited

Sussex has a higher than national average percentage of school pupils with social, emotional and mental health needs in all three of its local authority areas. Public Health England (PHE) also publishes estimated prevalence of social, emotional and mental health needs in school pupils. The most recent data, from 2018, shows both the England average and the South East regional average as 2.4% of pupils reporting specific needs.

This data, split by local authority areas, shows Brighton & Hove, East Sussex and West Sussex all to be marginally above the regional and national averages.

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[28] Brighton & Hove Local Transformation Plan, October refresh 2019
[29] West Sussex Local Transformation Plan, October refresh, 2019
[30] Brighton & Hove Local Transformation Plan, October refresh 2019

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Needs are highest in Brighton & Hove with East Sussex and West Sussex both reporting 2.5%.

Graph One: Percentage of pupils with social, emotional and mental health needs

% of school pupils with social, emotional and mental health needs 2018
(Source: PHE)
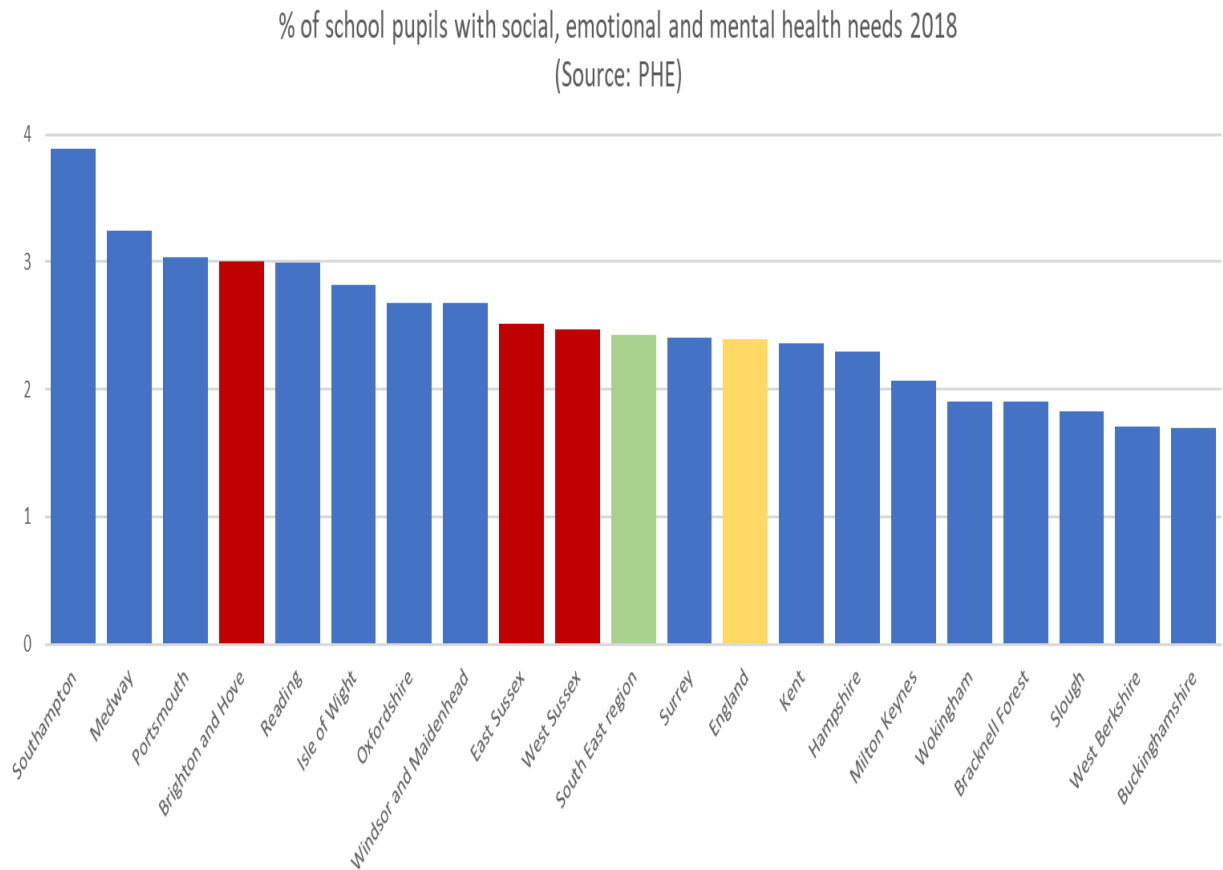
West Sussex sees a significantly higher percentage of 16-17 year olds not in education, employment or training with a figure of 9.8%. The other two local authority areas of East Sussex and Brighton & Hove both sit well below the national average, which is 6.0%, at 4.9% and 4.5% respectively.

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Section Three

Current service pattern

Across Sussex, there are a number of emotional health and wellbeing services for children and young people. Nationally, the average per CCG area is three and locally, each of the three CCG areas has more than eight. Although SPFT is the primary provider of specialist mental health services there are numerous other providers and services that are able to offer support and services to children and young people who may need help and support with their emotional health and wellbeing.

There are over 50 different services offering emotional health and wellbeing support across Sussex. Approximately half of that number are local, regional or national services with a specific focus on emotional health, wellbeing or mental health. Other services have a wider remit e.g. Allsorts, Youth Advice Centre and Amaze. Some of these services are commissioned locally, while others have a national delivery profile that can be accessed by children and young people locally. Some services are commissioned by partner organisations while others are grant or aid funded.

The Review Panel has mapped these services and organisations. The spread of provision, is set out here in maps detailing where those services are located.

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Map One: The Sussex landscape: CCG and Local Authority Boundaries

Service mapping of emotional health and wellbeing support services for children and young people across Sussex

In West Sussex (see Map Two), there are at least nine other providers of emotional health and wellbeing services in the CCG area not all of which are commissioned by the CCGs. This contributes to a complex pathway and sometimes confusing landscape of delivery.

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Map Two: West Sussex map and list of services
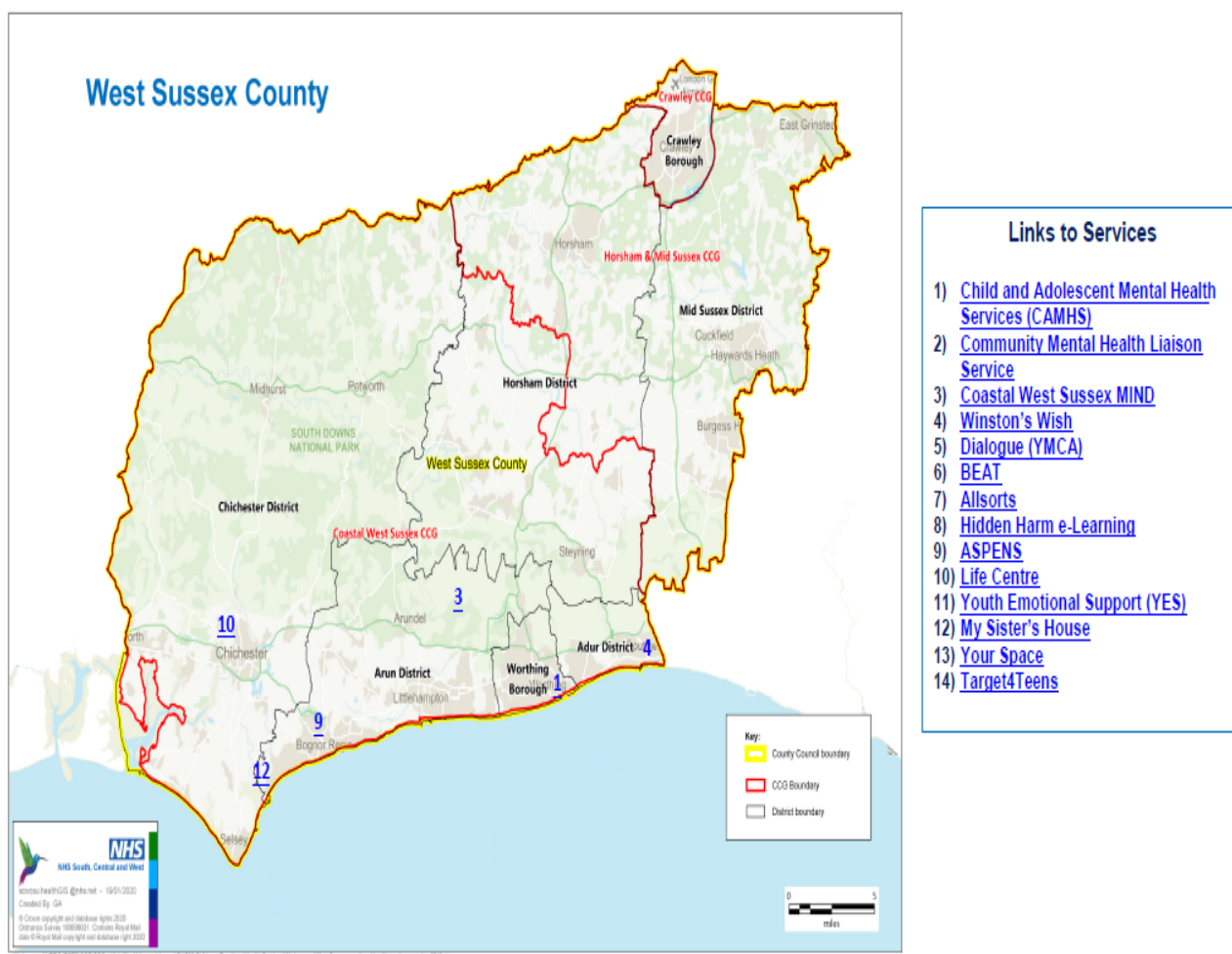
Where service numbers are not shown on the map, this may indicate a digital service or alternative form of contact. Please refer to the 'List of Services' for the corresponding County.

In East Sussex (see Map Three), there are at least 10 other providers of emotional health and wellbeing services in the CCG area, not all of which are commissioned by the CCGs. This contributes to a complex pathway and sometimes confusing landscape of delivery.

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Map Three: East Sussex map and list of services
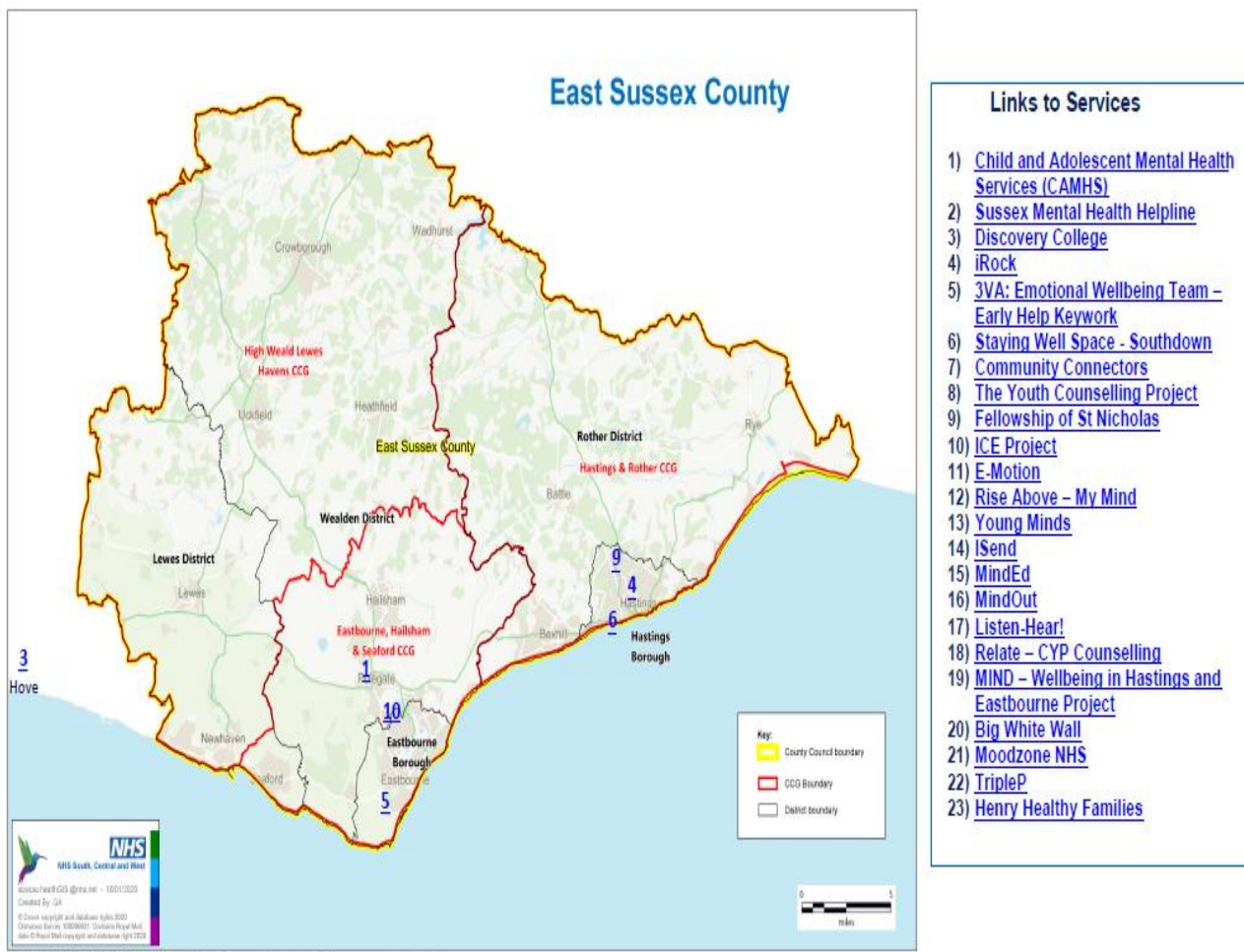
Where service numbers are not shown on the map, this may indicate a digital service or alternative form of contact. Please refer to the 'List of Services' for the corresponding County.

In Brighton and Hove (see Map Four), there are 11 providers delivering face-to-face interventions, not all of which are commissioned by Brighton and Hove CCG. This contributes to a complex pathway and a confusing landscape of delivery.

Map Four: Brighton & Hove map and list of services

Where service numbers are not shown on the map, this may indicate a digital service or alternative form of contact. Please refer to the 'List of Services' for the corresponding County.

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Section Four

Current performance and activity

In order to establish the pattern of performance and activity, the Review Panel considered both national and local data. This information was collected and analysed by the NHS Benchmarking Network (NHSBN).

The data reviewed and analysed by NHSBN relates predominantly to SPFT services and they advised us that this is an important caveat to note when considering the information presented. This is a limitation brought about by lack of data flow to Mental Health Services Data Set (MHSDS) from commissioned providers, a lack of data provided by other organisations and a lack of knowledge about other services that can be accessed locally but are not commissioned locally. Therefore making clear and reliable comparisons is not possible.

To establish a baseline position against which to compare Sussex, national data in relation to children and young people's services was reviewed. The data provided has enabled the Review Panel to gain an overview of current performance across a range of key measures and these have informed the Review Panel's enquiries, findings and recommendations.

The key findings from the data analysis are set out here and shown in Infographic One below.

Provision across Sussex

MHSDS data confirms 16 provider organisations within Sussex reporting data to the national data set. Provider organisations funded by the NHS are required to submit data to MHSDS. SPFT is the majority provider of specialist CYP (children and young people) MH (mental health) services to Sussex CCGs.

In addition to SPFT, several other local providers operate in Sussex, delivering targeted emotional wellbeing services. These services have the potential to increase access and choice for referrers, for children, young people and their families. Data does not flow to MHSDS from all provider organisations and creates issues in being able to provide a complete picture of data and information relating to all services in Sussex.

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Infographic One: Summary of key performance measures provided by NHSBN, 2019

Investment (health)	National average per capita spend on CYP mental health is £57
Spend (specialist CAMHs)	The average costs were £5.8 million per 100,000 population (age 0-18) for statutory providers in 2018/19
Prevalence	PHE Fingertips tool shows an England average of 9.2% prevalence of the age groups 5-16
Provision	National average of providers per CCG area is 3
Waiting times	National average referral to treatment (RTT) is 14 weeks (98 days)
Conversion	National average of referrals received which are accepted and brought to face to face assessment is 76%
Caseload	A national total of 1906 children and young people per 100,000 population (age 0-18) were on caseloads at year end (31st March 2019)
Activity	Across the UK, an average of 24,622 contacts were delivered per 100,000 population (age 0-18) in 2018/19
Activity	National average for the number of contacts each patient would receive if they were on caseload for a full year is 14
Workforce	National average of 84 WTE specialist CAMHs staff per 100,000 population (age 0-18)
Workforce	Nationally, 60% of the CAMHs workforce work 0.8-1 WTE per week

Referral rates

CAMHS is the fastest growing of all major specialties in healthcare. National data from NHSBN suggests a 97% increase in referral rates to CAMHS in the six years to 2018/19. SPFT is the single provider of commissioned specialist CAMHS in Sussex. A summary of SPFT's performance is shown in Infographic Two below.

Up until 2017/18, referral rates to SPFT specialist services had been consistently higher than national growth with numbers exceeding national averages by between 9% and 31%. In 2018/19, SPFT received 3,359 referrals per 100,000 population, a reduction compared to 3,422 referrals per 100,000 population in 2017/18. These 2018/19 referral rates were below national average levels. Referral rates in Sussex were consistently above national averages between 2014/15 and 2017/18. In 2018/19, national referral rates grew by 19% and SPFT referrals appeared close to national median average rates.

Across Sussex, 5,117 referrals were received by non-NHS providers, representing just under a third (31%) of total referral activity. 37% of referrals accepted across Sussex were within these services. We are unable to compare NHS and non-NHS activity across a number of years because of lack of information from the non-NHS sector. This is sometimes because services were not commissioned or required to provide that level of data or because those services were not commissioned three years ago.

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Acceptance rates for SPFT specialist mental health services

57% of referrals received by SPFT's specialist mental health services were accepted and brought for a face-to-face assessment. This is the lowest acceptance rate in the peer group, and below the national average position of 76%. There could be a range of reasons for this disparity including referral quality, waiting list management, diagnostic and risk threshold criteria, organisational resource and capacity management.

Conversion rates

Conversion rate data measures the proportion of children and young people who came in for assessment and was then added to caseload for a period of treatment. The most recent conversion rate data for SPFT shows a position of 46%. The national conversion rate from assessment to treatment is 69%.

Using these figures, for every 100 children referred to SPFT, 57 will be assessed face to face, and 26 of those (46%) will then enter treatment. Although there have been recent improvements in access to treatment within SPFT, the drop off rate appears to be around three quarters from the initial point of referral. SPFT will be using resources in terms of staff time and cost, to manage these referrals for children and young people who ultimately do not enter treatment with them.

Reasons for non-conversion to caseload might include; patients who do not engage, did not attends (DNAs), failure to reach provider eligibility thresholds, signposting to alternative services, and provision of successful initial contact intervention.

Waiting times for SPFT specialist services

Data supplied by SPFT focused on average waiting times and these were broken down by area - Brighton, East Sussex and West Sussex. The data excludes any tier two activity and also the work of specialist teams such as those providing eating disorder services. The data provided was up to and including June 2019. The data could not be further analysed into time waited and urgency of referral. It is accepted that the mean average can be skewed by the inclusion of people waiting for the longest amount of time, however, the mean value is the one most typically used in reporting.

The specialist service operates a needs led model and will be responding to urgent and routine referrals on a daily basis. In 2018/19 the proportion of urgent referrals received by SPFT was 13% which is consistent with the national average rate. Graph Two below details the average waiting times across all three areas. This data is limited in that it does not represent the number of referrals against the average waiting times. This is a level of detail that will come from any demand, capacity and productivity work with the provider.

Waiting times are measured from initial referral to specialist mental health services to date of assessment, and are measured in days. The period reviewed for this report was April 2017 to June 2019. Although there is variation across teams on a monthly basis, the position, averaged across the three teams, demonstrates a variation of waiting times from a low of 17 days in July 2017 to 42 days by June 2019. The chart below describes this variation. The longest monthly waits reported by individual teams over this period were Brighton & Hove at 50 days (August 2018), East Sussex at 46 days (May 2017) and West Sussex at 43 days (May 2019).

Graph Two: Waiting times referral to assessment, SPFT specialist services

Referral to Assessment - waiting times (days)
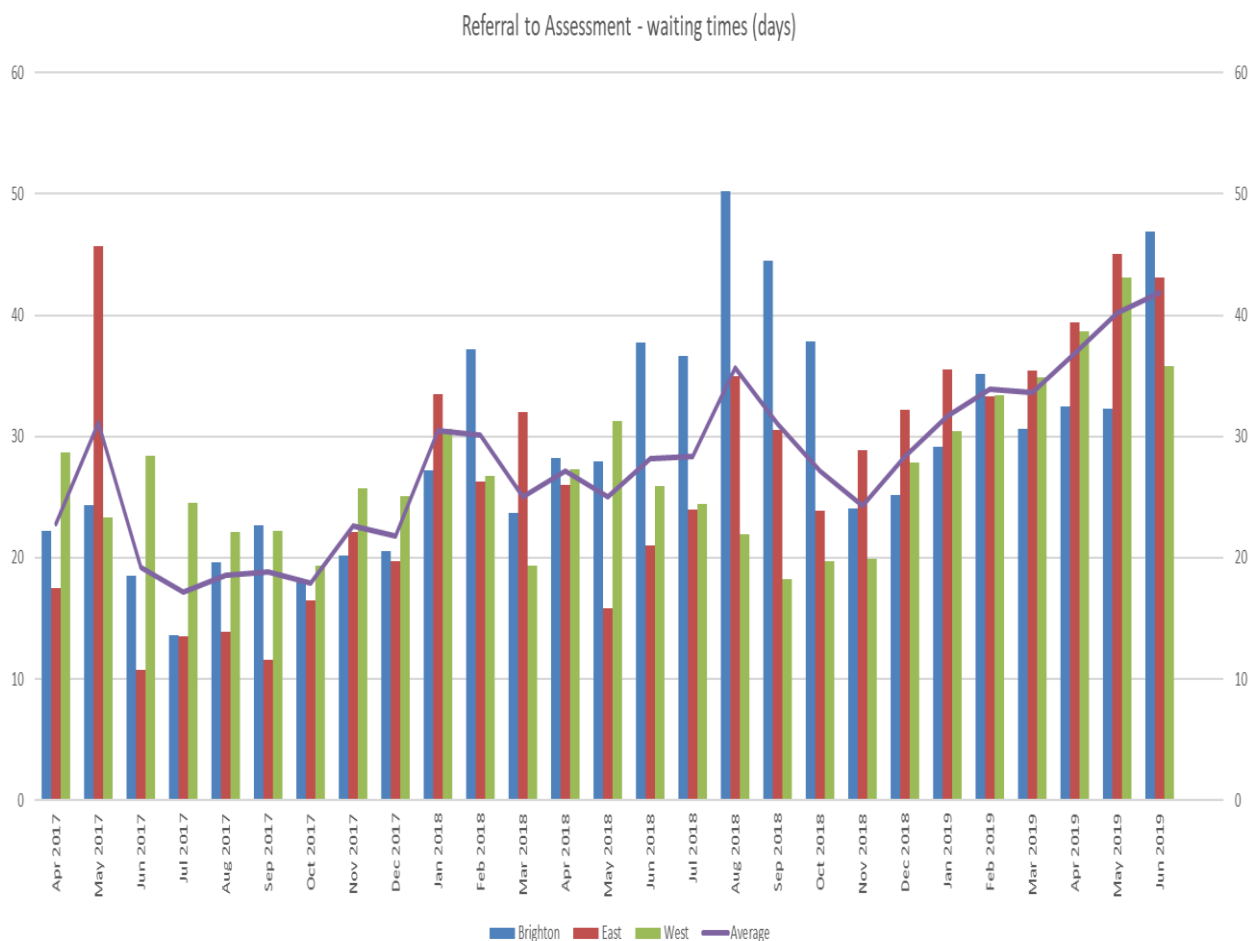
Details for each of the three areas for the same time period (April 2017 – June 2019) are given below.

Brighton & Hove

In Brighton & Hove, the range in waiting times for first assessment ranged from 14 days to 50 days with a general upward trend evident in the data from November 2018 to June 2019, suggesting lengthening waiting times. Subsequent waits for treatment also ranged from 14 days to 50 days with reductions in waiting times evident in recent months. As a general rule, months with longer waits for assessment were months with shorter waits for treatment, which may reflect prioritisation of the pathway or differing demand at different points in the year.

East Sussex

In East Sussex data suggests that initially, waits from assessment to treatment represented the longest part of the pathway. However in the 12 months from July 2018 to June 2019, this has reversed, with longer waits from referral to assessment, but quicker access to treatment following assessment for those children who are added to caseload. There is a general upward trend evident in the data from November 2018 to June 2019, suggesting lengthening waiting times.

Best access for referral to assessment was in June 2017 - 11 days on average and for assessment to treatment in May 2019 - 14 days on average. Longest waits for both referral to assessment and assessment to treatment was 46 days.

West Sussex

In West Sussex, wait from referral to assessment increased in February to June 2019 whilst wait from assessment to treatment reduced for the same period.

Longest waits were 43 days for referral to assessment in May 2019 and 46 days assessment to treatment in February 2018.

Overall, against a 12 week referral to treatment (RTT) measure, achievement was high, placing SPFT in the best performing quartile nationally.

Waiting times for other services

Waiting list information was not available from all providers. However, the table below displays the information that was available and highlights the extent to which waiting lists were evident in these services on 31st March 2019. The Brighton & Hove Children and Young People's (CYPs) Wellbeing Service reported the longest waiting lists, as a result of the waiting lists inherited when the service was first commissioned. This service supports children and young

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people in a tier two setting, i.e. those who do not meet the threshold for Sussex Partnership NHS Foundation Trust specialist services.

Table Eleven: Waiting times for non-NHS services at 31 March 2019 (days)

	Awaiting assessment	Awaiting treatment
Lifecentre (West Sussex)	30	Not known
MIND Be OK (Coastal West Sussex)	2	Not known
Sussex Oakleaf Be OK (West Sussex)	4	8
YES	Not known	Not known
Brighton & Hove children and young people Wellbeing Service	226	90
i-ROCK	0	0
Total (non NHS)	262	98

In Brighton & Hove, the Wellbeing Service is the main provider of targeted mental health services for children and young people. The waiting time for first assessment is 79.2 days; the waiting time for treatment is 85.6 days. This service demonstrates waiting times that are longer than those of statutory services. The conversion rate (referrals received that are accepted and brought to face-to-face assessment) is 45.1%, lower than that of specialist SPFT services locally and lower than the national average of 76%. This is in part due to the service inheriting a waiting list when it was commissioned and could also be because of the challenges identified by NHSE Intensive Support Team (IST), when they reviewed the service in December 2018, in terms of waiting list management and a clear diagnostic pathway.

In East Sussex, i-Rock is a partnership service delivered by SPFT and the local authority. i-Rock has no waiting time for assessment or treatment. Its conversion rate (referrals received that are accepted and brought to face-to-face assessment) is 100%.

In West Sussex, Youth Emotional Support (YES), a service commissioned by the NHS, has no data related to waiting times for assessment but for treatment the waiting time is 88 days. The conversion rate (referrals received that are accepted and brought to face-to-face assessment) is 100%. Waiting times for treatment at YES are longer than those for specialist services.

One of the specific areas the review was focussed on was the waiting times for assessments for ADHD (Attention Deficit Hyperactivity Disorder) and ASC (Autistic Spectrum Conditions). We were able to source waiting list information from SPFT i.e. the number of people waiting, but were not able to ascertain waiting times from either SPFT or from East Sussex Healthcare NHS Trust (ESHT). Sussex Community NHS Foundation Trust (SCFT) was able to provide

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waiting time information. This is a worrying lack of information that is addressed by the recommendations from this review.

In relation to neurodevelopmental disorders, children and young people wait for a very long time, up to two years, for an assessment of their needs. They wait longer for an assessment of their emotional health and wellbeing than those children and young people who do not have neurodevelopmental needs and often experience a challenging journey through the system.

Providers told us that in 2019/20, they have seen an increase in the numbers of referrals of children and young people for an assessment of their neurodevelopmental needs, of up to 40% more than in 2018/19.

Activity (caseloads)

A national total of 1,906 children and young people per 100,000 population (age 0-18) were on caseloads at year-end (31st March 2019). SPFT reported 1,208 per 100,000 population, which shows it has caseloads 37% smaller than average.

The lower caseloads seen in SPFT's services are also demonstrated in neighbouring Hampshire and Surrey. The peer group average position is 1,787 per 100,000 population, i.e. higher than the SPFT position but below national average levels. The Sussex position may be influenced by the extent of provision commissioned outside the statutory sector.

Activity (contacts)

Nationally, an average of 24,622 contacts was delivered per 100,000 population (age 0-18) in 2018/19. SPFT's average number of all contacts is 20,168 per 100,000 population, which is 18% below national averages.

A total of 89,855 CYP MH contacts were delivered across Sussex in 2018/19. SPFT's specialist services provided approximately 75% of these contacts with providers from other sectors delivering the remainder. This position is incomplete as data is not available for all providers.

Within SPFT, there is an indicative contact rate of 17 contacts per patient per year, which is above the national average of 14. This suggests the lower levels of contacts described above, are a reflection of the lower caseloads reported earlier, and that the intensity of input for a child who is on the caseload in SPFT is higher than for those on caseloads elsewhere nationally.

Workforce (community)

Across England, 2018/19 saw the sixth consecutive year of growth in the size of the specialist services workforce. The average position was 84 WTE (whole time equivalent) specialist community services (CAMHS) staff per 100,000 population (age 0-18).

In SPFT, the position was 69 WTE per 100,000 population (18% below NHS average levels).

Nationally, 60% of the CAMHS workforce work 0.8-1 WTE per week, but this rate is lower across the three Sussex teams, at 44% for Brighton, 39% for East Sussex and 23% for West Sussex. This suggests a more part-time workforce. This may in part be driven by a desire among the workforce, some of which migrates from London for work/life balance reasons, to work part time. Often the financial resources that are made available, sometimes on a short-term basis, can mean that only part-time staff can be recruited. This does not appear to affect the clinical interventions delivered, or their quality.

Infographic Two below summarises the SPFT position described above in relation to the national average position.

Infographic Two: Summary of SPFT specialist services information (arrows denote position in relation to national picture)

Spend (specialist CAMHs)
A figure of £4.3 million per 100,000 population was reported by SPFT which puts costs in Sussex 26% below the national NHS average

Conversion
57% of referrals received by Sussex CAMHs were accepted and brought for a face to face assessment, 19% below the national average

Caseload
SPFT reported 1,208 per 100,000 population, 37% smaller than the national average

Activity all contacts
SPFT reported 20,168 contacts per 100,000 population which is 18% below national averages

Activity – contacts per treatment episode
Methodology provides an indicative contact rate of 17 contacts per patient per year which is more than the national average of 14 contacts

Workforce
In SPFT, the position was 69 WTE per 100,000 population 18% below NHS average levels

Workforce
In SPFT, % 0.8 – 1.00 WTE per week is; 44% for Brighton, 39% for East Sussex and 23% for West Sussex

User experience
The CHI-ESQ tool demonstrates that over 90% of carers and over 75% of CYP say they were treated well in SPFT services

Self-harm in children and young people

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The Public Health England Fingertips resource provides an overview of the position in relation to self-harm resulting in hospital admission and death by suicide among children and young people. We reviewed the most recent data available covering the period 2017-18.

As Graph Three below shows, for those aged between 10-24 years old, Brighton & Hove, East and West Sussex all have rates per 100,000 population of self-harm leading to hospital admission that are higher than for the South East Region and those for England as a whole.

Graph Three: hospital admissions as a result of self-harm, age group 10 – 24 years, per 100,000 population (2017/18).

Area	Recent Trend	Neighbour Rank	Count	Value		95% Lower CI Lower CI	95% Upper CI Upper CI
England	–	-	41,218	421.2		417.1	425.3
South East region	–	-	7,394	467.6		457.0	478.4
Hampshire	–	-	1,299	591.8		559.9	625.0
Portsmouth	–	-	275	570.6		503.3	644.1
Southampton	–	-	329	555.6		494.2	622.2
Brighton and Hove	–	-	355	548.6		490.8	611.2
Bracknell Forest	–	-	110	537.3		440.8	648.4
West Sussex	–	-	685	535.9		496.3	577.9
West Berkshire	–	-	137	529.3		443.0	627.3
East Sussex	–	-	450	527.4		479.6	578.8
Reading	–	-	171	517.7		442.1	602.5
Wokingham	–	-	132	483.9		403.7	575.2
Surrey	–	-	943	467.6		438.1	498.5
Isle of Wight	–	-	96	453.3		366.9	553.9
Medway	–	-	226	442.0		386.2	503.5
Windsor and Maidenhead	–	-	102	439.0		355.6	535.7
Oxfordshire	–	-	558	435.4		400.0	473.2
Slough	–	-	109	433.5		355.5	523.4
Milton Keynes	–	-	164	386.2		328.9	450.5
Buckinghamshire	–	-	327	375.9		335.9	419.4
Kent	–	-	926	343.2		321.4	366.1

Graphs Four and Five show hospital admissions as a result of self-harm for the age ranges 10 -14 years and for 15 – 19 years.

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Graph Four: hospital admissions as a result of self-harm, age group 10 – 14 years, per 100,000 population.

Area	Recent Trend	Neighbour Rank	Count	Value		95% Lower CI Lower CI	95% Upper CI Upper CI
England	↓	-	6,662	210.4		205.4	215.5
South East region	↑	-	1,059	200.4		188.5	212.8
Portsmouth	➡	-	37	320.1		225.4	441.3
East Sussex	↑	-	89	298.8		240.0	367.7
Southampton	↑	-	35	285.4		198.8	397.0
Surrey	↑	-	189	266.8		230.1	307.7
Oxfordshire	↑	-	102	260.9		212.7	316.7
Brighton and Hove	➡	-	32	231.7		158.5	327.1
Medway	➡	-	39	230.6		163.9	315.2
Hampshire	↑	-	170	217.5		186.0	252.8
West Sussex	↑	-	97	205.6		166.7	250.8
Reading	➡	-	18	201.6		119.4	318.6
Bracknell Forest	➡	-	15	200.4		112.1	330.6
Isle of Wight	➡	-	14	197.6		108.0	331.6
Windsor and Maidenhead	➡	-	16	164.0		93.7	266.3
West Berkshire	➡	-	16	159.9		91.3	259.6
Buckinghamshire	↑	-	52	152.2		113.6	199.5
Wokingham	➡	-	15	139.0		77.7	229.2
Kent	➡	-	104	112.7		92.1	136.6
Milton Keynes	➡	-	13	73.8		39.2	126.2
Slough	➡	-	6	55.3		20.3	120.4

In the 10 – 14 age range, self-harm admissions for both Brighton & Hove and East Sussex are higher than the region and England average. West Sussex is lower than the England average but higher than the region average. Both East

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and West Sussex show an increasing trend with Brighton & Hove showing a stable position.

Graph Five: hospital admissions as a result of self-harm, age group 15 – 19 years, per 100,000 population.

Area	Recent Trend	Neighbour Rank	Count	Value		95% Lower CI Lower CI	95% Upper CI Upper CI
England	↑	-	20,240	648.6		639.7	657.6
South East region	↑	-	3,821	738.0		714.8	761.8
Southampton	↑	-	171	1,038.3		888.5	1,206.1
Portsmouth	↑	-	144	1,026.0		865.3	1,207.9
Hampshire	↑	-	699	927.4		859.9	998.7
Brighton and Hove	↑	-	163	926.8		790.0	1,080.5
West Berkshire	↑	-	79	840.5		665.4	1,047.5
Reading	↑	-	79	829.8		657.0	1,034.2
Wokingham	↑	-	80	823.9		653.3	1,025.4
Medway	↑	-	134	806.4		675.6	955.1
Bracknell Forest	↑	-	58	803.0		609.7	1,038.1
West Sussex	↑	-	351	795.2		714.2	882.9
East Sussex	↑	-	228	774.5		677.2	881.8
Slough	↑	-	65	760.3		586.8	969.1
Isle of Wight	→	-	53	731.9		548.2	957.4
Oxfordshire	↑	-	287	713.1		633.0	800.5
Surrey	↑	-	464	685.1		624.2	750.4
Milton Keynes	→	-	93	632.5		510.5	774.9
Windsor and Maidenhead	→	-	51	571.5		425.5	751.4
Buckinghamshire	↑	-	162	529.3		450.9	617.3
Kent	→	-	460	509.8		464.3	558.6

In the 15 – 19 age groups, all areas in Sussex are higher than the South East region and England average with an increasing trend.

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Suicide in children and young people

The Office for National Statistics (ONS) definition of suicide includes all deaths from intentional self-harm for persons aged 10 and over, and deaths where the intent was undetermined for those aged 15 and over. Graph Six shows information derived from the Public Health England Fingertips resource, which gives information for the age range 10 – 34 years.

Graph Six: Suicide crude rate 10-34 years, per 100,000 five-year average (2013 - 2017)

Area	Recent Trend	Neighbour Rank	Count	Value		95% Lower CI Lower CI	95% Upper CI Upper CI
England	–	-	4,595	10.5		10.2	10.8
South East region	–	-	730	10.8*		-	-
Slough	–	-	19	14.9		8.9	23.2
Milton Keynes	–	-	30	14.3		9.6	20.4
East Sussex	–	-	47	13.2		9.7	17.6
Portsmouth	–	-	28	12.9		8.6	18.7
West Sussex	–	-	70	12.4		9.7	15.7
Brighton and Hove	–	-	33	11.8		8.1	16.6
Kent	–	-	131	11.5		9.6	13.7
Hampshire	–	-	110	11.5		9.5	13.9
Windsor and Maidenhead	–	-	11	10.1		5.1	18.2
Isle of Wight	–	-	9	10.0		4.6	18.9
Oxfordshire	–	-	55	9.8		7.4	12.7
Southampton	–	-	26	9.8		6.4	14.3
Medway	–	-	22	9.6		6.0	14.5
Surrey	–	-	73	8.7		6.8	11.0
Bracknell Forest	–	-	8	8.5		3.7	16.8
Reading	–	-	13	8.5		4.5	14.5
Buckinghamshire	–	-	29	7.8		5.2	11.2
West Berkshire	–	-	8	7.1		3.1	14.1
Wokingham	–	-	8	7.1		3.1	14.0

All areas in Sussex show rates of death by suicide that are higher than the South East region and the England average. Local Transformation Plans (LTPs) and suicide prevention strategies and plans for all areas have been reviewed and information for each area is detailed below.

In Brighton & Hove, the LTP does not directly comment on suicide but refers the reader to, The Brighton & Hove Suicide Prevention Strategy: And Action Plan January 2019 - December 2021(December 2018) which provides the numbers set out in Graph Seven.

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Graph Seven: Brighton & Hove - number of suicide and undetermined injury deaths by age and gender, Brighton & Hove residents, 2006-2016
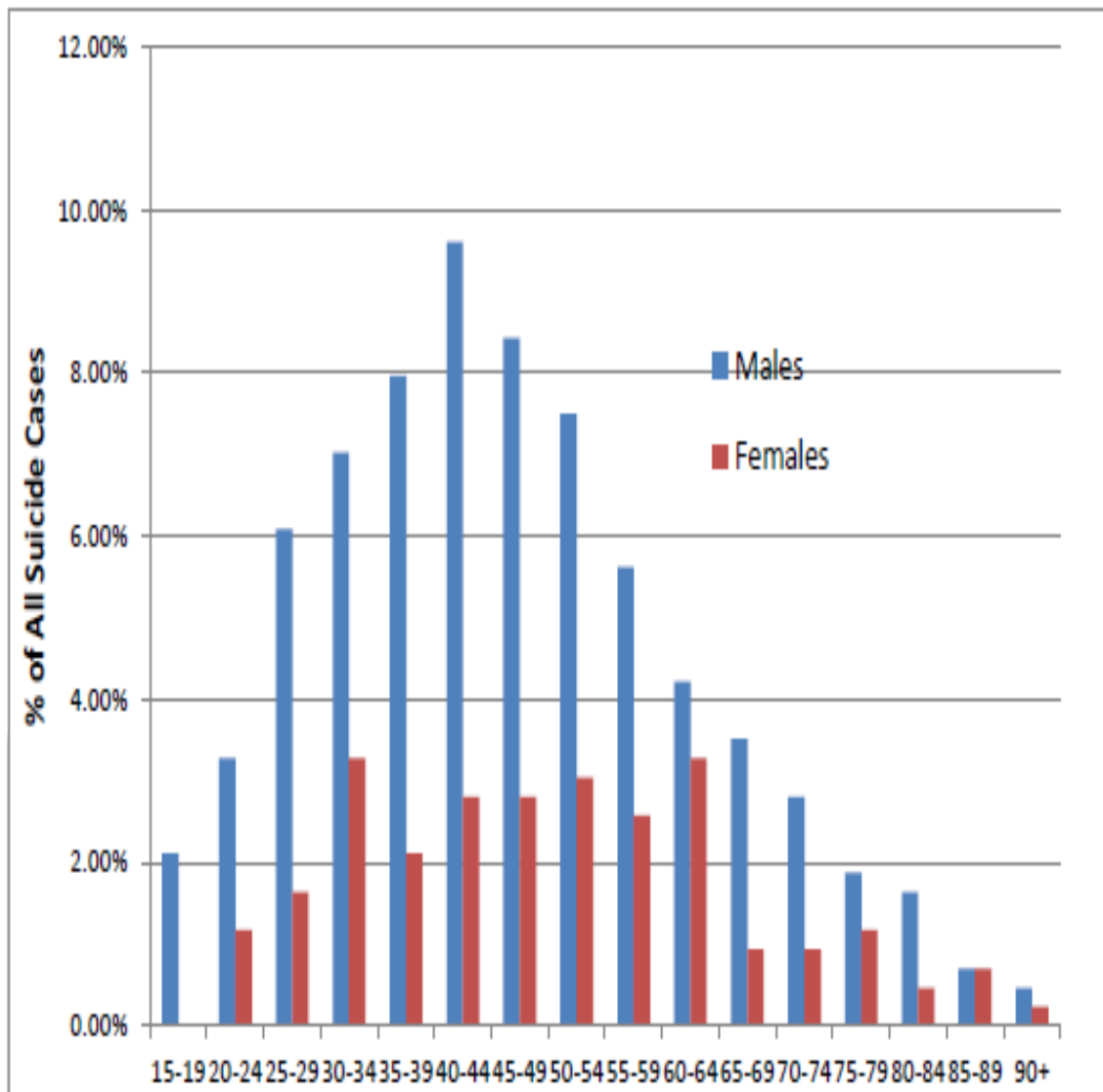
In East Sussex, the LTP has this to say about suicide, 'Suicide in under 18's is rare, although the East Sussex Child Death Overview Panel Chair has flagged an increase in recent years' and the suicide audit provides the numbers shown in Graph Eight:

Graph Eight: East Sussex - numbers of suicides of East Sussex residents by age group 2004 – 2016

Number of suicides of East Sussex residents by age group, all persons, 2004 -2016
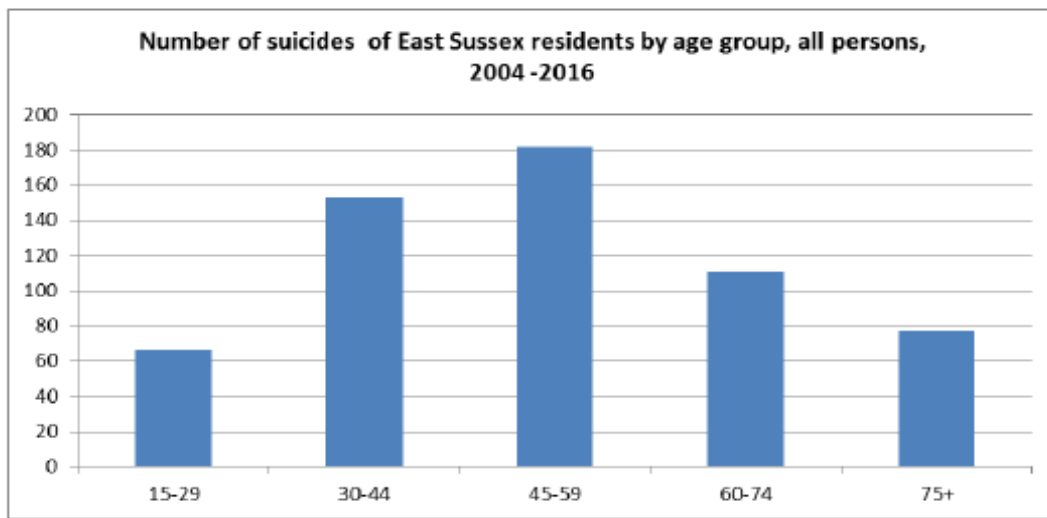
In West Sussex, the LTP details that, during a three-year period (2013-15) there were less than five deaths recorded among under-18's and 15 deaths in under-25's (7.0% of total). Graph Nine shows the number of deaths by suicide by age and gender drawn from the West Sussex Suicide Prevention Strategy (West Sussex Suicide Prevention Strategy, 2017-2020).

Graph Nine: West Sussex - Number of deaths by age and gender 2013-15

N = 213
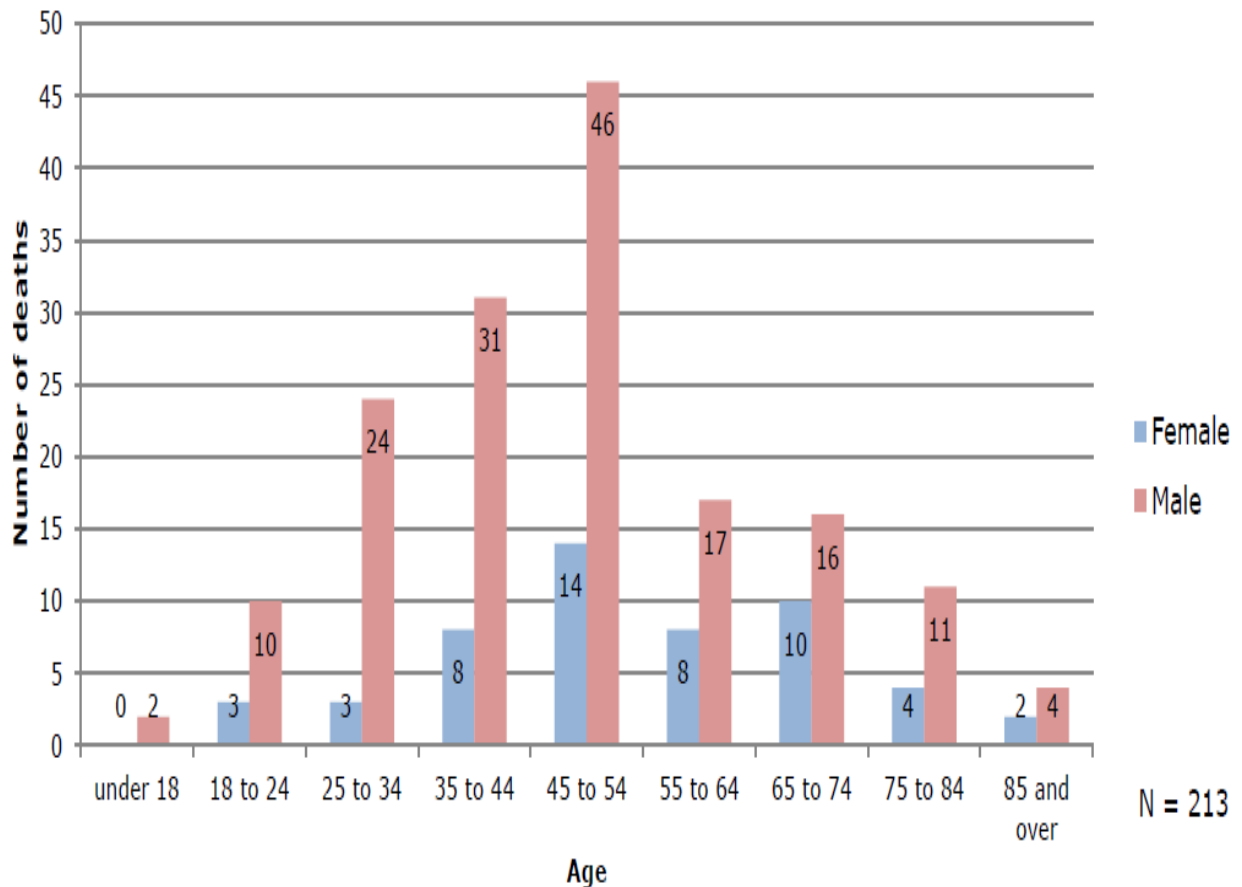
In 2015-17, there were 547 deaths by suicide across the Sustainability and Transformation Partnership (STP) area giving an age-standardised[31] rate of 11.1 per 100,000 population compared to 9.5 for England. Therefore, this figure and those below, is for all ages.

At CCG level, suicide rates in Brighton & Hove are significantly higher than England; rates in Eastbourne, Hailsham & Seaford and Hastings and Rother are the next highest.

By district/borough/unitary authority areas the rates in Eastbourne, Brighton & Hove and Hastings and Rother are significantly higher than for England.

The ability to compare by age range and gender within age range across Sussex is limited because each area suicide audit has collected information in a slightly different way. To compare parts of Sussex with England would require comparison of the respective rates in the adolescent population in the period quoted. At a Sussex-wide level the numbers of adolescent suicides are small (even using three years of data) and can give unreliable estimates of rates. We cannot draw any direct or sound conclusions on that basis.

School nursing

100% of referrals to school nurses were seen within 28 days, while also reporting some of the highest ratios of children to WTE school nurses nationally at over 2,500 children per WTE School Nurse.

Use of Mental Health Act assessment (MHAA)

In 2018, across England, there was an average of 35 Mental Health Act assessments per 100,000 population (age 0-18). The figure in East Sussex was 60, suggesting greater demand for assessments for young people in this area. Data for West Sussex and Brighton & Hove was not available. There may be several reasons for these apparently high rates of Mental Health Act assessment but it was not in the scope of this review to examine those directly. The issue of data is addressed in our wider recommendations.

Prevalence in schools

The estimated prevalence of social, emotional and mental health needs in school pupils from 2018 shows both the England average and the South East regional average as 2.4% of pupils reporting specific needs. This data, split by Council areas, shows Brighton & Hove, East Sussex and West Sussex all to be

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[31] In epidemiology and demography, age adjustment, also called age standardisation, is a technique used to allow populations to be compared when the age profiles of the populations are quite different.

marginally above the regional and national averages. Needs are highest in Brighton & Hove (3%) with East Sussex and West Sussex both reporting 2.5%.

Special Educational Needs and Disabilities (SEND)

In West Sussex, approximately 20,000 children and young people with SEND receive support in an early years setting, school or college, with over 4,000 of these having a Statement of Special Educational Needs or an Education, Health and Care Plan (EHCP).[32]In East Sussex, the proportion of children and young people with Maintained Statements and Education, Health and Care Plans has risen from 1.6% in 2011 to 2.2% in 2018.[33] In Brighton & Hove, in January 2018 5,432 children and young people had identified Special Educational Needs (SEN), which is 16.8% of the school population.[34]

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[32] West Sussex SEND strategy 2016-19
[33] East Sussex SEND strategy 2019-21
[34] Brighton & Hove SEND Guide for Professionals

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Section Five

Finance

One of the challenges for the Review Panel was to obtain a definitive picture of the amount of investment in children and young people's emotional health and wellbeing services in Sussex. Gathering this information and its analysis was intended to facilitate a clearer understanding of the financial commitments made by the CCGs and local authorities in Sussex, and the financial resources for Sussex Partnership NHS Foundation Trust. The Review Panel wanted to know:

- How much was invested on universal, targeted and specialist emotional health and mental health services as a proportion of all spend on children's and young people's services.

- How much was invested in universal, targeted and specialist emotional health and mental health services separately.

Universal services are those such as schools, health visitors and children's centres. Targeted services are those for children and families beginning to experience, or at risk of difficulties, for example school counselling, parenting programmes and support for teenage parents. Specialist services are those relating to children and young people's mental health, for example CAMHS.

In presenting this information, there are some caveats to be borne in mind and these are described with each area covered. Although the Review Panel Project Team requested financial data using a bespoke set of tables for completion, local organisations, including the local authorities were largely unable to supply the information in the format requested. This is likely to be because at source, the level of data and detail may not exist and as a result, it is hard to make reliable comparisons.

There is a lack of published national local authority data on children's services in relation to emotional health and wellbeing and benchmarking is therefore not available. However, there is some data on local authority provided children's services that is presented by the Department for Education.

Table Twelve provides an overview of local authority expenditure on children's services across the South East region and the total for England as a whole.

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Table Twelve: Local Authority Expenditure on Children's Services Net expenditure on children and young people's services by local authority 2017-18

LA Code		Children's and young people's services £000s	Pupil / Population Count	Spend per Capita (£)
	ENGLAND	**8,632,612**	**11,962,245**	**722**
	SOUTH EAST	**1,263,139**	**1,961,422**	**644**
867	Bracknell Forest	20,561	28,646	718
846	Brighton and Hove	57,335	51,571	1,112
825	Buckinghamshire	74,348	124,931	595
845	East Sussex	61,887	107,320	577
850	Hampshire	153,415	284,317	540
921	Isle of Wight	21,010	25,036	839
886	Kent	187,937	337,996	556
887	Medway	64,508	64,694	997
826	Milton Keynes	41,905	69,050	607
931	Oxfordshire	82,766	144,061	575
851	Portsmouth	36,131	44,695	808
870	Reading	39,225	37,513	1,046
871	Slough	29,744	42,542	699
852	Southampton	44,972	51,114	880
936	Surrey	179,461	263,131	682
869	West Berkshire	22,485	36,093	623
938	West Sussex	109,855	174,893	628
868	Windsor and Maidenhead	18,547	34,706	534
872	Wokingham	17,047	39,113	436

Source: Department for Education, Section 251 Outturn survey 2017/18 (included in NHSBN report).

The numbers indicate that Brighton & Hove are spending more than the England average and East Sussex and West Sussex are both spending less.

Brighton & Hove Local Authority financial data

For Brighton & Hove local authority, some information was provided for 2019/20 against the universal, targeted and specialist headings. No information was supplied which described the proportion of spend and 2020/21 provisional information was not available to be included in the return.

The total investment recorded was £6,294,000. Of this amount, just under £2.5 million was focused on those aged 0-11, £3,755,000 on those aged 12-18 and £125,000 on those in transition to adulthood aged 16-18.
In Brighton & Hove, the allocation of resource was as follows:

- £4,925,000 was invested in universal services, with just under £2 million that focussed on those aged 0-11 and just over £3 million on those aged 12-18. No investment was allocated in relation to those aged 16-18 and in transition to adulthood.

- In relation to targeted services, the total investment was £884,000. £364,000 was focused on those aged 0-11 and £520,000 of those aged 12-18. Again, there was no allocation for those aged 16-18 and in transition to adulthood.

- For specialist services focused on children and young people's mental health, those total invested was £485,000. This was split £180,000 for both those aged 0-11 and 12-18. For those in transition to adulthood aged 16-18, £125,000 was allocated.

East Sussex Local Authority financial data

For East Sussex, some information was provided for 2019/20 against the universal, targeted and specialist headings. No information was supplied which described proportion of spend and 2020/21 provisional information was not available to be included.

The total investment made by East Sussex was £48,003m.

In East Sussex, the split of the resource was as follows:

- For universal services, the total investment was £722,000 with a split of £419,000 on those aged 0-11 and £303,000 on those aged 12-18. There was no allocation for those in transition to adulthood aged 16-18.

- For targeted services, the total investment was £46,055m with a split of £26,685 for those aged 0-11, and £19,370 for those aged 12-18 of which £3,839 was for those in transition to adulthood aged 16-18.

- For specialist services focused on children and young people's mental health £1,226,000 was allocated with a split of £60,000 for those aged 0-11 and £1,166,000 for those aged 12-18. No allocation was made for those in transition to adulthood aged 16-18.

West Sussex Local Authority financial data

In West Sussex, there is an aligned budget between the county council and the CCGs and this is used in a combined way to create the investment profile. So, both NHS and local authority investment information is shown here. The information provided by West Sussex was not in the same format or split as for Brighton & Hove and East Sussex.

The total investment made by West Sussex was £10,226,561.

In West Sussex, the split of the resource was as follows:

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- For universal services, the total investment was £1.3 million for those aged 0-11. This included £1.2 million for Healthy Child Programme nurses and £100,000 for therapeutic interventions in early help. No allocation was reported for those in transition to adulthood aged 16-18.

- For targeted services, the total investment was £589,061. No allocation was reported for those in transition to adulthood aged 16-18.

- For specialist services focused on children and young people's mental health, £8,337,500 was allocated. No allocation was reported for those in transition to adulthood aged 16-18.

Clinical Commissioning Group investment

NHS Benchmarking Network reviewed the reported CCG baseline funding for mental health for each of the Sussex CCGs.

The average CCG devolved spend per capita – all ages - on mental health and learning disability services was £180 in 2018/19. The average across all Sussex CCGs was £163 (range £135 - £219). Therefore, the average all age investment across Sussex was 9% lower than the England national average.

Across England, CCGs spent 13.6% of their total devolved annual budgets on mental health and learning disability services – again this is all ages. In Sussex CCGs, the average was 11.9%, with a range from 9% to 19%. The data for Sussex confirms lower levels of both absolute and proportionate expenditure on mental health and learning disability services than overall England average levels. The position at CCG level is particularly pronounced with Brighton & Hove CCG the only one of the seven CCGs investing at above average levels for all age mental health services.

The position in relation to investment in specialist services (CAMHS) per child was only available for the 2016/17 financial year. This again showed variation in the amounts being spent, ranging from £45 per child (under 18) to £11 per child. The average across the Sussex CCGs was £30.

In England, average CCG spend per capita on children and young people's mental health (excluding learning disabilities and eating disorders) was £57 per capita (0-18) in 2018/19. The average across all Sussex CCGs was £55, however there was local variation ranging from £39 to £76 per capita.

Per capita spending on children and young people's mental health services by Sussex CCGs is marginally below national average levels; however, there is variation evident across the seven Sussex CCGs. Table Thirteen below details spend per CCG and Graph Ten shows the CCGs' position in relation to the national position.

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Table Thirteen: CCG investment on children and young people's mental health services 2018/19[35], excluding learning disabilities and eating disorders

CCG	GP registered population 0-18 years	Total spend (£s) 0-18 years	Total spend per head (£s) 0-18 years
Brighton & Hove	55,278	4,184,000	75.69
Coastal West Sussex	92,942	5,425, 080	58.37
Crawley	29,634	1,242,346	41.92
Eastbourne, Hailsham and Seaford	35,889	1,983,511	55.27
Hastings & Rother	34,653	1,724,714	49.77
High Weald, Lewes Havens	33,187	2,141,000	64.51
Horsham & Mid Sussex	50,257	1,974,882	39.30

Graph Ten: CCG spend per capita 0-18 years on children and young people's mental health services, excluding learning disabilities and eating disorders 2018/19

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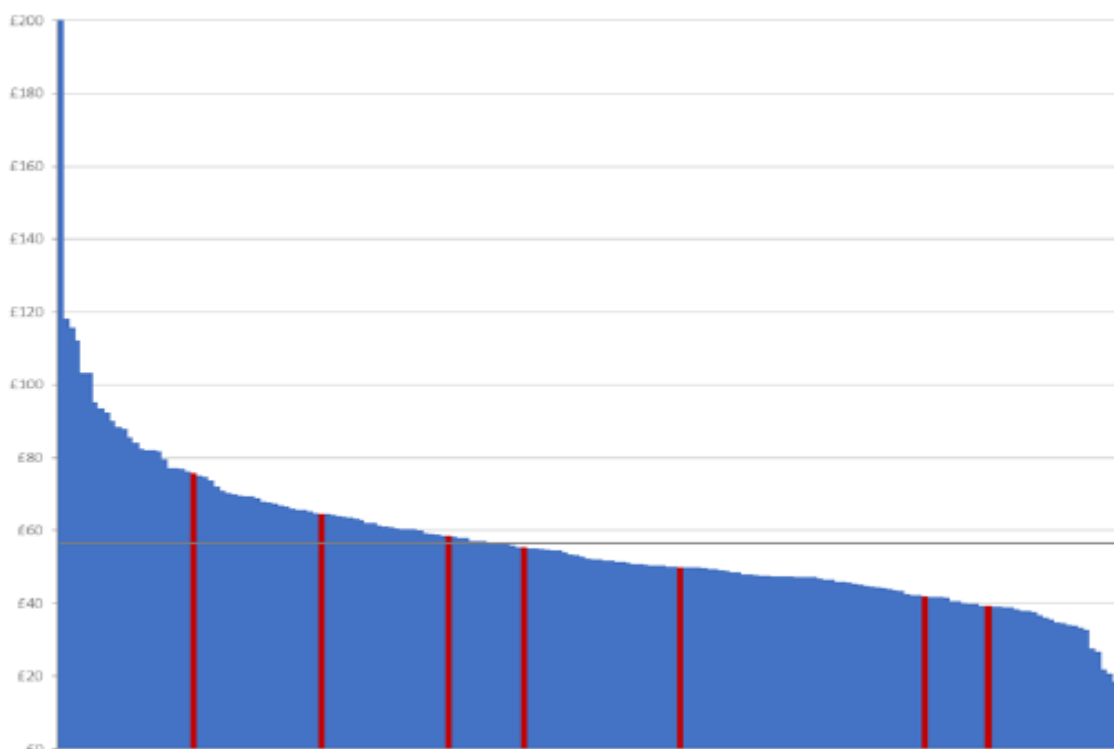
[35] Five Year Forward View Dashboard 2018/19

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Breakdown of key finance and performance data by CCG area

Brighton & Hove CCG

Brighton & Hove CCG spend per capita on children and young people's mental health is £76. This is £19 per capita more than the national average. The prevalence of mental health within the age group 5-16 is 8.5%. Brighton & Hove therefore has a lower prevalence level than the national average but invests more per capita.

East Sussex CCGs

Between the three CCGs in East Sussex the spend per capita on children and young people's mental health varies from £50 in Hastings and Rother, £55 in Eastbourne, Hailsham and Seaford to £65 in High Weald Lewes Havens. The prevalence rate is broadly similar across the three CCGs, with High Weald Lewes Haven at 8%, Hastings and Rother at 9.3% and Eastbourne, Hailsham and Seaford at 9%.

High Weald Lewes Havens invests £8 more per capita than the national average despite having one of the lowest prevalence rates in Sussex. Hastings & Rother and Eastbourne, Hailsham & Seaford invest less per capita (£7 and £2 respectively) with Hastings & Rother having a higher prevalence rate.

West Sussex CCGs

Between the three CCGs in West Sussex the spend per capita on children and young people's mental health varies between £58 in Coastal West Sussex, £42 in Crawley and £39 in Horsham & Mid Sussex. The prevalence rate varies with Coastal West Sussex at 8.5%, Crawley at 9% and Horsham and Mid Sussex at 7.8%.

Crawley invests £15 less per capita despite having national levels of prevalence. Horsham & Mid Sussex invests the least of all CCGs per capita at £18 less than the national average. It is noted that Horsham and Mid Sussex also has the lowest rates of prevalence.

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Section Six

What we heard

The Review Panel received a significant amount of information, views and opinions during the engagement process. The process used a mixture of methods, which included five Open Space listening events, three focus groups, service visits, and attendance at a variety of local community events. This face-to-face engagement was supported by the responses to the five online surveys and individual responses that were sent in to the Review Panel.

Overall, during the four-month engagement period we heard from over 1,500 people. Of the 1,500, over 700 people responded to the online survey for children, young people, families and health and social staff and 1 in 4 local GPs responded to the specific survey created for them.

Most importantly of all, the Review Panel heard directly from children and young people, their families and carers during the course of the engagement programme.

All of the comments, feedback and responses received through the engagement period have been analysed, synthesised and summarised to inform the report findings and recommendations. We heard and read a range of very important messages. The most consistently cited issues are set out in this section.

In these sections we have described; what people told us about their experiences of accessing services; what staff told us about delivering services locally; and the challenges faced by commissioners and managers in Sussex.

In previous sections, we have described the range of objective and quantitative data we analysed; this section focuses on experiential and qualitative information. It is important to understand that one position may not necessarily support the other, so for example, when we describe waiting times, without exception, the experience is that children and young people wait for a long time and that services describe increasing difficulty in managing waiting times. However, the data taken from the MHSDS (Mental Health Service Data Set) describes a picture of reducing waiting times and waiting times that are within local and national targets.

Access

Access to services was a consistent and strong theme throughout the review and it featured the most prominently in responses from all those with whom the review engaged. We heard of a number of examples where parents had paid for private support due to these challenges of access to local services.

They told us that:

It is not always easy to access services in Sussex because there is a confusing landscape, people are not sure what services can offer, and people don't know where to find help and criteria is unclear or inconsistent.

There is always a wait to access services and sometimes the waiting time can last many months. The view of many is that waiting times are an issue that is defined by resources and growing demand. A consistent message from those who responded was that if resources are not likely to increase, then it is important to focus on how services can become more efficient with the resources they have.

It is not easy to contact services, particularly specialist services, by phone or email and there are many occasions when there is no response to enquiries. We were told that getting a phone response is especially problematic.

Some GPs reported feeling reluctant to refer to specialist services due to long waiting times. We also heard that there are GPs who do not know how to refer to specialist services or other services.

We heard that particular groups of children and young people appear to be more affected by accessibility issues. This was especially the case for those who have an ASC (Autism Spectrum Condition). We heard that these services are not currently adequate and that there was a lack of post-diagnostic support in Sussex, which impacts on the accessibility of support. We found that there is a waiting time for access to neuro-developmental assessment services but we did not find evidence that children with neuro-developmental needs wait longer for an assessment of their emotional health or mental health from targeted or specialist mental health services. It is important to understand where children and young people are waiting and what they are waiting for.

The obstacles to access

Although many people who engaged with the review felt that waiting lists and waiting times were in and of themselves an obstacle to access, they also cited a number of other factors.

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For example, knowledge of the services available is not widespread and this applies not only to children, young people and their families, but also to professionals. There was a perception among some that certain services were easier to access than others, but that the directory or map of services is not clear, not current or up to date or widely publicised.

Although there was some recognition that there are a variety of different services on offer, we heard that people observed a clear gap in services for young people who are presenting with what they experience as significant mental health difficulties but who do not appear to meet the threshold for specialist services. The reported experience of many young people was that they end up being re-referred to services multiple times for ongoing support, even though these services are not commissioned to provide that support. We heard that families are informed of long wait times, but not then offered any support in the interim.

It was reported that children and young people living in rural areas experience particular difficulty accessing services as a result of where they live. These difficulties include; inflexibility of services in location and opening times, lack of transport with some children and young people having to rely on family members to escort them and isolation of some communities. For example, the visit to the armed service personnel on Thorney Island demonstrated their isolation from services and support.

A lack of resources was regularly reported as being a significant obstacle to improving access, with many of those who engaged with the review sympathetic to the financial challenges that services face, but less sympathetic to resources not being prioritised for children and young people.

Parents in particular expressed difficulty in accessing emotional health and wellbeing support for their children and felt this needed to be addressed, and in addition more up to date information about what is available was important to them in being able to seek the right help and support.

Equity of access

Those who took part in the engagement process reported that there was a sense of inequity of provision across Sussex. This issue was especially marked in relation to neuro-developmental services and access to them, but also related to other forms of service and support. There was a perception that children and young people who had neuro-developmental issues waited longer for emotional health and wellbeing interventions and support. The section above on access describes what we found in relation to this.

Where services are located, was reported as being difficult for some children and young people and this was seen as particularly problematic where community

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services are limited by their location. This can often be the case for those children and young people living on a geographical border between particular parts of Sussex. This was described as being of concern as where you live should not determine the level of service you receive or the access to it.

People told us that they were concerned about populations and groups who might be hidden from view e.g. those young people who were school refusers, those who were educated at home or who were absent from school.

Some parents and families told us that they felt they had to resort to paying privately for care and support in order to receive a service more quickly than local services could provide.

What could be done to improve access?

Those who took part in the engagement process offered their ideas about what could be done to improve access. The responses covered a range of options and included:

- Bringing referrals together in one place
- Reducing waiting times
- Asking young people what they want
- Collaborating - professionals should work together more and share information between them
- Improving communication between services, particularly specialist services and referrers
- Promoting and publicising - more up to date and widely available information about what is available and where is needed
- Providing interim support while waiting for more specialist services
- Delivering practical support and advice for parents and carers
- Supporting teachers and schools to deliver a range of responses.

What worked well?

Many people told us that once they were receiving services that they were very pleased and that they experienced teams and individuals as being highly competent, experienced and qualified.

Capacity

The capacity or amount of time and resource, of services to respond to the level of demand for their help was a concern for many people who took part in the engagement process.

Staffing/workforce

Those who took part in the engagement process told us that a lack of staff was, in their view, a significant contributory factor in not being able to support as many children and young people as were asking for help. Some reported that it appeared that staff working in local services were overworked and very stretched.

There was a perception that demand was high and that this was contributing to the high workload that some of those responded had observed or experienced. This experience does not match with the reduction in referrals to specialist services for example. Staff in emotional health and mental health services described being overwhelmed by the amount of referrals and numbers of people they had on caseload.

We heard the view that reductions in funding can mean cuts to workforce, and more pressure on the existing workforce to work twice as hard. We also heard about reductions in non-specialist services, some of which are local authority commissioned, for example youth services, Sure Start and others.

The nature of the 'system'

We heard that there was concern about meeting organisational performance objectives and the sense that this can sometimes get in the way of doing what is right for young people and families. It was put to us that systems are often set up to benefit organisations rather than families.

It was reported to us that the way in which services are structured is felt to be too rigid and that there is no middle ground – a sense that it is specialist services e.g. CAMHS or nothing. The importance of having a robust pathway that reserves specialist services for the most complex/high risk cases utilising other community and third sector services was stressed to us. Some of those we spoke to held concerns about the level of expertise in non-specialist services because the perception is that the most highly qualified staff work in the specialist services. This might, in part, help us to understand why families believe that only specialist services can offer the necessary support for their children and young people.

Workforce

As has been identified earlier in this report, the issue of ensuring sufficient numbers of skilled staff to deliver services is central to delivering effective help. This was highlighted through the engagement process and some of the following issues were raised:

- Workforce is not just about nurses or health care staff. It is also about those working in the third sector and local authorities
- Consideration of the knowledge and skills of the workforce in other agencies such as housing, education and leisure is needed so they can be more aware of the needs of children and young people
- Ensuring that services that can provide early help and engage in prevention and promotion activity are adequately staffed
- Need to get the balance right in the workforce across Sussex
- Importance of planning strategically for recruitment and retention
- Importance of the delivery of and impact of training across organisations and sharing knowledge.

The overriding message we heard in relation to capacity was that it was, at very least, perceived to be insufficient to keep pace with current and future demand. While much of this concern was focused on specialist services, it also applied to people's experience of third sector organisations and general practice, which also experiences capacity issues. It also relates to the reduction of other forms of community based youth and young people's services that have been reported to us.

What could be done to improve capacity?

Those who took part in the engagement process offered their ideas about what could be done to improve capacity. The responses covered a range of options and included:

- More funding to expand and improve services
- Looking at how to prevent children and young people needing help in the first place
- Needing to support children and young people earlier to stop problems happening
- Commissioning services jointly
- Commissioning a pathway rather than services.

The experience of children, young people, their families and carers

Understanding the experiences of children, young people and those who care for them provides valuable insights into how to improve those experiences, what works well and consequently what services should do more of.

As might be expected there were a variety of experiences, ranging from the very positive to those that fell below the standard that might be expected. These experiences were not simply confined to the use of services, but to the broader

issue of the awareness of and experience of poor emotional health and wellbeing.

The experience of poor emotional health and wellbeing

We heard that for many children and young people it is still hard to acknowledge and accept that they are experiencing difficulties. Even when they do, it remains challenging for them to talk about them, both with parents and carers as well as professionals.

Some children and young people expressed a preference to raise concerns about their emotional health and wellbeing with teachers or friends, rather than with health professionals, at least in the first instance. Although there is much written about the reduction of stigma, we heard that for some children and young people, it remains hard to be open about their difficulties because they are concerned about the thoughts and views of their peers and others.

The experience of the pathway

The current pathways and services were often reported to us as being confusing. There was a particular focus on the wish to seek support from specialist services and that this was experienced as a predominant and a preferred option, despite the range of other services available, although the view of many was that these also require development. We heard that there is particular confusion about what help is available for children and young people and that many parents and carers want to know who can help them decide what activity or service is best for their child.

We were told that parents are sometimes left to cope alone, trying to support their child's emotional wellbeing, but often such issues are new to them, and result in them also becoming stressed and anxious. This stress is amplified when they are left to seek help, navigating a world of services where very few people have the right information to give them or where they are challenged in being able to find that help easily for themselves.

Some told us that they needed to feel more trust in the information that is given to them about other services or support, and to have more confidence in them if they are not being referred to specialist services. For example, we were told that people might feel they want or need specialist services for their child or young person but are referred to other services such as i-Rock instead and do not really understand what it is and why it is a more relevant service for them.

Some of those who engaged with the review reported that services were not flexible enough, including their hours of operation, where the services were delivered and by which organisations. There was a sense that communication between organisations impacted on the experience of those accessing them. We

heard about inconsistency of support and that sometimes the person working with a child or young person changed. This affected the relationships they were attempting to build and meant that sometimes they had to tell their story too many times. The services were described to us as disjointed and that information is not shared well between professionals and organisations.

When services were received the response of many of those we heard from was positive, but the delays in access had a detrimental effect on the overall experience. There was a desire for more to be done in relation to looked after children, who it was reported, often experience complex difficulties that cannot be addressed through time-limited support.

We heard that some people think there is a particular problem with support for those aged 16-18. They identified this group as being underserved and felt this was a gap, with more support being needed for those in transition to adulthood, particularly when that young person may not be referred on to adult services for continued support. This is also relevant to other transition points e.g. moving from primary to secondary school settings and from school to college.

Many of those we heard from reported receiving helpful support from schools and teachers.

Do children and young people experience their voice being heard?

Decisions about the way in which services are developed and delivered, what services a child or young person should or could access are best made in close collaboration with that child, young person and their parents and carers.

We heard that this does happen and that more voices are being heard but that it was not the day-to-day, business as usual experience of many people. For some children and young people their view was that their voice is only heard if they have the self-confidence to share their views and opinions and that more needs to be done to encourage everyone to express their views.

What works well and what could be improved?

Those who took part in the engagement process offered their ideas about what had worked well for them and what could be done to improve their experiences. The responses covered a range of options and included:

- Some said that nothing works well, this included parent and carers, children and professionals. This was at odds with some of the experiential data seen in the NHSBN reporting, but nonetheless, the proportion of those who felt nothing was helpful was significant

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- This was countered by those who told us that their experiences had been much more positive, particularly once they had been able to access a service
- Waiting times, lack of communication, resources and ease of access were key issues for improvement
- The provision of peer support, earlier help, more support in schools and a focus on helping children and young people to support themselves were suggested as areas for development
- Opportunities for children and young people to have more say in their care and to be able to make choices about it, were cited as an important area for improvement.

Commissioning of services and support

Throughout the review, the issue of how services and support are commissioned has been identified as a consistent theme. The engagement process provided additional insights to this, though mostly from professionals rather than from children, young people, their families and carers. The following issues were ones that were consistently raised by those we heard from:

The commissioning structures

We heard that and observed that there are multiple commissioners across Sussex, which is not unique. These include NHS and local authority commissioners and commissioners from Public Health. The inherited legacy of the current number of CCGs has led to particular challenges, and this should be addressed by the planned and ongoing organisation changes. However, the historical impact for Sussex is that commissioners have often procured and contracted services with different service criteria and this has led to a mixed pattern of provision across Sussex. People were often not sure if the pathway worked well, if different services communicated with one another and whether computer and data systems were shared.

The limitations of geography, the boundaries between CCGs and local authorities were cited as factors in what some described as a lack of a joined up approach. We heard about good examples of commissioning and of opportunities for the CCGs and the local authorities to work together, but there was concern from some we spoke to that this was sometimes focused on specific projects or initiatives rather than on broader collaboration and development, at strategic level.

It was reported to us that the multiplicity of commissioners could make it harder to know where decisions were being made and by whom, and that the impact of those decisions on other parts of Sussex might not always be well understood, given the focus on particular localities.

We heard that for some, the experience in Sussex could be one of protective organisational behaviours, and a reluctance to think and act beyond that. This applies across the whole range of organisations. We observed a willingness to act across boundaries but also recognised that the boundaries themselves, for example thresholds and service criteria can become an impediment.

Strategic development

We often heard that the level of investment available impacts the development and performance of services. Local stakeholders appear to have accepted this as a factor that had to be worked around. We were also told that investment was not necessarily aligned with priority or need.

It was reported that longer term planning was impacted upon by the sporadic availability of targeted funding for specific purposes. This means that when such funding becomes available, a service is commissioned, but is often short term, and thus might not be sustained.

The approach to service transformation

We heard from a number of stakeholders that they wanted service transformation to be based around the needs of the child, with those needs at the centre of the thinking about transformation, rather than the needs of the organisation, with clearly defined pathways, reduced reliance on thresholds and where impact can be measured by outcomes. Where services are proven to have an impact, the need to roll these out on a larger scale was identified. It was also reported to us that more needed to be done to focus on evidence-based pathways.

We were told that commissioning needed to focus more on enabling easier and more open access, creating a set of services and supports that can improve prevention, earlier intervention and that focused less on specialist services. Prevention was seen as two things – firstly, preventing the onset of mental health issues or emotional distress, and secondly, preventing the escalation from mild or moderate difficulties to a more complex set of issues.

What could be improved?

Those who took part in the engagement process offered their ideas about what could be improved. The responses covered a range of options and included:

- Align commissioning arrangements across Sussex services for children and young people
- Address the barriers that commissioning arrangements can create e.g. only commissioning for under 18 years or 11-18 years or not family services

- Move towards pathway commissioning rather than service commissioning
- Ask young people what the issues are.

Other issues of note

Throughout the course of the review, a number of key issues have arisen.

Schools and colleges

Every engagement event or survey highlighted the role and expectations of schools and colleges. Many, many responses highlighted how important schools were both in identifying those children and young people in difficulty, and supporting them through it. People clearly felt that more support and resource could and should be offered by schools and colleges. The issues they focused on included:

- A whole school approach to emotional health and wellbeing
- Upskilling staff in schools and colleges to aid awareness of emotional health and wellbeing difficulties experienced by their pupils, to build confidence in staff groups. It was felt that it was necessary to facilitate time, space and resource, in schools to support emotional health and wellbeing
- Ensuring that mental health support for children and young people can be provided in the school and college environment and developing stronger links between schools and local services
- Increasing the number of school nurses that can conduct work in relation to emotional health and wellbeing
- Being effective in identifying and meeting the needs of children and young people who are home educated or are 'school refusers' so that they have the same access to help and support.

Children and young people who may be at 'multiple disadvantage'

Identifying and supporting children and young people who face 'multiple disadvantage' was highlighted through the engagement process. We heard that particular attention should be paid to meeting the needs of children and young people who may be affected by one or more of the following issues:

- Familial or individual homelessness
- Those living in households that are in financial hardship
- Those living in households where domestic abuse or violence is experienced
- Those children and young people in and leaving the care system, who can experience particular challenges as they transition from that environment
- Children with dual diagnosis e.g. learning disabilities or substance misuse and emotional health.

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Organisational change, policy and their impact

In common with many other health and social care systems, Sussex continues to experience organisational change and challenge. Throughout the engagement process and the broader work of the Review Panel, we heard concerns about the potential impact that such change and challenge could have. The following issues were highlighted to us:

- What will be the impact of the recent reports about Children's Services in West Sussex?

- National policy is seen as top down and not necessarily reflective of the particular needs, not only of Sussex as a whole but the specific localities within it. There needs to be a balance in the approach.

- More effective partnership working between all organisations is needed but there is concern that this could be impacted by, among other things, resources and organisational change. Leadership and co-ordination is needed to give greater focus to children's emotional health and wellbeing through shared priorities and increased collaboration.

- Given the resource pressures on Public Health, locally and nationally, how can a more preventative approach be secured and sustained?

Emerging good practice from literature review

As part of the process the Review Panel sought to identify examples of good practice in Sussex and in other parts of the UK and internationally. Some of those examples were identified through contact with local services, while others emerged from a review of literature (both published and grey), research and evidence. The literature review was conducted by Public Health in East Sussex on behalf of the Review Panel.

The Review Panel posed two questions for the researchers to consider:

1. Is there any evidence about the optimal allocation of resources and skill mix in a system i.e. the amount allocated to each tier of service provision?
2. What does a good collaborative system look like? (This might include governance / oversight / reporting structures / measures used)

The researchers found no relevant studies in the UK (published up to September 2019) that fully answer the above questions. However, there are three promising approaches undergoing academic evaluation. These are Solar, Oxford and The THRIVE Framework.

There are also a number frameworks, which could be usefully employed to assess system readiness for any proposed changes to the way in which the emotional health, wellbeing and mental health needs of children and young people are met in Sussex. Some also offer guidance for establishing effective collaboration between the key stakeholders.

Models of specialist services provision

In Solihull, **Solar** offers an integrated model with a different approach to providing specialist mental health services to children and young people. It aims to create a comprehensive system designed around the needs of children and young people. It has been set up as a service not about thresholds or tiers but about timely access to appropriate support in line with children and young people's needs. It operates an open door, single referral point and by its integrated nature enables a co-ordinated approach to intervention across its service pathway.

In Oxford, the **Oxford Health NHS Foundation Trust** has been conducting a retrospective observational study of CAMHS transformations across its delivery sites in Oxfordshire, Buckinghamshire, and Swindon, Wiltshire, Bath and North-East Somerset.

The CAMHS services provided by Oxford Health share common transformation goals, for example the improvement of accessibility and early intervention. They are all working towards a THRIVE model and have some similar core components of transformation, variously:

- A Single Point of Access (SPoA) for referrals;
- A School In Reach Service;
- Changes to pathways for treating young people who need a more intense or targeted approach;
- Community InReach, where CAMHS work more closely with third-sector partner organisations.

The **THRIVE framework** for CAMHS has been developed by the Anna Freud Centre for Children and Families at the **Tavistock and Portman NHS Foundation Trust.** It represents a shift away from the traditional tiered structure of CAMHS, instead focusing on the needs of children, young people and their families. There are 10 THRIVE sites and 10 non-THRIVE sites in England involved in a National Institute for Health Research programme.

The THRIVE Framework provides a set of principles for creating coherent and resource-efficient communities of mental health support for children, young people and families. It aims to talk about mental health and mental health support in a common language that everyone understands. The Framework is needs led; meaning that children, young people and families alongside professionals through shared decision making, define mental health needs. Needs are not based on severity, diagnosis, or health care pathways.

The THRIVE Framework brings together all local-area agencies working with children, young people and families into a 'one house' approach to mental health need, using a common language. All children, young people and families who are in need of mental health support are seen as getting one of four types of help at any one time: Advice, Help, More Help and Risk Support.
Importantly, it also prioritises maintaining young people's wellbeing through community-based prevention and promotion strategies for those who do not currently need professional support. In the Framework, these young people are thought of as 'Thriving'.

Single Point of Access

A feature of systems that are transforming their approach, including those in Solihull, Oxford and via the THRIVE framework is the use of a Single Point of Access (SPoA).

Brighton & Hove operates a SPoA. Referrals are received by a central triage hub staffed with clinicians from the partners within the Community Wellbeing Service (including Here, YMCA Brighton & Hove, SPFT specialist services, and GP's).

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Parents, carers, children and young people, as well as professionals working with them, can refer directly to the team.

The East Sussex model[36] offers a triage system for SPFT specialist services and East Sussex County Council Children's Services and a single point of advice. Benefits of the improved service include:

- One referral to the SPoA (Single Point of **Advice**), instead of multiple referrals to specialist services
- Reduced duplication
- Fewer 'touchpoints' for young people, families and referrers
- More timely and easier access to the 'right service'
- Simplified referral route.

Approaches to system change and collaboration

Working together through effective collaboration is a well-recognised element of an effective system. This is especially true in relation to the design, commissioning and delivery of emotional health, wellbeing and mental health services for children and young people. A range of organisations and professionals are needed to provide the variety of supports and interventions needed. This 'cross-sectorial' working has come to be seen as central to addressing both the determinants of poor emotional health and wellbeing and the responses required to tackle their effects.

The environmental conditions required to deliver transformational and sustainable change may differ from place to place but there are some things that are consistent. In their report, *'Are We Listening? A review of children and young people's mental health services'*[37] the Care Quality Commission (CQC) provided a number of recommendations specific to children and young people's mental health that focused on systems and local environments. In this context, the environment could include a wide range of people and organisations spanning statutory services, third sector services, children, families, communities and businesses.

Among the recommendations was the need for:

- Sustainability and Transformation Partnerships (STP) and Integrated Care Systems (ICS) to collaborate beyond the boundaries of health and social care to oversee joined-up improvement with education, police, probation and the third sector.

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36 https://www.eastsussex.gov.uk/childrenandfamilies/professional-resources/spoa/
37 Care Quality Commission, 2018

- Local systems to be given greater power and responsibility to plan, publish and deliver a shared 'local offer' that sets out how each part of the system will make their individual contribution and ensures the system delivers for children and young people.

- Commissioners and providers across education, local authorities and the NHS to facilitate cross-sector improvement in the quality and availability of data, information and intelligence.

- Commissioners, providers and staff to draw on evidence and good practice to drive local improvement.

Work by the Community Interest Company (CIC) Collaborate, in conjunction with the Lankelly Chase Foundation[38] has focused on the infrastructure needed for system change. Working with local authorities and the NHS, including in Coventry, Essex and Oldham, they have identified nine building blocks for collaborative local systems. These are the components that are needed to move from a 'siloed' way of working to a model that embraces a place-based approach and creates the conditions for collaborative practice. The nine building blocks they suggest should be in place are:

- Place-based strategies and plans
- Good governance
- Focus on outcomes and accountability
- Collaborative commissioning and investment
- Culture change and people development
- A focus on delivery
- Use of good quality data
- Making best use of both digital and physical collaboration
- Effective communication and engagement in the system.

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[38] Building collaborative places. Randle, A. & Anderson, H. Collaborate/Lankelly Chase 2017

Section Eight

Our findings

The Review Panel has considered and analysed a wide range of evidence and information. Drawing on this has enabled the identification of a series of key findings in relation to children and young people's emotional health and wellbeing in Sussex.

We have set out our findings under a series of headings that, where possible, align with the Key Lines of Enquiry, though there are some that are broader than those specific areas.

Return on Investment (RoI)

One of the questions we have been asked is what is the return on investment in the current pathway of care? In simple terms, can we demonstrate that outcomes for children and young people are improved by their contact with those services that are provided in Sussex? Understanding this, is underdeveloped in the current systems: some services can demonstrate outcomes, albeit it for very small numbers, while others either have not been commissioned to do so or cannot provide that information at this time.

Where we do collect, analyse and evaluate outcomes, these largely have a clinical base or a focus on improvements in emotional health and wellbeing rather than a holistic view of the child or young person's wellbeing. Strategically, there would need to be a shared suite of outcomes and priorities in order for services to be commissioned to provide this. Only by doing this, will it be possible to reliably establish the return on investment.

Access to Services

Our overarching finding is that for many children and young people, it is not easy to access the range of services. Too many children, young people, their families and carers report that their direct experience is one of frustration, delay and helplessness. The pressures on services mean that there can be waits for assessment and receipt of service. This is an issue across all services in the Sussex system.

In some cases, these challenges of access relate to an inability to find out about the services and support that are available in a particular area. It can also be a matter of logistics – simply getting to a service, particularly if a child or young person lives in a rural area can be problematic. This is exacerbated where there is a reliance on public transport, or if a child or young person has parents who work full time and find it hard to get time off work to take them to appointments.

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For many children and young people the issue of access to services and support centres on waiting, both for an assessment of their needs, but following that assessment, a further wait for the service to be delivered. Although in Sussex, specialist services is within the national target of 12 weeks, waiting times for assessment have risen from 19 days in July 2017, to 42 days in June 2019, more than doubling in that two-year period.

Acceptance rates into specialist services (by this we mean that the number of people referred and accepted for assessment) in Sussex remain below the national average. For every 100 children referred, only 57 are accepted for assessment.

For those children and young people who then go on to receive treatment, it is encouraging to see that the waiting time has reduced, from 31 days in April 2017 to 18 days in June 2019. We understand that this trend has continued during the period of the review.

Much time is spent by specialist services in sign-posting people to other options, or indeed, no other options, rather than engaging them in the service itself. There are many reasons for this, referrals that are not appropriate or those that do not meet the service criteria, for example. However, this is experienced as a feeling of lack of confidence in those services, among professionals as well as children, young people and their families and carers. This is particularly felt when the service has not fully communicated with them.

There is a prevailing culture among referring professionals and families that accessing specialist services is the only appropriate local offer and that these services should always intervene, help and support children and young people experiencing the wide range of emotional health, wellbeing and mental health difficulties.

There is a perception that specialist services only can offer interventions that will be of benefit. In fact, for many children and young people, specialist services may not be appropriate, given that there are a number of targeted services commissioned in all local areas that can respond to mild to moderate mental health issues and emotional health and wellbeing presentations.

The over reliance on the use of specialist services as a first response is one of the factors that could be contributing to higher levels of demand for access to those specialist services. Although those levels have plateaued in the past year, the demand remains significant. At the same time, many of the other services are also experiencing high levels of demand. This suggests that even though they may not be as widely known about, they are being fully utilised.

This highlights the importance of ensuring that across Sussex there is sufficient provision of early help, support and preventative services that can meet the needs of children and young people. Shifting the balance to a more upstream approach could have a positive impact on the demand for specialist services and broaden the options available to referrers, children and their families.

In turn, this suggests that they also have challenges in relation to the capacity and ability to respond swiftly.

We have found that there are a number of factors that are contributing to this position. These are set out below:

The pattern of provision

- The service landscape in Sussex is complex. Although there is one main provider of specialist mental health services, a network of other providers and services are commissioned to offer support and services to children and young people who may need help and support with their emotional health and wellbeing. From drop-in centres where children and young people can access help and support without a GP referral, to groups and networks run by the third sector offering a wide range of advice and support, this multiplicity of provision is welcome and has the advantage of providing wider choice for referrers and service users. However, it is evident that many professionals, children, young people, and their families are not aware of many of these other services and find it difficult to navigate a complex pathway of care and support. There is also a lack of confidence in these services being able to deliver the help and support to children and young people that families think they need. Organisational websites do not promote or offer an easy way of finding the appropriate service.

- The mix of provision means that navigating a path to the right services can be challenging. This is borne out by the experience of people who report feeling passed from pillar to post. This is compounded by a broader lack of knowledge about those services. The result of this is that too often, these services are not accessed and professionals then pursue a reliance on specialist mental health services. A move to more open access to services and support that is not reliant on professional referral in the first instance, could be beneficial.

- Many services in Sussex are located in the urban centres of population. Those children, young people and their families who live in more rural parts of Sussex experience greater difficulty in getting access to services to support them. This is often exacerbated by poor public transport links, or lengthy journeys to service locations. Those living in the rural parts of Sussex therefore experience particular disadvantages in accessing services.

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- The variations in access are in part a consequence of an inconsistent approach to the commissioning of services across Sussex. The need for a pan-Sussex approach to specialist service delivery is needed to address that inconsistency. It must pay attention to the particular needs of specific populations and locations. It is this question that needs a partnership response, to ensure that the right pathway and service models are developed and the right balance between pan-Sussex provision and a place-based focus is achieved. This needs to be supported by an expansion of upstream options for support that can ensure a range of alternative options for children and young people, which in turn can free up capacity in specialist services.

- Statutory and third sector services remain rooted in a traditional model of operation. There is little flexibility in relation to the hours that services are available, with some working a 9-5 working week, with little access outside of working hours or at weekends. There are also examples of services that are open for only half a day at a time. Where services such as i-Rock have a much more flexible approach and operate an open door policy, this is seen as much more accessible and helpful.

Access to the right services at the right time is critical. Children and young people should not have to wait for extended periods to get the help they need. Neither should they have to become so unwell that only specialist mental health services are appropriate.

There are different types of services and support that can intervene earlier, as well as opportunities for improved self-care. The review has found that these opportunities are not being grasped often enough, that there is an overreliance on referral to specialist services, and that the provision, knowledge of, and access to other forms of services remains underdeveloped.

Referral criteria and waiting times

- The current thresholds and criteria are perceived to be a barrier to access. For both referring professionals and the public they are not well understood and militate against enabling access for too many children and young people. What services do or do not provide is unclear to too many people.

- Waiting times for both assessment and treatment in specialist mental health services have been a key feature of the review. There appears to be a disparity between the data reviewed, and the experience of children, young people and their families. The data indicates waiting times to access services provided by SPFT are shorter than for peer statutory providers and yet the overriding perception of people trying to access services is one of waiting for an unacceptable amount of time.

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- Numbers on the waiting list at 31st March 2019 held an NHS wide average of 450 patients per 100,000 population (age 0-18) awaiting a first appointment with specialist services. For SPFT, this figure was 209 per 100,000 population, putting the Trust in the best performing quartile nationally.[39] The rationale for why SPFT has lower waiting list numbers could be due to accepting fewer children and young people into the service than national averages.

- This picture was not replicated in what people told us. They described experiencing long waits for both assessment and the service itself. However, the data indicates that waiting times for treatment following assessment have reduced. However, waiting times for assessment have more than doubled. The consistent message to the Review Panel was that waiting times for assessment are lengthy and in some cases even deter professionals, often General Practitioners, from making referrals. This latter issue is of particular concern.

- From interviews and survey responses it is clear that the confidence in specialist services, particularly among general practitioners, is low and work is needed to address that. Their experience and that of the public is that the response to referrals by SPFT is not swift enough, can be inconsistent regarding decision making and the service is not flexible in its approach i.e. that acceptance criteria are too rigidly applied and that sign-posting to other services is not always proactive enough.

- The adoption of a Single Point of Access (SPOA) model has proved to have some success in Brighton & Hove. We have observed that the SPOA model has brought benefits for referrers as well as children and young people and their families. It is an example of good practice, being a joined up approach that is having a positive impact on the experience of those who utilise it.

- We also heard positive experiences of i-Rock youth and wellbeing service, which offers open access without the need for a referral from a doctor.

Safety of services

We were concerned that the data we reviewed suggests that children and young people in Sussex may be at higher risk of hospitalisation through self-harm and that rates of death by suicide are higher than those living in other parts of the South East and the rest of England.

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[39] NHSBN report 2019

- Whether what we have seen and heard has directly contributed to this position is not clear, therefore, we cannot draw any reliable conclusions about the safety of services but we can say that we saw no direct evidence during the review that would demonstrate that specialist or other services are not safe.

- However, there is a clear need to positively address, monitor and respond to the current trends and the recommendations we have made seek to positively mitigate any continuing upward trend.

Workforce

- We found that there is a dedicated, hardworking and skilled workforce within specialist services and indeed in other services. They are working in an environment of high demand and a need to respond swiftly. They share frustrations about the challenges they face in the provision of responsive and effective services.

- In 2018/19, the CAMHS workforce in England grew for the sixth consecutive year. The ambitions set out in the Five Year Forward View included a continuing drive to recruit and retain more people to work in CAMHS. All providers continue to experience recruitment and retention challenges. In many cases, these challenges are related to a range of factors that can include pay levels, local costs of living (including house price affordability), transportation, as well as career progression prospects. Sussex is not unique in experiencing these pressures.

- In the past year the average workforce position nationally in community CAMHS was 84 Whole Time Equivalent (WTE) staff for 100,000 population (0-18). The current 69 WTE per 100,000 population in SPFT's specialist community services is 18% below the national average, with a workforce made up of more part-time workers than national comparators.[40] There are several reasons for this workforce pattern. Often the financial resources that are made available, sometimes on a short-term basis, can mean that only part time staff can be recruited. It may also be driven in part by a desire among the workforce, some of which migrates from London for work/life balance reasons, to work part time. From what we observed, this does not appear to affect the clinical interventions delivered, or their quality.

- The profile of the workforce in SPFT's specialist services differs significantly across the three local areas. For example, in East Sussex nursing is the predominant profession, making up 37% of the workforce, whereas in West Sussex nursing comprises less than 10% of the workforce. There is an almost direct inversion of these proportions when looking at psychology provision in East and West Sussex. Overall, the SPFT skill mix is stronger than the

[40] NHSBN report

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national average with fewer unqualified staff. However, staffing levels are lower than the national average when assessed on a per capita benchmark position. The question is whether this position has arisen directly as a result of identified local need or whether this represents an inequity of provision across Sussex? Sickness absence rates average 4% nationally across the NHS, with the peer group also reporting a 4% average. The SPFT specialist service is towards the lower end of this distribution. Staff turnover rates in specialist community services average 16% annually across the NHS and 20% across the peer group. SPFT reports a position of 17%. These two metrics suggest no immediate workforce issues for SPFT's specialist services.

- Strategically, the challenge in Sussex is how to recruit and maintain a sufficiently skilled and appropriately mixed professional workforce that is best placed to meet the needs of children and young people. This is not just a challenge for the NHS but one more broadly for Sussex commissioning and other provider partners including those in the third sector to get to grips with.

Not being joined up

- There are services that operate in a state of isolation from one another and the connectivity between them is often lacking. In the third sector, this was especially the case, where there were examples of organisations working in the same town, with similar services being offered to similar cohorts, where they were unaware of each other's existence. Within the statutory sector there are also instances of this.

- The join up or progression between different services across all sectors is sometimes lacking. This has the effect of an incoherent pathway of support. It should begin with prevention, support with building resilience and self-care, early intervention and specialist services for those with the highest levels of need. At present, the map of that pathway is punctuated by a lack of clear signage, bumps in the road and numerous diversions.

Commissioning of services in Sussex

The commissioning landscape in Sussex is changing, with a move to merge the current CCGs from seven into three, creating a new more streamlined system that should reduce duplication and provide renewed focus. These forthcoming changes will provide opportunities for improvements to be made.

Our overarching finding is that the current commissioning structures for children and young people's services in Sussex have been too inconsistent and not strategic enough. Variability of provision across the county remains a feature, with examples of CCGs commissioning their own pathways. This needs to be addressed but cannot be done solely through by the existing Local

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Transformation Plans (LTPs)[41], which by their very nature are focused on a specific geography. The opportunity to examine what elements of commissioning and service delivery could be done at a pan-Sussex level need to be explored. This would have a direct impact on the services that are commissioned, developed and reviewed.

The connectivity between the CCGs and the local authorities in relation to commissioning is not as strong as it could be. Although there are examples of joint working, these are not consistent across Sussex.

Given that Sussex has one provider of specialist services and there is variability in relation to access, performance, outcomes and experience as well as investment across the pathway, a single, overarching, longer term commissioning and strategic plan for children and young people's emotional health and wellbeing services and support is needed. The LTPs are rightly focused on individual localities, but the opportunity to take a Sussex-wide view in relation to commissioning has so far not been grasped.

In terms of specialist provision for example, across Sussex there is an opportunity to eliminate the current inequity of service through the adoption of a pan-Sussex commissioning approach, which would result in better value for money, demonstrable return on investment, efficiency and demand and capacity management.

We have found that there are a number of factors that are contributing to this position:

Leadership

- Although the statutory duty for children and young people rests with local authorities, there remain challenges in relation to leadership. These have most recently been reflected in inspection reports and concerns. It is not only these statutory duties and the leadership of them, but also the role and function of public health, which also lies within local authorities. It is critical that local authorities play their leadership role, working closely with colleagues in the NHS and third sector to ensure the right range of services and support for children and young people.

- More broadly, there has been a lack of capability and co-ordination in relation to commissioning of children and young people's emotional health, wellbeing and mental health across Sussex. The inherited legacy of the existing structures has led to commissioning that is fragmented and that

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[41]LTPs set out how local services will invest resources to improve children and young people's mental health across a whole system

takes place in a set of local silos. This has resulted in a lack of focus at a sufficiently senior level to oversee and co-ordinate commissioning for children and young people's emotional health and wellbeing and mental health.

- The oversight of, and connectivity between children's physical health and their emotional health and wellbeing is not clear. The Five Year Forward View for Mental Health[42] made clear the need for parity of esteem between physical and mental health. This is not yet a reality.

- If the public statements about the need to prioritise the needs of children and young people are to ring true, they need to be supported by senior leadership that can not only bring commissioning together across Sussex, but can engage with SPFT, the third sector, education and Children's Services in the local authorities to bring about a more co-ordinated approach at a pan-Sussex level, but also give focus to the needs of specific places.

- Commissioners' ability to work together is being hampered not only by an overall lack of single leadership, but also by a mix of roles, responsibilities and posts. Fundamental rethinking about the way in which commissioners operate and the capacity and capability that is needed to achieve the aspirations of children, young people and their families will be necessary.

- The inconsistency and variation observed in commissioning is mirrored in the delivery of services and requires a similar level of senior leadership vision and capability to address that variation. At present, there is not a sufficiently strong connection between providers and joint working between them, particularly between the statutory services and the third sector is not as effective as it could be. The ability of all providers to work together in meaningful partnership is critical to building a network of services that form a clearer, more easily navigable pathway for children, young people and their families.

The commissioning focus

- The focus in commissioning has historically tended to be on mental health rather than emotional health and wellbeing. There is evidence that current Local Transformation Plans have attempted to take a broader view in relation to emotional health and wellbeing but there is more to be done.

- There must be a wider field of vision that includes the determinants of poor emotional health and wellbeing and further exploration of the role of prevention, and public health approaches. In this context, we refer to prevention as those approaches to stop emotional health, wellbeing and

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[42] Five Year Forward View for Mental Health Farmer, P et al 2016

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mental health problems before they emerge and preventing escalation to more serious mental illness as well as work that supports people with and without mental health problems to stay well.[43]

Targets and outcomes

- Commissioning has tended to be driven by a need to respond to national targets and policy imperatives. Whilst this is recognised as being necessary and part of the current 'system' of delivery and accountability it fails to take a broader stance in relation to the outcomes being achieved.

- The key test for children and young people, their families and carers, other than actually getting support or a service, is most likely more about the outcome of the service(s) they receive and the impact they have had. Put simply, has the service or support they received resulted in a positive outcome for them and if not, why not? This test could equally be applied to providers and their performance to gain an understanding of what return on investment is possible or achievable.

- While there is a need to respond to nationally set targets and policy imperatives, there now needs to be a shift in approach from being input and output driven to being more focused on outcomes aligned to local priorities.

Strategic vision

- The Review Panel observes that current local arrangements in each of the three local authority areas have provided a demarcated and uneven structure, and the complexities of this, combined with the current CCG structures are clear. These arrangements and NHS England NHS Improvement (NHSE&I) national imperatives have necessitated the development of three separate Local Transformation Plans. These plans have some similarities but have contributed further to the sense of a fragmented approach across Sussex. The plans are not consistent in terms of the approach they offer. We should expect that local plans share a similar methodology and strategic approach to meeting the needs of their population. This would enable clarity of vision, provision and outcomes.

- Commissioners have not set out a clear or unified strategic vision in relation to children and young people's emotional health and wellbeing. Too often, the process has been characterised by short-termism. Services have been developed and plans put in place in response to specific, usually small amounts of targeted, non-recurring funding being made available either locally or nationally, rather than to local need. This has meant that the resource has been the driver for setting up services or developing particular

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[43] Mental Health Foundation definition of prevention accessed December 2019

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plans, rather than a coherent strategic vision or a response to identified needs. In part, this has contributed to a complex provider landscape that has already been identified as an issue in our findings.

- Conversely, the dominant investment feature in the children and young people's commissioning landscape remains the significant resource that flows to SPFT and has done for a number of years.

- This is not an issue that is unique to Sussex; the challenge here for local leaders is to have the ambition to be radically transformative on a whole system basis. There is a pressing need for a more long-term strategic vision that is developed, agreed and shared by all local partners and then implemented jointly.

As a Review Panel, our finding is that there is an urgent need for explicit senior leadership, streamlined structures, improved capacity and capability and improved co-ordination. A single commissioning plan and strategy would begin to address the current deficits in relation to variability by enabling a clear focus across Sussex. It would, of course be necessary for any plan to address the particular place-based issues of specific local areas, but the need for a single Sussex-wide plan, with a stronger focus on outcomes is clear.

Finances and investment

Gathering a clear picture about the levels of investment and spending on children's emotional health and wellbeing has proved a more challenging task than should have been expected.

Our overarching finding is that in relation to CCG investment in children and young people's mental health services, whilst the sums being provided are broadly in line with the national average, at £55 per capita across Sussex versus £57 per capita average nationally for mental health and learning disability, variations in investment in CCGs are not aligned to need and prevalence.

- Local authority investment in emotional health and wellbeing is harder to establish. There are known reasons for this, but a clearer understanding of investment levels is required. Current systems do not neatly or easily allow local authorities to identify such spending. This means that the review cannot draw reliable conclusions about levels of investment or where they are targeted, both in terms of services and in terms of localities.

- The investment figures stated highlight the disparities between the individual CCGs. The levels of investment are not currently distributed in a way that takes account of the levels of need across Sussex. Areas of high need are actually spending *less* than those with lower need. Access to, and

improvement of services will not be resolved by further investment alone. It will require a structural change with a coherent pathway to achieve success.

- The Review Panel has received a 'patchwork quilt' of financial information very little of which can be compared, contrasted or relied upon. The direct and targeted investment in broader, emotional health and wellbeing services and support is almost impossible to establish, this is especially the case in relation to local authority investment and expenditure. This would suggest a need to re-base the current investment profile to better take account of levels of need and to better distribute the resources where they will have the greatest impact.

- In the main, investment remains focused on reactive, treatment-focused services. The balance between investing in those services and investing in prevention, promotion, self-care and resilience, schools based support (even allowing for the Mental Health Support Team pilot) does not appear proportionate. Achieving this balance should be the responsibility of both the NHS and local authorities.

- There needs to be a better balance between investing in the specialist services and investing in prevention, promotion, self-care and resilience, and schools based support in order to create a more effective pathway.

Establishing the current levels of investment and expenditure is not straightforward. As a Review Panel, we believe that this is a consequence of counting different things against different areas of investment and work is needed to gain a clear and agreed interpretation of the numbers.

The role of schools, colleges and education

In the 2017 government Green Paper 'Transforming children and young people's mental health provision'[44] priority was given to ensuring schools and colleges are adequately supported to build whole school environments and to develop approaches within which pupils can achieve their full potential.

Children and young people spend a great deal of time at school and in college. As such, the relationships they build with their friends and fellow students, as well as with teachers and school support staff play a central role in their emotional health and wellbeing, as well as their educational development and attainment.

There are particular challenges for schools and colleges as educational institutions working in a highly regulated and achievement based environment.

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[44]
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664855/Transforming_children_and_young_people_s_mental_health_provision.pdf

They are increasingly being asked to expand their roles beyond what might be termed more traditional pastoral care to playing a greater role in ensuring the emotional health and wellbeing of their students, and being able to identify and respond to signs of emotional or mental distress. Ensuring that they are equipped to do this, and know how to access the necessary support services quickly is key.

Our overarching finding is that schools and colleges do have, and should continue to have, a central role in relation to children and young people's emotional health and wellbeing. However, at present, they are not uniformly equipped to do this, nor is it clear that they are sufficiently resourced.

From what we heard and observed, school leaders clearly see and understand the issues relating to emotional health and wellbeing, indeed they observe them first hand every day. They want to respond and to do so with urgency. They agree it is part of what they should do. What they need is the help, resources and support to do it in the best way possible.

We have found that there are a number of factors that are contributing to this position:

Funding

- The level of resource allocated to emotional health and wellbeing in schools is variable. Even within the small sample that responded in the review the variance was significant with some spending 0.01% and others up to 20%. To place it in context, a message we heard consistently is that on average, over 80% of resource is spent on classroom staff and for the majority of schools in Sussex; there is no dedicated budget for emotional health and wellbeing.

- School budgets as well as those of colleges are under significant pressure. Head teachers, like their colleagues in the NHS and local authorities have difficult and complex decisions to make on an almost daily basis in relation to the prioritisation of resources.

Workforce and training

- Schools and colleges employ a mix of staff to support children and young people's emotional health and wellbeing. Some utilise external counsellors, others have learning mentors, early help leads and welfare co-ordinators. The use of Mental Health First Aid features in the approach of many schools and colleges.

- There does not appear to be any co-ordinated programme of training for school staff, either teachers or support staff in relation to emotional health and wellbeing. There are examples of individual schools taking their own initiative, for example in East Sussex where the Youth Cabinet developed their own Top Ten Tips for Teachers and the commissioning of mental health first aid training across Brighton & Hove, both of which have proved helpful. However, a gap remains in the knowledge base and this is acknowledged by those who have contributed to the review.

Increasing prevalence

Nationally, 90% of school leaders have reported an increase in the number of students experiencing anxiety or stress over the last five years.[45] Emotional health, wellbeing and mental health issues are starting earlier and earlier in schools and the number presenting is rising. Half of all lifetime cases of diagnosable mental health problems begin before the age of 14.[46]

- The numbers of children and young people with Special Educational Needs and Disability (SEND) appears to be increasing nationally. In the period January 2017 to January 2018, it increased nationally to 1,276,215 representing 14.6% of pupils. The picture in Sussex is more mixed, but there remains a significant proportion of pupils with SEND living in the county. Brighton & Hove for example has over 6,000 children with SEND[47] and in West Sussex, it is reported there are around 20,000 children and young people with SEND receiving support in an early years setting, school or college.[48]

Knowledge of and access to services

- The Review Panel has heard from head teachers that they find the map of provision to be complex and that many schools and colleges do not have the knowledge, capacity or resources to seek and build relationships with providers that could assist them in the longer term.

- There is a reliance on referral to specialist services, school nurses and local GPs and schools experience the same challenges that parents and carers have reported in relation to accessibility. There is a sense that for many schools, such referrals feel like the only option available to them to seek support for their pupils and students.

- The piloting of Mental Health Support Teams (MHST) in parts of Sussex is welcomed and will improve access to specialist support. This is particularly

[45] Wise up to wellbeing in Schools, Young Minds
[46] ibid
[47] Summary of local strategies prepared for the Review Panel
[48] West Sussex SEND strategy 2016-19

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the case in Brighton & Hove where, if MHST was increased by one more team, they would achieve 80% coverage. However, the majority of schools in Sussex are not part of the pilot and will not benefit until further roll out of these teams take place.

- At present all referrals to school nursing across Sussex are seen within 28 days but the area has some of the highest ratios of children to WTE staff in the country, at over 2,500 children per WTE school nurse.[49] This clearly places significant demands on those staff. School nursing can have a key role in identifying emotional health and wellbeing issues in pupils and supporting the children and young people affected by them but their capacity to do this as effectively as possible is impacted by these capacity challenges.

Those not in school or who are home schooled

- Children and young people who are not in education do not have access to the support that those who do attend are able to access, however limited that support might be. They are at a disadvantage and are in essence, a hidden group whose needs are not well understood or responded to.

- The number of children who are home schooled (Electively Home Educated) is rising across Sussex. Information contained in the Local Transformation Plans indicates that in Brighton & Hove there were 247 EHE children. In East Sussex the figure is 903.[50] In West Sussex the number of EHE children was believed to be 917 in 2018.[51] Although representing a proportionately small number, again they are a largely hidden group of children whose needs are not well known.[52]

The Review Panel has found that schools and colleges clearly see the need for good emotional health and wellbeing among their pupils and students and the need for improved parental and family support. Our educational services representatives told us of the additional challenge of responding to the mental health and emotional wellbeing needs of parents as well as their children. There are frustrations with accessing services and teaching staff are feeling increasingly under pressure to respond within the school setting. The hidden costs in the school system are growing and are not sustainable.

The need to collaborate across education, health and children's services is critical to ensuring a joined up approach that enables schools and colleges to be equipped to identify and appropriately respond to the emotional health, wellbeing and mental health needs of their pupils and students, as well as supporting

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[49] NHSBN report 2019
[50] Local Transformation Plans
[51] BBC Freedom of Information Act request findings April 2018
[52] ibid

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parents and carers. In addition, the needs of children who are not in education or who are home schooled remain largely hidden from view.

Directors of Children's Services can and should take an active role in working with schools, academies and colleges to ensure that resources and plans are in place to support the emotional health and wellbeing of pupils and students. Head teachers and principals need to work together closely, perhaps through a senior leader's forum to create joint approaches to address the needs of their students and pupils.

Learning from the personal experiences and engagement of children, young people and the families and carers

The development of services and the monitoring of their quality, as well as strategic planning will always be enhanced and improved by engaging with those who use those services. Even when those messages are hard to hear, we need to actively listen and respond to them. These messages should form a central part of the contribution to current and future thinking about improvement.

The Review Panel has found that the experience of children, young people and their families of local services is not always positive and in too many cases, the personal testimony we have heard highlights some significant concerns about the way in which services have responded, or more often not responded. In many cases, these concerns are directed towards specialist services, but they are not confined to that area alone.

We did not observe that the opportunities to engage children, young people and their families and carers and draw on their experiences and views have brought about change. This has led to a lack of confidence in local provision, which, even if it were only perception, should cause concern not only for the NHS but also for other agencies including the local authorities and third sector organisations in Sussex.

There are two central factors that contribute to this position:

Not drawing on the experience of children and young people who use services

- The picture in relation to the direct experience of the children and young people who use services is mixed. Overall, the evidence suggests high levels of satisfaction with statutory and third sector services once they are accessed. This is encouraging but only provides a snapshot of those who actually received a service and should be treated with caution given that these responses relate to relatively small numbers. We are also struck by the dichotomy contained in the survey responses, which suggested that between

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40-80% of respondents said that nothing they were offered was helpful. This means that it is hard to establish a clearer overall view.

- The voice of children and young people is not being heard or used as effectively as it could be. This is not to say that they have not been listened to, there are many examples of that happening. However, the extent to which their experiences, both good and bad have influenced the way in which services adapt and improve their operation and practice is not clear.

- The mechanisms for engaging children, young people, their parents and carers in a meaningful process of listening and responding has not yet been demonstrated or featured in co-design and co-development. It is not embedded or evidenced in day-to-day practice.

Creating the opportunity to engage with children and young people

- Although there are opportunities, forums and participation programmes across Sussex, children and young people appear to be more peripheral to local processes that relate to planning, strategy and commissioning development than would be hoped. They do not appear to be present in the process of monitoring and evaluation of improvement and their influence is not as strong as it could be.

- There are some good examples of engagement and co-production in Sussex. These include youth forums, in particular Youth Cabinets, the development of the Top Ten Tips for Teachers and guide for parents, as well as numerous surveys seeking views. There should be more opportunities to engage in a sustained and regular way on matters relating to emotional health and wellbeing in type, scope and regularity.

- New ways need to be found to ensure that the voices of children and young people are heard. This will mean going to where they are, rather than where professionals are. Informal as well as formal mechanisms will be needed. Organisations such as Amaze, Allsorts and Healthwatch can all play a part in this. There needs to be movement to a position whereby organisations and services treat children and young people with due regard as being experts in their own experience, so far these appear to be lacking. Models and approaches such as Citizens Panels and Open Space events can be particularly useful mechanisms to achieve this. If they were to be adopted, the partner organisations could facilitate truly meaningful input to local planning, service development and improvement.

The two key issues the local partners must consider are: how best to use the experience of children and young people and how best to create the

circumstances, environment and opportunity for them to contribute in a meaningful way that ensures their voice is not only heard, but acted upon.

Transition to adulthood

Services that meet the needs of young adults, and provide safe and smooth transitions between children's and adult services still appear to be in the minority. The challenges faced by young people moving from adolescence into adulthood have been well documented for almost two decades. The extra challenges of negotiating service transitions at the same time have received similar attention.

This report also recognises the wider transitions that impact on children and young people – from primary to secondary school and from secondary school to college, which might also involve moving from home to campus. It is essential that we have responses and support in place to make those transitions easier for children and young people.

What should, for all young people, be a time of increasing independence and opportunity can, for young people with emotional health and wellbeing needs or mental health problems, signal a period of uncertainty and even deterioration in their mental health. This issue is not unique to Sussex but remains an issue of concern for many young people and their families and carers.

The use of CQUIN (Commissioning for Quality and Innovation) has provided a helpful lever in incentivising local organisations to achieve better outcomes in relation to transition. The CQUIN approach is one where NHS funded organisations can earn 1.25% extra income over and above the contracted amount as an incentive to improve the quality of care. The current CQUIN plan ends in March 2020.[53]

The issue of poor transition can be seen in the following challenges:

- Many transitions are still unplanned and result in acute, unanticipated and crisis presentations.[54] Barriers to transition are not restricted to age boundaries. There can be differences between children's and adult services in relation to thresholds regarding acceptance criteria, professional differences and service structures or configurations that affect the transition process.

- Joint working across the two sectors is not facilitated and it does not enable a sharing of ideas and solutions. As a result, separate service development has taken place that has not properly addressed the issues relating to transition.

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[53] West Sussex LTP refresh October 2019
[54] Planning mental health services for young adults – improving transition Appleton, S. Pugh, K. NMHDU/NCSS 2010

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Data gathering

The Review Panel sought to gather a variety of information and data as part of the review process. The majority of quantitative data requested related to performance and activity, quality and finance. Much of this was derived from the Mental Health Services Data Set (MHSDS), which was independently analysed by the NHS Benchmarking Network.

The MHSDS submissions are compiled through a national process and are made available for analysis via NHS Digital. The process of gathering and analysing the quantitative data has not been straightforward and have meant that a number of caveats have had to be applied to both the data itself and its interpretation.

There are two central factors that contribute to this position: data completeness and the focus of the data being collected.

Data completeness

- A significant amount of data was supplied by SPFT and it forms the core of the information used by the NHS Benchmarking Network in relation to community-based care. It is valuable and has provided particular insights into a range of issues. However, it does not represent the totality of the provision across Sussex and so it can only form part of what is a larger and more complex picture. It should not be seen in isolation.

- The development of a complete analytic position for Sussex children and young people's emotional wellbeing services is compromised due to the gaps in the data already described. The review of MHSDS revealed several providers who do not submit data to the MHSDS system, even though as NHS funded services they are required to do so. This creates an incomplete position in interpreting pan-Sussex activity levels.[55]

- A large number of additional providers make submissions to MHSDS but not all providers routinely submit required datasets to MHSDS. The need to submit MHSDS data is mandated by NHS Digital but compliance rates for non-NHS providers in particular are variable with this issue being evident within Sussex. This needs to be addressed as a whole system issue, with all organisations supplying and sharing data so that it can more effectively inform service planning.

- Providers are beginning to collect, analyse and provide information. They are demonstrating a desire to do more but their ability to do so is sometimes limited by what they are commissioned to do and report on.

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[55] NHSBN report 2019

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- Efforts have been made to access supplementary content from CCGs and Local Authorities, but this process has only been partially successful with gaps in data being evident.

The focus of the data being collected

- As is the case across many services and systems, the collection of data is largely focused on outputs. Outputs are a quantitative summary of an activity. They only show that an activity has taken place, not the impact of that activity.[56]

- There are examples of organisations seeking to measure and report outcomes, however, current measures do not focus sufficiently on them. Outcomes are the change that occurs as a result of an activity. At present, it is difficult to determine the range of outcomes, both positive and negative in relation to children and young people's emotional health and wellbeing.

The partners will need to take account of the data gathered and what it shows. They will also need to recognise the caveats that have been described and in that context, consider how best to make the data that is captured more robust, representative and useful.

They will need to take account of the apparent dichotomy between the quantitative data and the qualitative feedback, where the wider experience of children, young people and their families does not bear out the quantitative data. For example, the data shows good performance in relation to waiting times against national targets, but the experience of children, young people and their families is not as positive. Similarly, some of the data indicates higher levels of satisfaction with services than the responses received as part of the review. In relation to the collection of data on self-harm and suicide among children and young people, there is a need to target the monitoring of these specific indicators to evaluate the impact of existing reduction and prevention plans.

The partners will need to consider more fully the outcomes that should be achieved and focus more closely on this aspect of the information they capture and use to inform local decision-making. They must work together to address the gaps in data completeness as a whole system, so that they can better understand them, as well as utilising the data they do have more effectively.

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[56] Outputs, outcomes and indicators New Economics Foundation Presentation

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Section Nine

Recommendations

These recommendations have drawn on the wealth of information and evidence, both qualitative and quantitative, provided to the Review Panel. They have been developed in response to the key themes and findings that have emerged. They are also rooted in the principles contained in Future in Mind,[57] which provides the building blocks for promoting, protecting and improving children and young people's emotional health and wellbeing.

In making the recommendations, the Review Panel has focused on the things that it believes will have the most positive impact and benefit. There are a number of enabling factors that will assist in the delivery of the recommendations and these are described here.

The recommendations have been designed to provide the foundations for changes that will not only improve the structures and systems that should underpin both the commissioning and delivery of services, but, most importantly, lead to improvements in the experience of children and young people in Sussex.

Some of the recommendations are deliberately bold. This was the challenge set for the Review Panel by the health and social care leaders that commissioned this review. The recommendations invite the leaders of the partner organisations to share the ambition for change that will prioritise children and young people's emotional health and wellbeing and make Sussex a beacon of good practice.

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[57] Future in Mind Department of Health/Department for Education 2015

1. Partnership, accountability and implementation

Why change is needed

The partnerships in relation to children and young people's emotional health and wellbeing across Sussex have not always been as strong or effective as they could be and this has hindered joint working and improvement. Although current Local Transformation Boards are in place, the Review Panel believes that a new approach will be needed to ensure that change is embedded across organisations and that improvement is seen to be sustainable.

The Review Panel makes the following recommendations to address this:

1. **The Oversight Group should become a body that takes responsibility for the implementation of the recommendations. Children and young people, parents and carers, third sector organisations and education services representatives should be part of this group. It should hold local organisations to account for implementation and take a role in enabling progress and unblocking any barriers to delivery. It should link to existing forums and governance groups to ensure a co-ordinated approach to delivery and communication. A new chair should be appointed before the inaugural meeting to take this forward.**

2. **A concordat agreement should be developed and agreed. It should 'seal in' the commitment of all partners to work together on implementation of the review recommendations and should produce a quarterly update on the implementation of these recommendations and an annual statement of progress. All leaders of the partners who commissioned the review and published with the report should sign it. It is incumbent on the partner organisations and their leaders to work collaboratively to deliver the recommendations together to bring about the change that is needed.**

The intended impact of the recommendations

The impact of this approach should be to bring partners together in an agreed, collective and collaborative process that will facilitate more effective joint working, ensure the recommendations of the review are fully owned and implemented and that accountability and responsibility for that is both strengthened and demonstrated to the public.

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2. Commissioning

Why change is needed

The review has found that there is a lack of clear commissioning leadership that closes the gap between children and young people's services, emotional health and wellbeing and mental health delivery, resulting in fragmented and confusing pathways of care.

This has also led to the disparities in investment and service development. This is not a sustainable position for Sussex and it serves children, young people and their families poorly. We propose that aspirations need to be refreshed and revitalised and commissioning structures should be amended and adequately resourced to deliver these ambitions.

The Review Panel makes the following recommendations to address this:

3. **The NHS and local authorities should jointly create a post of Programme Director for Children and Young People's Emotional Health and Wellbeing with dedicated resource for change. This post should take a pan-Sussex responsibility for the improvement of emotional health, wellbeing and specialist mental health services and the implementation of the recommendations in this report, providing clear leadership and accountability.**

   A job description and person specification should be developed and where possible, the post should be recruited and in place as soon as is practical. During this time, continuity of leadership should be secured through a suitable candidate. The dedicated resource for change should also be identified, secured and deployed in line with the timeframe for the Director post, to support the ambitious implementation time-scales. The Director post should be fixed term for a minimum of two years, to see through transformational change.

4. **A co-ordinated commissioning structure should be established for children and young people's emotional health, wellbeing and mental health across Sussex. As part of establishing that structure, consideration should be given to the capacity and capability that exists within current commissioning teams. It should also consider how to achieve better integration of physical and emotional health. The new structure should comprise commissioners from the NHS, local authority children's leads and education to create a holistic approach that is cross-sectorial in nature. The underpinning approach should be one that ensures the commissioning of a range of services and supports needed across Sussex, in line with Future in Mind, as well as giving focus to localities where specific needs dictate that local**

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variation in service is needed. A shadow form structure should be in place where possible ahead of formal establishment.

5. **Specialist mental health services for children and young people should be commissioned on a pan-Sussex basis to provide improved consistency in terms of service expectations. This arrangement must consider and develop a clear understanding about how best to achieve the right balance between clinical consistency across Sussex and the flexibility to meet local, population needs, for example in rural and urban areas.**

6. **There should be one strategic plan for children and young people's emotional health and wellbeing and mental health in Sussex. It should set a single strategic vision for Sussex, which is underpinned by a place-based approach to meeting local need. In so doing, it must set the overall strategic direction and provide a clear and demonstrable focus on addressing the diversity of need in specific localities through its strategic intentions.**

7. **Commissioning must focus on outcomes. There should be a Sussex-wide outcomes framework that is strengths based and resilience led with clear and auditable measures of quality and effectiveness across services, both pan-Sussex and at locality level.**

The intended impact of the recommendations

The proposed changes to commissioning are intended to have a positive impact on the consistency of approach and lead to a more strategic way of commissioning, taking account of the need for some local, place-based variation. They will provide a clear demonstration of the priority the partners place on improving both the services and experiences of children and young people across Sussex by providing a specific commissioning focus and will pave the way for an integrated approach to physical and emotional services for children and young people.

3. Investment in children and young people's services and support

Why change is needed

Health investment in children and young people's mental health services across the Sussex CCGs is broadly in line with the national average. However, there are disparities in the way in which that financial resource is distributed, with areas of high need and prevalence actually investing less than those with lower need. It is

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also not clear that sufficient financial resource is being focused on services that sit earlier in the pathway.

The picture in relation to local authority funding is not as clear. This can be attributed to the fact that current systems do not neatly or easily allow the local authorities to identify spend on emotional health and wellbeing. This means that drawing reliable conclusions from the review about levels of investment or where they are targeted, both in terms of services and localities is not possible. Work is needed by the local authorities to better understand and clarify the position in relation to investment so that they can play their important role within the partnership in shaping the range of services that need to be commissioned and provided, as well as influencing the outcomes that they and the partners want to see delivered.

The need to invest upstream in public health and prevention or early intervention resources is critical to building a more effective pathway of support and intervention.

The Review Panel makes the following recommendations to address this:

8. **The CCGs financial investment in children and young people's mental health services should be re-based to ensure that the level of spending is commensurate with the level of need and that the national investment targets are met. The local authority partners must work with the CCGs to ensure a fuller and jointly understood picture of current investment and identify areas for similar re-basing and rebalancing.**

   This must include consideration of the opportunities to recast the investment in specialist services and ensuring appropriate investment from commissioners into early help, prevention and other non-specialist support services. This should be accompanied by a commitment to the transformation of specialist services to ensure a more effective system wide pathway. To aid that process, SPFT should lead a rapid process of modernisation of their specialist services to improve pathways, access and outcomes. Given the scale of transformation across partner organisations, it is recommended that a transformation programme is initiated on inception of this work.

9. **The CCG and local authority partners should work together to determine and provide clarity about how much is invested and where, particularly the amount of investment in wellbeing support and commit to improving levels of financial resource being directed into public health, prevention, early intervention and promotion delivery.**

The intended impact of the recommendations

Re-organisation and re-basing of health and social care investment will ensure that financial resources are appropriately allocated according to levels of prevalence and need. This will have the effect of improving equity of investment across Sussex, while ensuring those areas with highest need have the right level of investment to meet that need. By utilising those prevention and third sector targeted services more effectively, the commissioned pathway will be better placed to intervene and potentially prevent the need for referral to specialist services, allowing those services to focus on those with the highest needs.

Considering the balance of investment, and particularly the return on that investment, is critical in achieving the best outcomes, ensuring that financial resources are appropriately directed and that they are driving improvements.

4. Changing the service landscape

Why change is needed

The current service picture in Sussex is complex, complicated and hard to navigate. Although the specialist mental health provider NHS Trust is a central and important player, there are a myriad of other services and forms of support across Sussex. They do and should play a key role but are often under-utilised; sometimes because they are not known about. Schools and colleges report that they struggle to respond to the rising rate of need being presented to them, and in common with other professionals, families and children and young people, are confused about how, when and where to access help and support. It is unacceptable that children, young people and their families are waiting for treatment and interventions and experience limited options of support while they do so.

Too often, the specialist mental health care services are seen as the only option available when this is far from the case. The effect of this is to exacerbate waiting times, generate numerous inappropriate referrals and children and young people and their families and carers being left disillusioned and without support. This is unacceptable and unnecessary, and requires a step change in the model currently in place.

The Review Panel makes the following recommendations to address this:

10. **The current landscape of provision requires further review by commissioners. The focus of this should be an examination of the number of providers and what they provide. It should have the aim of ensuring the right range of services and supports within a sustainable system and that are more easily navigable for children, young people**

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and their families. This should include the need to ensure a fuller understanding of the range of services that need to be commissioned to build the right pathway that includes universal services, prevention and early help as well as specialist services.

11. **The Single Point of Access (SPOA) model should be swiftly developed and implemented across Sussex. The development of the model should draw on the current local experience as well as looking at models of good practice. It should provide improved and open access to universal services as well as targeted input, with minimum waiting times. It should be open to children and young people to refer themselves, as well as to their families, schools and colleges and general practitioners.**

12. **As part of the recommended specialist services transformation and modernisation process, the partners, led by SPFT should review and re-describe current thresholds and criteria for access to their services for children and young people. This should be done through a process of co-production between the partners to determine the most appropriate model so that it forms part of the overall pathway, which should include earlier help and support provided by non-specialist services.**

13. **To better support schools and colleges, the current piloting of Mental Health Support Teams in Sussex should be accelerated and expanded so that 20-25% of all schools and colleges have access to mental health professionals in line with the Green Paper.**

The intended impact of the recommendations

The experience of children and young people, their families and many professionals, including those working in general practice needs to improve. Through these recommendations it is anticipated that a number of positive impacts will be delivered.

Reductions in waiting times, easier and more rapid access to advice help and support without the need to demonstrate a particular degree of illness to get that help will improve the current reported experience greatly. So called 'inappropriate referrals' will be reduced and people will get the right help at the right time. It will enable local services to be more responsive and provide greater clarity about what they do and do not do.

They will better support schools and colleges who are not only key partners, but as professionals, have the most regular and sustained contact with children and young people.

A greater focus on prevention and public health approaches, with easier access to advice, information and service details will enable children and young people, their families and carers to take informed and positive steps to improve self-care, resilience and to know where to get the help they need.

5. Access, capacity, demand and productivity

Why change is needed

Access to appropriate services is critical to ensuring that children and young people and their families and carers get the right help and support, in the right place at the right time. The review has found that too often this does not happen. In addition, the capacity of some services to respond remains problematic evidenced by waiting times and conversion rates. National models such as the THRIVE Framework developed by the Anna Freud Centre or the System Dynamic Modelling Tool for Children and Young People's Mental Health Services[58] could help with this.

There is a need to better understand the part that workforce pressures play as well as issues of efficiency and productivity within services and whether these hinder their ability to respond.

The Review Panel makes the following recommendations to address this:

14. **All commissioned services will be expected to deliver a demand, capacity and productivity review.**

15. **The organisations in Sussex should ensure service levels and capacity that are matched to local need. The changes required are likely to take some time to achieve. In the interim, the organisations must put in place the necessary pathways and interventions to support those children and young people who are waiting.**

16. **There should be a programme of awareness and education directed to statutory referrers that clearly describes the agreed pathway model and about when and to where to refer. This will include embedding the importance of, and confidence in, the full range of commissioned services.**

17. **To improve accessibility, and given the geography of Sussex, services must operate more flexibly. This includes working beyond traditional 9-5 working hours and school hours and should include evenings and weekends. In addition, services must be offered from a**

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[58] https://cypmh.scwcsu.nhs.uk/

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broader range of locations and where appropriate, in locations that are not necessarily based in statutory sector buildings. Exploration of on-line consultation, advice giving and support as well as the use of other digital options should be explored. This could include advice from specialist services to general practitioners and social prescribers.

18. **A Sussex-wide audit and review of the targeted and specialist workforce should be undertaken. From this, plans should be developed to ensure that the number and mix of professionals working in services is appropriate. This audit should take account of any current or recent work conducted as part of the Local Transformation Plan process.**

The intended impact of the recommendations

Children and young people should not have to wait for extended periods to get the help and support they need. The impact of these recommendations, coupled with those made earlier in relation to service models, should be to reduce those waiting times, and ensure that if they do have to wait, they do not do so without some form of support.

By making services more flexible, both in terms of operating hours, locations and online solutions, it is expected that more children and young people will be able to access those services in a timely and appropriate way.

6. Co-production and engagement

Why change is needed

Children and young people have also told us loudly and clearly that they want the opportunity to co-design local services.

Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) states that children and young people have the human right to have opinions and for these opinions to matter. It says that the opinions of children and young people should be considered when people make decisions about things that involve them.

The chances to use children and young people's experiences in considering how to improve local services have been missed. Children and young people have not had enough say or influence in how services are designed to address their needs. This must change. The Review Panel makes the following recommendations:

19. **Children and young people should have a greater say in how resources are spent. An agreed proportion of the available financial resources should be delegated to children and young people to prioritise for their own communities and neighbourhoods. Commissioners and providers must also be able to demonstrate that children and young people have co-designed services and pathways.**

20. **A Children and Young People's Panel should be created. It should be composed of children and young people, their families and carers. It must attract dedicated resource to support its operation. The panel should be independently facilitated and run. It should provide an opportunity for children and young people to contribute to, and participate in the development of local services, strategies and plans. Recruitment to the panel should have as wide a representation from across Sussex as possible.**

The intended impact of the recommendations

The impact of these developments will be a demonstrable commitment to hearing and responding to the voice of children and young people. It would bring their opinions and views to the fore and enable them to contribute in a meaningful way to decisions being made about local services and involve them in ensuring that their views are heard and acted upon. It would also enable the partners in Sussex to demonstrate that they abide by Article 12 of the UNCRC.

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A road map for implementation

The implementation of the recommendations contained in the report will require not only a commitment to partnership, but also the initiation of a programme approach, with clear leadership, planning and a support structure to take them forward. To ensure and maintain momentum it will be critical to have the revised Oversight Group, with a chair, the Programme Director and concordat in place by April 2020.

A concordat agreement

The review panel is aware of the risk faced by many similar reviews that worthy recommendations fail to be translated into actions, so no one actually benefits. We believe that a different approach can be taken. The concordat that has been published with this report, and to which the partners have signed up, provides a basis to ensure a sustained, collective commitment from the partner organisations to act on the recommendations.

It could helpfully be supported by an underpinning set of working principles.

Developing a plan for implementation

To aid the development of the planning process, we have set out the recommendations (by number only) and identified those that can be categorized as short, medium and longer term, so that work can be initiated and programmed in a co-ordinated way.

These are indicative and aspirational timeframes and further work will need to be undertaken as part of the programme, to define, develop and identify the required resources, as part of an overall programme management approach for the implementation process.

Short term and immediate priorities

Recommendation One

The identification of members of the reconstituted Oversight Group, both organisationally and the individuals from those organisations, should be completed by the end of March 2020.

The first meeting of the reconstituted Oversight Group should take place by the end of April 2020. The appointment of the chair of this group should be concluded by the end of March 2020. In advance of the first meeting, work will be needed to provide role descriptions for the members of the group and its Terms

of Reference as well as putting in place the necessary governance arrangements, both internal and external.

Recommendation Two

The concordat agreement has been signed and included in this report. Should any further underpinning principles to support the partners in working together be needed, these should be developed and in place by the end of March 2020. The new chair should approve any principles and in addition confirm the membership of the Oversight Group and its Terms of Reference prior to the first meeting.

Recommendation Three

The role of Programme Director should be recruited to as soon as possible. In the meantime, interim arrangements should be confirmed no later than the end of February 2020.

By the end of March 2020, the necessary funding for the role should be in place and a role description and person specification should be agreed. This should include management and responsibility lines.

By March 2020 the fixed term role should be advertised and an appointment made as soon as is practical, ideally by the end of that month.

Recommendation Ten

By the end of April 2020, the parameters for the review of all commissioned services should be agreed, for example which services and delivery areas.

By the end of July 2020 a rapid review, led by commissioners should be completed, of promotion and publicity describing the local offer. This should include how to access the services offered, for example through websites, and ensuring information is up to date and accurate.

Recommendation Twelve

By the end of December 2020 a reviewed, co-produced and co-designed thresholds and criteria should be in place.

By July 2020 the development of co-production parameters and agreement of stakeholders and participants in this process should be agreed.

By August 2020 a programme of delivery should be agreed and work then undertaken, to deliver the reviewed thresholds and criteria by the end of December 2020.

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Recommendation Fourteen

By March 2021 an agreed capacity and demand plan should be in place.

By June 2020 the parameters for this work should be agreed and the resources needed to deliver the review must be agreed by July 2020, including the commissioning of any additional expertise that may be required.

Between August and December 2020 the review work should be undertaken and a plan agreed with the Oversight Group by January 2021.

Recommendation Sixteen

By June 2020 a central communication plan should be developed.

By July 2020 commissioners should provide updated information on local service offers and a communication and promotion plan should have been developed and agreed. It should be included in available system literature at this point.

Recommendation Eighteen

By December 2020 a workforce strategy plan should have been developed.

Between March and July 2020 existing workforce plans should be reviewed and the expectations of qualifications, skill mix and expertise for targeted and specialist workforce should be agreed and included in the plan.

Recommendation Twenty

By October 2020 a functional Children and Young People's panel should be in place.

By July 2020 the resources needed to support this should be identified and agreed.

By September 2020 the way in which the panel will be supported should be agreed, including any lines of escalation and its position in reporting and governance structures. By this time, agreement should also be reached about the organisation that will lead recruitment to the panel. This should include consideration of the commissioning of specialist expertise to support this process.
By the end of September 2020 the independent facilitation for the panel should have been commissioned and be place.

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Short to medium term priorities

Recommendation Nine

By the end of October 2020 a clear and targeted investment plan should be in place.

By July 2020 the parameters for this should be agreed and the appropriate and agreed proportions against universal, targeted and specialist provision should be identified and agreed.

By September 2020 this should be signed-off by the partners through the Oversight Group.

In the more medium term this work may be revisited in 2021 to take account of any additional priorities or changes arising from the proposed strategic plan.

Recommendation Fifteen

By March 2021 a capacity and demand plan should be agreed and in place.

By December 2020 waiting time interventions in each commissioned service should be in place.

The capacity plan should be agreed by the Oversight Group by January 2021 and the delivery expectations on the service provider(s) agreed by March 2021.

If any additional investment is required to address waiting times across the service provider landscape, this should be identified by December 2020.

Recommendation Seventeen

By January 2021 the delivery of an extended local service offer should be achieved.

By September 2020 service providers should develop a delivery plan in partnership with commissioners, co-produced with children and young people so that the greater access and flexibility required by the recommendation is informed by and responds to their needs.

Medium term priorities

Recommendation Four

By the end of 2020/21 a shadow form structure for commissioning should be established.

Between April and September 2020 the Programme Director should lead the review of current capacity and capability and present recommendations to the Oversight Group no later than October 2020.

Between December 2020 and March 2021 the change management processes required should be completed.
The process will need to take account of any current or planned organisational restructures within the partner agencies and take account of any existing or required formal partnership arrangements, including those covered by Section 75.

Recommendation Five

By the end of March 2020/21 pan-Sussex commissioning and contracting arrangements should be in place.

By the end of July 2020 the structural responsibilities, for example, the length of current contract and current investment should be identified.

By August 2020 any barriers to the proposed new arrangements must be identified and included in contractual discussions for 2021/22.

By November 2021 service specifications, performance reporting parameters and other essential contractual requirements must have been reviewed and re-drafted.

Recommendation Six

By the end of March 2020 a strategic plan should have been developed and agreed.

This will require the identification of any barriers to system wide planning, and the necessary governance steps needed to agree such a plan.

Recommendation Seven

By the end of January 2021 an outcomes framework should be developed and agreed for implementation from the start of April 2021.

This timing will enable the proposed Children and Young People's panel to input to the process.

It will need to take account of organisational and system priorities and be informed by them. Agreement will be needed by the partners and stakeholders and ensure that service specifications and performance reports can deliver on the expectations in the framework.

Recommendation Eight

By the end of October 2021 an investment plan must be developed and agreed.

By July 2021 the parameters for re-basing of investment must be agreed by all the partners. This should include consideration of whether the task should encompass emotional health and wellbeing services or include all mental health services.

By July 2021 the supporting information needed should be compiled and should include prevalence and needs data, demographics and anticipated population growth and should draw on Public Health expertise to support this work.

By the end of January 2021 the work to develop a change management programme for specialist services should be presented to the Oversight Group for approval.

Recommendation Eleven

By April 2021 Single Point of Access (SPOA) models should be in place across Sussex.

This will require review of current arrangements, identifying the good practice that exists and could be adopted and the agreement of an appropriate SPOA model.

A change management process should be put in place to deliver the change.

Recommendation Nineteen

By the end of March 2021 a resource plan that identifies investment, who will manage the resource and how it will be accessed and managed should be in place. The following milestones are indicated;

- By September 2020 the amount of resource should be identified
- By December 2020 the deliverable for that resource should be agreed

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- By March 2021 the management of the resource should be commissioned through an appropriate process.

Long term priorities

Recommendation Thirteen

By March 2023 the achievement of mental health support team provision in schools should be completed.

A programme to support delivery through existing operational and investment planning will need to be developed.

Anticipated challenges

As with all plans for implementation there are challenges associated with the delivery and the proposed timescales, we have described these to inform the discussions that will take place to agree the plan.

Recommendation Four – This is considered challenging. It is anticipated that single commissioning arrangements changes can be achieved more easily whilst joint commissioning arrangements will require more time and attention. If joint commissioning arrangements are held within a Section 75 agreement this will necessitate legal input for all parties.

Recommendation Five – Any recommendation that impacts on the commissioning and contracting of services will need a generous lead in period. Contract discussions with providers will usually commence in October or November depending on NHSE's position on last sign off date. In order to deliver this recommendation, it is proposed that there is a significant period of preparation, a duration of at least 12 months.

It is noted that this recommendation will be impacted by any senior decisions on the future organisational design of mental health commissioning in Sussex in the future.

Recommendation Eight - This recommendation includes a request that the specialist service modernises its operation. This is a large-scale change management process that will take time to; identify, plan, gain agreement for and deliver. The actions described thus far below focus on planning rather than delivery. It is proposed that this should be discussed further to understand and gain agreement about the scope of modernisation which will inform timescale delivery.

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Recommendation Nine – This is considered challenging because the important part of this recommendation is the commitment to **improve** levels of investment. Given that investment plans for 2020/2021 will already be committed by April 2020 and are already well into the planning phase, it is anticipated that partners will need time to; identify, apportion and approve any improvement levels in funding.

Recommendations Fourteen and Fifteen – Both recommendations are dependent on delivering Recommendations 5 and 10.

Recommendation Seventeen – This recommendation is considered challenging because providers will need to cost any new models and gain agreement for investment in the new model.

This set of indicative timescales, initial prioritisation and anticipated challenges is offered as a means of assisting the partners to begin to plan the implementation process. It will be for them to agree the prioritisation and some amendments may be needed to take account of other demands, parallel work and potential slippage.

The prioritisation and timescales should be kept under regular review and it is suggested that formal independent review of progress should be undertaken at the six, 12 and 18-month points in the delivery process.

The enablers that could assist with implementation

The Review Panel recognises that the recommendations will require significant work to implement and that there will be structural challenges to overcome in doing so. However, there are some enabling factors that will be of assistance in not only implementing the recommendations, but also in addressing some of the other themes and findings from the review. Many are implicit within the recommendations; others are distinct but are linked. The following are the enablers the Review Panel believes could be most helpful:

A concordat approach

The review panel is aware of the risk faced by many similar reviews that worthy recommendations fail to be translated into actions, so no one actually benefits. We believe that a different approach can be taken. We have recommended and put in place the use of a concordat approach to action planning and implementation.

Children and Young People's Panel

The creation of a Children and Young People's Panel, based on a Citizen's Panel model, will provide the opportunity for the voice of children and young people to be heard and acted upon. It will enable the partners to make decisions that are based on the views and opinions of the people they most affect. By using this method of engagement, the partners can then establish ways in which the Panel members can further contribute to monitoring and review of service developments and responses to the review. It will need to play a role in advising on how further engagement and targeted and effective communication about services and support can be relayed to children and young people. The current system of Youth Councils would also provide a helpful forum for testing ideas, gathering views and opinions.

Map of services and what they have to offer

The review has found that there is lack of up to date and accurate information available to children, young people and their families about the range of services available to support them. This is equally true for some professionals, particularly General Practitioners, who too often default to referring to specialist mental health services.

In Sussex, it should be *'business as usual'* that accurate and up to date information about local services is available easily. All NHS and local authority websites should be up to date, and refreshed at least every six months. Information about services should routinely be shared with general practitioners to the same timescale. It should also be made in a range of other settings,

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including schools, colleges, libraries, youth clubs etc. If this is the case, it will help to publicise and inform children and young people, their families and carers and other professionals about the range of services and supports that are available.

Review of contracts

The review has identified gaps in data in relation to standards, quality and performance as well as in relation to financial investment. This has a direct impact on the effectiveness of local planning, review and improvement. The current data sets collected by local organisations should be identified and reviewed. Attention should be paid to current known gaps and plans put in place to address them. In particular, there should be a focus on quality of service and the experience of those who use the services. This will better inform commissioning and monitoring of services and supports and provide a platform for more informed decisions and strategic development.

Current contracts with providers should be reviewed with particular attention paid to outcomes achieved, effective use of resources and the achievement of standards and quality measures. This process should provide assurance, and where it does not, the re-tendering of contracts should be considered.

If data about service performance and quality is routinely shared between organisations this will place transparency at the heart of the way in which the partners work together. Third sector organisations should routinely contribute to local data sets. All NHS funded services should flow data to MHSDS (Mental Health Services Data Set) and where this is not happening, this must be rectified by end of April 2020.

Finance and planning

For financial planning, the partners to the concordat must have an open book approach and identify investment to meet any statutory duty as well as what proportion of that will be used to meet emotional health and wellbeing needs. Where possible, this should be benchmarked. This level of transparency is essential to understanding how much is spent on ensuring the emotional health and wellbeing of our children and young people.

In developing a set of outcome measures, Sussex should identify a suitable comparator area against which it can benchmark its performance. By doing this is can provide the partners with a means by which to compare and contrast their position and be a lever for continued improvement.

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Conclusion

This review has been thorough and rigorous. It has adopted an approach that has sought engagement from a range of stakeholders and used the evidence from those conversations, the review of data and information, policy and research to shape the findings and recommendations.

We believe that this report provides an opportunity for the local partners to undertake changes and deliver improvements that will ensure there is a firmer foundation for the future for children and young people who experience emotional health and wellbeing difficulties in Sussex.

Acknowledgements from the Chair

A number of people contributed significantly to the review process and without them it would not have been possible to have conducted it so thoroughly, not least the Review Panel members, but also the members of the Oversight Group. Four people in particular deserve recognition:

My particular thanks go to Kim Grosvenor. Her leadership of the programme ensured that we kept on track, and upheld the aspirations and vision of the review. Her attendance at the engagement events, input to the development of this report, as well as her regular guidance and advice throughout the process was especially valuable and much appreciated.

My thanks also go to Sue Miller. Her work in gathering and analysing much of the data has been particularly helpful. Sue also visited several services and attended engagement events across the whole of Sussex as well as providing assistance with the development of this report.

My thanks to Sarah Lofts and Ruth Edmondson who supported the engagement process with diligence and were instrumental in helping to gather information on services, contacts and arranging meetings.

Steve Appleton
Independent Chair

Appendices

Appendix One
Review panel members

Steve Appleton	Contact Consulting - Independent Chair
Helen Arnold-Jenkins	Parent/carer Expert by Experience
Rachel Brett	Director of Children and Young People YMCA
Gill Brooks	Lead Commissioning Manager Children's Mental Health and Wellbeing, Brighton & Hove CCG
Ben Brown	Consultant in Public Health, East Sussex County Council *(on Panel from August 2019)*
Georgina Clarke-Green	Assistant Director Health SEN and Disability, Brighton & Hove City Council
Alison Cousens	Assistant Principal (Student Services) Brighton & Hove Sixth Form College *(on Panel from July 2019)*
Atiya Gourlay	Equality and Participation Manager Children's Services, East Sussex County Council
Amy Herring	Children and Young People's Representative Kent and Sussex / NHS England Youth Forum
Brian Hughes	Head of Targeted Youth Support and Youth Justice, East Sussex County Council
Abigail Kilgariff	Headteacher High Cliff Academy, Newhaven *(on Panel from July 2019)*
Alison Nuttall	Head of Commissioning All Age Services West Sussex County Council and CCGs
Dr Sarah Richards	Chief of Clinical Quality and Performance, High Weald Lewes Havens CCG
Jim Roberts	Headteacher Hove Park School *(on Panel from July 2019)*
Helen Russell	Lead Clinical Quality & Patient Safety Manager Brighton & Hove Clinical Commissioning Group *(on Panel from August 2019)*

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Victoria Spencer Hughes   Consultant in Public Health, East Sussex County Council *(on Panel until August 2019)*

Frank Stanford   Headteacher, SABDEN Academy (*on Panel from July 2019)*

Dr Alison Wallis   Clinical Director Children and Young People's Services, Sussex Partnership NHS Foundation Trust

Dr Ann York   Clinical Lead – NHS South East Clinical Network *(on Panel until August 2019)*

A project team whose role was to assist the Independent Chair and the panel in conducting the review supported the review panel.

Kim Grosvenor   Deputy Director – Primary and Community Care Sussex CCGs. Project Lead for the review

Sue Miller   Special Programmes Manager

Sarah Lofts   Senior Programme Delivery Officer

Ruth Edmondson   Senior Programme Delivery Officer *(from July 2019 until November 2019)*

Appendix Two
The governance structure for the review

To ensure that the review was undertaken in a rigorous and fair way, it was important to establish clear oversight of the Review Panel and to ensure that it conducted its work in accordance with the Terms of Reference and in line with the stakeholder agreed, Key Lines of Enquiry. The Review Panel was accountable to local organisations through the Oversight Group.

An Oversight Group was established, chaired by Chief Executive of the Sussex Clinical Commissioning Groups. The role of the Oversight Group was:

- To establish the membership of the Review Panel drawn from local stakeholders
- To ensure that the Review was fair and rigorous
- To ensure that the Terms of Reference were applied consistently
- To receive regular updates from the Independent Chair of the Review Panel on progress
- To suggest additional key lines of enquiry where necessary
- To be a forum for the Review Panel to test emerging themes, key messages
- To ensure oversight of the review is conducted by an appropriate and representative group of key local stakeholders.

Membership of the Oversight Group

Adam Doyle	CEO of the CCGs in Sussex and the Senior Responsible Officer for the Sussex Health and Care Partnership. Chair of the Oversight Group
Samantha Allen	Chief Executive, Sussex Partnership NHS Foundation Trust
Karen Breen	Deputy Chief Executive and Chief Operating Officer, Sussex Clinical Commissioning Group
Andrew Fraser	Interim Director of Children and Family Services, West Sussex County Council (*until mid-May 2019*)
Pinaki Ghoshal	Executive Director, Families, Children and Learning Brighton & Hove City Council
Stuart Gallimore	Director of Children's Services, East Sussex County Council
Wendy Carberry	Executive Director of Primary Care, Central Sussex & East Surrey Commissioning Alliance *(until August 2019)*

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John Readman   Interim Director of Children and Family Services, West Sussex County Council *(from mid-May 2019 until January 2020)*

AnnMarie Dodds   Interim Director of Children and Family Services, West Sussex County Council *(from January 2020)*

Steve Appleton, Independent Chair and Kim Grosvenor, Project Lead attended Oversight Group meetings.

Appendix Three
The Terms of Reference

- How effectively are children and young people and families engaged?
- How effective is the pathway in terms of equality of access, reach of service provision, integration, knowledge of services within the system, quality of referrals and responses to referrers, families and young people?
- What is the quality and timeliness of services delivered to children and young people?
- How well do stakeholders understand current contractual arrangements, thresholds, services and monitoring data?
- What evidence is there of outcomes from interventions?
- Review of the Children and Young Person's Journey
- The story of children/young people as developed through case file audits and talking to children/young people and families
- Experiences of all who are part of the system as referrers, sign-posters, practitioners, commissioners
- Developing core points for future contracting.
- Setting the Sussex service provision in the context of regional and national delivery
- Identification of key quality and outcome criteria with a robust reporting framework to allow robust assurance for statutory commissioning organisations i.e. Clinical Commissioning Groups, Local Authorities, NHS England/Improvement
- Issues for future mental health strategy and commissioning of CYPMHs in Sussex going forward i.e. how much should we be investing and where? How do we ensure best value for money in meeting the needs of children across Sussex?

Appendix Four
The Key Lines of Enquiry

Having considered the Terms of Reference for the review, it was agreed to distil these into a concise set of Key Lines of Enquiry (KLOE). This enables the Review Panel to remain focused and to consider a series of questions that informed the final report and its recommendations.

1. Access to services

- How easy is it to access services?
- What obstacles exist and why?
- Is there equality of access across Sussex? If not, why?
- How responsive are local services?
- What could be done to improve access?

2. Capacity

- What is the level and type of provision of services for children and young people?
- Is current capacity sufficient? If not what needs to change?

3. Safety of current services

- How are children and young people kept safe within and without services in Sussex?
- Effectiveness of local safeguarding processes?

4. Funding and Commissioning

- How and by whom are services commissioned?
- What are the available financial resources?
- How do these compare to other similar areas?
- What are the local strategies, how have they been implemented?
- Should there be an overarching plan for Sussex?

5. The experience of children, young people and their families

- What is the experience of children, young people and their families?
- How do they experience the pathway?
- What knowledge do they have of local services?
- How do they think their voice is being heard (if it is)?
- What do they think works well?
- What do they think needs to change or improve?

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6. Effectiveness

- How effective are local services for children and young people?
- Do the current pathways deliver?
- What are the quality and outcome measures?
- Do these help to inform service development and improvement?
- Do they need to change?

7. Relationships and partnership

- How well do services work together?
- How do the LAs, NHS and third sector collaborate?
- How can these relationships and partnerships be strengthened?

GLOSSARY

CAMHS – Child and Adolescent Mental Health Services
CAMHS are the NHS services that assesses and treats young people with emotional, behavioural or mental health difficulties. CAMHS support covers issues such as depression, problems with food, self-harm, abuse, violence or anger, bipolar, schizophrenia and anxiety.

CCGs - Clinical Commissioning Groups
CCGs are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.

An upstream approach
Upstream services, interventions and strategies focus on improving the supports that allow people to achieve their full emotional health and wellbeing potential. An upstream approach requires the whole system to consider the wider social, economic and environmental origins of emotional health and wellbeing problems, not just the symptoms or the end effect.

Such an approach can be used to address not only the policies and strategies in a cross-sectorial way that will improve the conditions that affect emotional health and wellbeing, but also the provision of specific services to address their impact on it for children and young people. Typically these focus on prevention, self-care and promotion.

Tier 1 - universal services
These include general practitioners, primary care services, health visitors, schools and early year's provision.

Tier 2 - targeted services
These services include mental health professionals working singularly rather than as part of a multi-disciplinary team (such as CAMHS professionals based in schools or paediatric psychologists in acute care settings).

Tier 3 – specialist services (CAMHS)
These are multi-disciplinary teams of child and adolescent mental health professionals providing a range of interventions. Access to the specialist team is often via referral from a GP, but referrals may also be accepted from schools and other agencies, and in some cases self- referral. Specialist CAMHS can include teams with specific remits to provide for particular groups of children and young people

Tier 4 - highly specialist services
These include day and inpatient services, some highly specialist outpatient services, and increasingly services such as crisis/ home treatment services, which provide an alternative to admission. Such services are often provided on a

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regional basis. Each of these services will have been commissioned on a national basis to date.

Transition

This is a time of change from one place/service to another. In terms of mental health, this may mean the transfer of clinical care from child to adult mental health services. It is also possible that a young person may no longer need the support of the CAMHS team, so they will be discharged and will continue to receive support from others, but is not referred on to adult mental health services.

For those young people who do continue to have severe mental health problems that require a transition to adult mental health services, this transition from one service to another should be a smooth process that offers uninterrupted continuity of care.

There are other transitions that impact on children and young people e.g. the move from primary to secondary school and from secondary school to college, which might also involve moving from home to campus.

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