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To: All Members of the Health and Wellbeing Board

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6 July 2023

Your contact is: Nicky Simpson - Committee Services

NOTICE OF MEETING - HEALTH AND WELLBEING BOARD 14 JULY 2023

A meeting of the Health and Wellbeing Board will be held on **Friday, 14 July 2023 at 2.00 pm** in the **Council Chamber, Civic Offices, Bridge Street, Reading RG1 2LU**. The Agenda for the meeting is set out below.

AGENDA Page No

CIVIC OFFICES EMERGENCY EVACUATION: *If an alarm sounds, leave by the nearest fire exit quickly and calmly and assemble on the corner of Bridge Street and Fobney Street. You will be advised when it is safe to re-enter the building.*

A report outlining the key findings and recommendations of Community Participatory Action Research carried out in 2021-22 to research and evidence the striking inequalities facing minority ethnic communities in accessing healthcare in Reading.

6. HEALTHWATCH READING ANNUAL REPORT 2022/23 61 - 86

Healthwatch Reading's Annual Report for 2022/23, giving details of the work carried out by Healthwatch Reading in 2022/23.

7. HEALTH AND WELLBEING STRATEGY QUARTERLY IMPLEMENTATION PLAN NARRATIVE AND DASHBOARD REPORT 87 - 116

A report giving an overview of the implementation of the Berkshire West Health and Wellbeing Strategy 2021-2030 in Reading and detailed information on performance and progress towards achieving the local goals and actions set out in the both the overarching strategy and the locally agreed implementation plans.

8. AUTISM STRATEGY: YEAR 1 ACTION PLAN UPDATE 117 - 190

A report giving an update on the progress of the Year 1 (2022/23) All Age Autism Strategy Action Plan across Reading.

9. BERKSHIRE WEST PLACE-BASED PARTNERSHIP - BRIEFING 191 - 198

A report on the revised Unified Executive arrangements as a Place-Based Partnership including the governance, programme of priority areas as well as seeking to strengthen accountability of the United Executive into the Health and Wellbeing Board and its delivery against the Health and Wellbeing Board Strategy.

10. BOB ICB JOINT CAPITAL RESOURCE USE PLAN 199 - 208

A report presenting the BOB ICB Joint Capital Resource Use Plan, which sets out the planned capital resource use for the ICB and its partner NHS and Foundation Trusts.

11. COVID-19 PANDEMIC UPDATE 209 - 216

A presentation giving an update on the latest situation on the Covid-19 pandemic.

12. DATE OF NEXT HEALTH & WELLBEING BOARD MEETING - 6 OCTOBER 2023

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Present:

Councillor Ruth McEwan (Chair)	Lead Councillor for Education and Public Health, Reading Borough Council (RBC)
Tehmeena Ajmal	Chief Operating Officer, Berkshire Healthcare NHS Foundation Trust (BHFT)
Councillor Jason Brock	Leader of the Council, RBC
Andy Ciecierski (Vice-Chair)	Clinical Director for Caversham Primary Care Network
Tracy Daszkiewicz	Director of Public Health for Berkshire West
Councillor Graeme Hoskin	Lead Councillor for Children, RBC
Councillor Alice Mpofu-Coles	Chair of the Adult Social Care, Children's Services and Education Committee, RBC (substituting for Councillor Ennis)
Lara Patel	Executive Director of Children's Services, Brighter Futures for Children (BFfC)
Belinda Seston	Interim Director of Place Partnership Development, Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) (substituting for Sarah Webster)
Eamonn Sullivan	Chief Nurse, RBFT
Melissa Wise	Acting Executive Director of Adult Social Care & Health

Also in attendance:

Chris Greenway	Assistant Director for Commissioning and Transformation, RBC
Bev Nicholson	Integration Programme Manager, RBC
Amanda Nyeke	Public Health & Wellbeing Manager, RBC
Councillor Simon Robinson	Conservative Group Observer

Apologies:

Sarah Deason	Healthwatch Reading
Paul Illman	Royal Berkshire Fire & Rescue Service
Alice Kunjappy-Clifton	Lead Officer, Healthwatch Reading
Gail Muirhead	Prevention Manager, Royal Berkshire Fire and Rescue Service (RBFRS)
Sarah Webster	Executive Director for Berkshire West, BOB ICB
Martin White	Consultant in Public Health, RBC
Jackie Yates	Chief Executive, RBC

51. MINUTES

The Minutes of the meeting held on 20 January 2023 were confirmed as a correct record and signed by the Chair.

52. QUESTIONS IN ACCORDANCE WITH STANDING ORDER 36

The following questions were asked by Tom Lake in accordance with Standing Order 36:

a) New Surgery Premises for South Reading:

There has been much talk over new surgery premises for South Reading over a number of years. Church land appears to have been allocated for the purpose, yet no progress has been made. Will there be new premises or a new surgery in South Reading?

REPLY by Belinda Seston (Interim Director of Place Partnership Development – Berkshire West) on behalf of the Chair of the Health and Wellbeing Board (Councillor McEwan)

The Integrated Care Board continues to liaise with GP providers regarding the potential development of a new site in Whitley. We are also working with Reading Borough Council to update our assumptions regarding housing growth and population change which will inform decision-making around what is required in the area.

b) Primary Care Commissioning

Under the Berkshire West CCG we had regular meetings in public of the Primary Care Commissioning Committee. Investments in primary care, closing and opening of patient lists, additional services, vaccination campaigns and additional clinical roles in primary care networks were discussed in public, attracting public engagement. There was also a strong and developing quality and performance report on primary care.

None of this is now available to the public. It ceased when the Primary Care Commissioning Committees across BOB amalgamated after the meeting of 14th April 2021, almost two years ago.

Will the BOB ICS seek to engage the public with primary care where they experience much difficulty and frustration?

How and when will this be restored? Will provision be covered to the depth indicated above?

REPLY by Belinda Seston (Interim Director of Place Partnership Development – Berkshire West) on behalf of the Chair of the Health and Wellbeing Board (Councillor McEwan):

The requirement to have a Primary Care Commissioning Committee (PCCC) meeting in public related to CCGs' status as a membership organisation made up of its constituent GP practices, and was therefore important for managing potential conflicts of interest. The structure and status of the recently formed ICB (Integrated Care Board) is not the same, and we have taken the opportunity to streamline decision-making processes as a result.

PCCCs were not intended as a sole means of involving the public in decisions. Instead, where appropriate, public service user engagement should have occurred prior to matters being brought to the Committee meeting. This remains the case and we continue to ensure that residents' views have been taken into account when considering issues such as those you mention, working with GP practices to link in with Patient Participation Groups, Healthwatch and other forums as appropriate. Our ICB also holds public Board meetings. In addition this Health and Wellbeing Board is also an important link to the public and we thank you for your question.

In response to a supplementary question from Tom Lake "Will the Board take an interest in Patient Participation Groups and see that they are meeting actively and are patient-led?", Belinda Seston responded that it was important to ensure that the voices of Reading residents were heard and that this was an important point. She said that she would take this matter back to the BOB ICB Communications Lead to make sure that existing forums were as strong as they could be and that these voices were heard, and she would get back to Mr Lake.

53. HEALTH AND WELLBEING STRATEGY QUARTERLY IMPLEMENTATION PLAN NARRATIVE UPDATE

Amanda Nyeke submitted a report that provided an overview of the implementation of the Berkshire West Health and Wellbeing Strategy 2021-2030 in Reading and gave detailed information on performance and progress towards achieving local goals and actions set out in both the overarching strategy and the locally agreed implementation plans.

The Health and Wellbeing Implementation Plans Update was attached at Appendix A and contained detailed narrative updates on the actions agreed for each of the implementation plans and included the most recent update of key information in each of the five priority areas.

- Priority 1 - Reduce the differences in health between different groups of people;
- Priority 2 - Support individuals at high risk of bad health outcomes to live healthy lives.
- Priority 3 - Help families and children in early years;
- Priority 4 - Promote good mental health and wellbeing for all children and young people;
- Priority 5 - Promote good mental health and wellbeing for all adults.

Paragraph 2.1 of the report set out details of updates to the data and performance indicators which had been included since the last report.

In response to a query, Amanda Nyeke explained the red/amber/green status: red was where no work had commenced in the area, the one area which was amber was because although work had been developed, the data was outdated and needed refreshing, and green meant that all sub-actions were taking place. It was suggested that this information should be included in the narrative for future reports.

Resolved –

(1) That the report be noted;

(2) That further information explaining red/amber/green status be included in future reports.

54. INTEGRATION PROGRAMME UPDATE

Bev Nicholson submitted a report giving an update on the Integration Programme and its performance against the Better Care Fund (BCF) targets covering the period October to December 2022 (Quarter 3) and outlining the spend against the BCF Plan and the Adult Social Care (ASC) Discharge Fund Plan (2022/23), an additional fund provided by NHS England to be used to support hospital discharge over the Winter period.

The report noted that the BCF metrics had been updated for 2022/23 and that targets for each of the metrics had been agreed with system partners during the BCF Planning process. It noted that the 'Length of Stay' target had been removed for 2022/23 but was still being tracked locally. The four remaining metrics and their outcomes as at the end of December 2022 were as follows:

- The number of avoidable admissions (unplanned hospitalisation for chronic ambulatory care) (Met);
- An increase in the proportion of people discharged home using data on discharge to their usual place of residence (Met);
- The number of older adults whose long-term care needs were met by admission to residential or nursing care per 100,000 population (Met);
- The effectiveness of reablement (proportion of older people still at home 91 days after discharge from hospital into reablement or rehabilitation) (Not Met).

Further details of the delivery against each of the targets were set out in the report alongside the performance of the local schemes demonstrating the effectiveness of collaborative work with system partners. Spend against the BCF Plan and the ASC Discharge Fund was also outlined in the report.

Resolved -

(1) That the Quarter 3 (2022/23) performance and progress made in respect of the Better Care Fund (BCF) schemes as part of the Reading Integration Board's Programme of Work be noted;

(2) That the spend against the Adult Social Care (ASC) Hospital Discharge Fund Plan for 2022/23, which was subject to fortnightly reporting to NHS England until the end of March 2023, be noted.

55. ROYAL BERKSHIRE NHS FOUNDATION TRUST - OPERATING PLAN 2023/24

Eamonn Sullivan gave a presentation on the Royal Berkshire NHS Foundation Trust Operating Plan 2023/24. The presentation slides had been included in the agenda papers.

The presentation covered the following areas:

- Operating Standards for Acute Trusts – 2023/24 – expectations set by NHS England that the Trust planned to overachieve against and were already delivering to in a number of areas.
- Trust Strategic Metrics for 2023/24
- Improvement Priorities for 2023/24, including the following cross-cutting breakthrough priorities:
    - Recruit to establish – to support delivery of improved quality of care for patients, staff retention and financial performance
    - Reduce the number of stranded patients, supporting the reduction in waiting times for inpatients and improving patient experience and care
    - Reduce the number of 62 day cancer waits to improve patient care, reduce waiting times and improve patient experience.

Resolved - That the presentation be noted.

56. ROYAL BERKSHIRE NHS FOUNDATION TRUST – INTEGRATED PERFORMANCE REPORT

Eamonn Sullivan submitted a report summarising the Royal Berkshire NHS Foundation Trust's performance as at 31 December 2022 against the eight strategic metrics measured for its five strategic objectives, three breakthrough priorities and a range of watch metrics.

The report stated that, during the period of reporting, the Trust had continued to experience demand pressures in excess of 2019-20 levels across non-elective pathways and had continued to reduce the pandemic-related elective backlog.

Despite the sustained pressure, the staff had continued to provide high quality, safe care, and both the experience and harm indicators remained at normal levels. However, the Trust had not met the national and local targets within the Deliver in Partnership objective resulting in all the metrics alerting. The same pressures were limiting the Trust's progress in delivering care closer to home.

Good progress continued to be made in reducing the average wait for elective care, but high levels of demand and challenges in maintaining flow through the hospital continued to impact performance against the four hour standard. Waiting times for diagnostic services and especially MRI, Endoscopy and Pathology, continued to be challenged and were impacting on cancer performance. Actions to address this were set out in the Breakthrough priority on cancer.

The Trust's workforce turnover rate and vacancy rates had remained above target, having been suppressed during the pandemic. The Trust had invested in additional resources to support recruitment and retention and this would be a focus of the People directorate for the next few months.

The combination of elevated demand for services, challenges in recruiting and retaining staff and inflationary pressures had resulted in the Trust recording a financial deficit of £14.3m in the year to December 2022. Remedial actions were in place to mitigate this but the Trust did not expect to deliver its planned surplus for the year.

A range of watch metrics had been alerting in December 2022 which would be discussed by the quality, workforce and finance committees. The majority of alerting metrics were closely related to strategic metrics. A further set related to action the Trust had in place to enhance completion of mandatory training and timely appraisals.

The report gave further details of performance against each of the metrics, also setting out actions and risks.

It was noted at the meeting that the Reading Urgent Care Centre had opened in December 2022 and it was queried how much difference this had made to the extreme pressure on the Trust. Eamonn Sullivan said that the impact of the Urgent Care Centre was currently being evaluated and the Trust was working closely with partners to ensure the best use was made of the Centre and digital systems in order to help reduce the pressures, but on initial analysis it did seem to have made a positive difference.

Resolved – That the report be noted.

57. BOB INTEGRATED CARE SYSTEM - UPDATE

Belinda Seston gave a presentation on the development of the BOB Integrated Care System. The presentation slides had been included in the agenda papers.

The presentation covered:

- The BOB ICS Construct
- The Draft BOB Integrated Care Strategy
- The BOB ICB Joint Forward Plan
- The development of the Berkshire West Place Based Partnership (PBP)

It was noted that there was a senior officer joint Working Group established to develop the PBP which was meeting weekly and involved NHS Directors and the Directors of Adult Social Care and good progress was being made.

Resolved – That the position be noted.

58. PROCEDURAL REPORT ON BOB ICB PLANNED CONSULTATIONS

Melissa Wise submitted a report giving details of four strategic documents that the Integrated Care Board planned to consult with the Health and Wellbeing Board on, in line with the statutory requirements set out in the report:

- Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) Joint Forward Plan
- The BOB ICB Annual Report
- NHS England Performance Assessment of the ICB
- The BOB ICB Joint Capital Resource Use Plan

Each of the documents had specific timescales for consultation which did not easily coincide with the programme for meetings of the Board. To manage this, the report proposed that officer delegation was given to allow for timely responses to the consultations on the ICB Annual Report and NHSE performance assessment of the ICB on behalf of the Board each year. It stated that for 2023, a joint letter from the ICB and NHS England was planned to be sent by 13 March 2023, asking for a response by 27 March 2023 to the following questions:

- How effectively has the ICB worked with its NHS and wider system partners to implement the Joint Local Health & Wellbeing Strategy (JLHWS)?
- What steps has the ICB taken in implementing the JLHWS?
- What more could the ICB do to support implementation of the JLHWS?

The report noted that, as 2023 was the first year of the new BOB ICB, the deadline for the consultation on the BOB ICB Joint Forward Plan was 30 June 2023, and since the next scheduled meeting of the Board was not until July 2023, it proposed that an additional meeting of the Board should be held in June 2023 to consider the Joint Forward Plan.

The report explained that, once the BOB ICB published its Joint Capital Resource Use Plan, it would send a copy to the Chairs of the Integrated Care Partnership and Health and Wellbeing Boards. There was no requirement for the Board to formally respond but it could be reported to a future meeting of the Board for information.

Resolved:

(1) That the Executive Director for Adult Social Care & Health be delegated authority to respond, on behalf of the Health and Wellbeing Board, to consultations on the ICB Annual Report and NHSE performance assessment of the ICB, in consultation with the Chair of the Board;

(2) That an additional meeting be held in June 2023 to allow an opportunity for the Board to respond to the BOB ICB Joint Forward Plan and approve its statement of opinion before the deadline of 30 June 2023;

(3) That the position regarding the BOB ICB Joint Capital Resource Use Plan be noted.

59. COVID-19 AND READING VACCINATION UPDATE

Amanda Nyeke gave a presentation on the latest Covid-19 data and on Covid-19 and Flu vaccination uptake in Reading. The presentation slides had been included in the agenda papers.

The presentation provided statistics, including national, regional and Reading figures, for the number of Covid-19 infections, cases, hospital admissions, and deaths. The presentation also included statistics for the uptake of Covid-19 vaccinations, the Autumn Booster and flu vaccinations.

It was reported that it was not yet known who would be providing the Spring Covid-19 Booster and Amanda Nyeke said that she would find out.

It was noted that, at the meeting held on 7 October 2022 (Minute 19 (c) refers), a parent had reported that she had personally been unable physically to submit written consent for her child's vaccination but had also been unable to access an online permission facility and so her child had not received their vaccination; it was queried whether the process for permissions had now been improved. Amanda Nyeke said that she would take this back to colleagues and investigate.

It was suggested that, as Covid-19 vaccination was now becoming routine, with expected spring and autumn boosters, it would be sensible for the Board to receive six-monthly or annual updates on the situation on infections and vaccinations, instead of to every meeting. Before the pandemic, the Board had received an annual update on the seasonal flu campaign.

Resolved –

(1) That the position be noted;

(2) That Amanda Nyeke find out more information about the Spring Booster programme delivery and whether the school vaccination permission programme had been improved:

(3) That future updates on Covid-19 and Vaccinations be submitted either annually or six-monthly rather than to every meeting.

60. READING COMMUNITY VACCINE CHAMPIONS - EVALUATION REPORT

Futher to Minute 4 of the meeting held on 15 July 2022, Amanda Nyeke presented a report with, attached, the Reading Community Vaccine Champions (CVC) Evaluation Report which had been published in February 2023 by the Public Health and Wellbeing Team.

The report explained that the Reading CVC programme had been funded by the DLUHC with the aim of increasing vaccination uptake, increasing visibility, awareness and interaction of CVC Champions within the local area and increase the reach and trust of public health messaging for target communities. The programme had taken place between January and October 2022.

The report set out the six workstreams which had been formed and gave details of five areas of key achievements. It presented the successes, challenges and key learning from the programme and made overarching and case study recommendations for the future, including looking for opportunities to develop a pathway to enable the CVC Champions network to continue.

The report stated that a further report about the recommendations within the Evaluation Report and the current developments in the Champions Network would be submitted to a future meeting.

Resolved – That the report be noted and a further report be submitted to a future meeting.

61. DATES OF FUTURE HEALTH & WELLBEING BOARD MEETINGS

Resolved – That the meetings for the Municipal Year 2023/24 be held at 2.00pm on the following dates:

- 14 July 2023
- 6 October 2023
- 19 January 2024
- 15 March 2024

(The meeting started at 2.00 pm and closed at 3.17 pm)

Present:

Councillor Ruth McEwan (Chair)	Lead Councillor for Education and Public Health, Reading Borough Council (RBC)
Tehmeena Ajmal	Chief Operating Officer, Berkshire Healthcare NHS Foundation Trust (BHFT)
John Ashton	Interim Director of Public Health for Reading and West Berkshire
Councillor Jason Brock	Leader of the Council, RBC
Andy Ciecierski (Vice-Chair)	Clinical Director for Caversham Primary Care Network
Councillor Paul Gittings	Lead Councillor for Adult Social Care, RBC
Alice Kunjappy-Clifton	Lead Officer, Healthwatch Reading
Steve Leonard	West Hub Group Manager, Royal Berkshire Fire & Rescue Service
Councillor Alice Mpofu-Coles	Chair of the Adult Social Care, Children's Services and Education Committee, RBC (substituting for Councillor Hoskin)
Rachel Spencer	Chief Executive, Reading Voluntary Action
Sarah Webster	Executive Director for Berkshire West Place, Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB)
Melissa Wise	Interim Executive Director of Adult Social Care & Health, RBC

Also in attendance:

Chris Greenway	Assistant Director for Commissioning and Transformation, RBC
Rob Bowen	Acting Director of Strategy and Partnerships, BOB ICB

Apologies:

Councillor Graeme Hoskin	Lead Councillor for Children, RBC
Caroline Lynch	Trust Secretary & Data Protection Officer, Royal Berkshire NHS Foundation Trust (RBFT)
Lara Patel	Executive Director of Children's Services, Brighter Futures for Children (BFfC)
Steve Raffield	LPA Commander for Reading, Thames Valley Police
Eamonn Sullivan	Chief Nurse, RBFT
Martin White	Consultant in Public Health, RBC
Jackie Yates	Chief Executive, RBC

1. BOB INTEGRATED CARE SYSTEM JOINT FORWARD PLAN

Rob Bowen submitted a report presenting the draft Buckinghamshire, Oxfordshire and Berkshire West (BOB) Joint Forward Plan (JFP), which described how the BOB Integrated Care Board (ICB) and partner NHS trusts were required to develop an annual, five year Joint Forward Plan and the first JFP had to be published by 30 June 2023. The Health & Wellbeing Board was required to provide comment on the JFP's alignment to the current Joint Local Health and Wellbeing Strategy – specifically whether the draft JFP took proper account of the strategy - by 30 June 2023, when the first JFP would be formally published. The report had appended a summary of the JFP and included weblinks to supporting documents and appendices.

The report explained that national guidance set out that the JFP needed to describe how the ICB and partner NHS Trusts intended to arrange and/or provide NHS services to meet their population's physical and mental health needs. This should include the delivery of universal NHS commitments. Systems were also encouraged to use the JPF to develop a shared delivery plan for the Integrated Care Strategy and the Joint Local Health and Wellbeing Strategies (JLHWS).

The plan intended to balance delivery of the BOB Integrated Care Strategy ambitions with delivery of the other NHS commitments. The plan had been developed jointly with BOB Integrated Care System (ICS) partners with input and feedback from wider system and public engagement, including input from local authority partners, which had informed the development of the JFP.

The BOB JFP addressed the ambitions across the organisations and also recognised the value and importance of partnerships with local authorities in the ongoing development and delivery of services for the benefit of the people and communities who lived and worked in the area. The JFP set a rolling five-year ambition and would be updated annually before the beginning of each subsequent financial year.

The report stated that the JFP aligned with and built on the strategies, approaches and targets set out by the three JLHWSs developed by the five Health & Wellbeing Boards across BOB. It referred to the five key priorities in the Berkshire West JLHWS and explained that the JFP took into account these strategic priorities and they were picked up in the service delivery plans aligned to the five themes of the Integrated Care Strategy:

- Promoting and Protecting Health
- Start Well
- Live Well
- Age Well
- Improving Quality and Access to Services.

A table in the report set out this alignment, mapping the Berkshire West Health & Wellbeing Priorities to the BOB JFP.

The Board discussed the draft Joint Forward Plan and the comments made included:

- The JFP did take proper account of the Berkshire West Joint Health & Wellbeing Strategy and aligned appropriately with the Strategy.

- The Board's formal response should embrace the principle of integration, reflecting the integrated care system partnership role and avoiding a 'you and us' approach.

- The response should acknowledge that Place would be an appropriate level to focus on some of the health priorities, rather than being excessively Local Authority-focused. The Berkshire West Health and Wellbeing Boards would need to look at how to collaborate to have a coherent overview and the Berkshire West Local Authorities and partners would need to re-orientate their thinking and delivery to the Place-Based level in order to make the system work.

- One of the areas not yet sufficiently fleshed out in the JFP was how the NHS would engage as a system with supporting change around the wider determinants of health, for example looking at housing and other partnership areas, such as

schools. Rob Bowen agreed that the JFP did not currently say much on this and later iterations of the Plan should include more on the NHS's role and responsibility in wider determinants of health.

- The Start Well section of the JFP was a bit more superficial than was ideal and was not as detailed or clear as the Live Well section. Rob Bowen stated that there was more that could be included in future iterations of the JFP on how the NHS would work with partners in the delivery of national and local ambitions around early years development.

- Over the next few years, it would be good to be able to build health strategies from the neighbourhoods upwards, for example by educating the public about when they did not need a GP consultation, building homes to enable people with dementia to stay at home as long as possible, etc.

- The JFP would be reviewed and refreshed each year, and so as the Place-Based Partnerships developed, there would be opportunities to refine local needs.

- The delivery plans were mixed, with some good examples of co-production, services for people, language and culture being reflected in the maternity area, but there were some which were not as good, for example assuming that GP access was about phone answering.

- The JFP needed a glossary, and easy read versions and translations into different languages should be provided. It was also queried how it would be communicated to the Voluntary and Community Sector and the wider community, so that it was transparent how the delivery of the JFP would work and where accountability for the delivery plans would fall.

- Rob Bowen reported that an Easy Read version of the JFP would be produced, starting with the summary, but this would not be available by 30 June 2023. Information would also be produced in other languages.

Resolved:

That the Director for Public Health, in consultation with the Chair of the Board, be authorised to develop a formal opinion statement on the BOB ICS Joint Forward Plan on behalf of the Board to be submitted by the 30 June 2023 deadline, taking into account the comments made at the meeting.

(The meeting started at 2.00 pm and closed at 2.50 pm)

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Community Participatory Action Research 2021–2022

ABBREVIATIONS USED THROUGHOUT

ACRE: Alliance for Cohesion and Racial Equality
BAME: Black, Asian and minority ethnic
CPAR: Community Participatory Action Research
IDRC: Integrated Research and Development Centre, Berkshire, UK CIC
HEE SE: Health Education England South East
NHSEI: NHS England and Improvement South East
OHID: Office for Health Improvement and Disparities
PAR: Participatory Action Research
PHE: Public Health England (NB, PHE became the Office for Health Improvement and Disparities during the course of this programme).
RBC: Reading Borough Council
RCLC: Reading Community Learning Centre
RVA: Reading Voluntary Action
SCDC: Scottish Community Development Centre
UoR: University of Reading

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Please do share the contents of our report but remember to give credit to the Reading CPAR 2022

Below: CPAR team with Professor Adrian Bell (UoR) during the showcase event

Introduction

Throughout the Covid-19 pandemic, inequalities in health, especially mental health, have become magnified amongst some Black, Asian and minority ethnic (BAME) groups disproportionately affected. Public Health England's report, Beyond the data: Understanding the impact of Covid-19 on BAME groups (2020), demonstrates the widening of existing health inequalities and as a result Health Education England South East implemented a programme of work to support Community Participatory Action Research (CPAR), in which researchers and community stakeholders engaged as equal partners. A partnership involving Reading Borough Council (RBC), Reading Voluntary Action (RVA), the Alliance for Cohesion and Racial Equality (ACRE), Reading Community Learning Centre (RCLC) and the University of Reading's Participation Lab were successful in gaining a grant to train and support 5 local researchers in Reading to co-produce and carry out the research with the support of a part-time facilitator, Dr Esther Oenga. Over the last year, they have worked tirelessly to research and evidence the striking inequalities facing minority ethnic communities in accessing healthcare in Reading and this report outlines their key findings and recommendations on a range of issues from men's mental health and maternal services to the challenges of accessing health care services by ethnic minority women and the impact of Covid-19 on Nepalese community.

The five community researchers were trained by the Scottish Community Development Centre (SCDC) in Community Participatory Action Research (CPAR), an approach which stems from a type of research known as Participatory Action Research (PAR) and grounded in the principles of equal partnership, collaboration and community action. Centred around the notion that communities themselves have the skills and expertise to best understand local needs through their lived experiences, PAR seeks to disrupt traditional power relations between researchers and the researched by locating knowledge generation at the local level and enable communities to explore and action issues that matter most to them. The use of participatory methods helps to break down barriers between communities and service providers and it is this community-centred approach that creates and strengthens the relationships and trust that are foundational to lasting social change. This hopefully gives more control to the people who are actually living the experience, and their engagement with pinpointing problems and finding solutions ensures that projects and their impact are relevant and hopefully sustainable into the long term. In the words of my late colleague, John Ord, who started many community research teams in Reading:

> "Community researchers are not blank sheets – they hold tacit or implicit knowledge of their community and 'know' it intuitively in a way that non-residents do not. They also have experience – and the need to know and what to do derives from their direct engagement in the world. . . . what carries understanding and skills/knowledge forward is a collective and co-operative search for the truth of *residence* – not simply what is lacking but what counts as asset; the skills and awareness that people already have and this is what the research with the community releases."

The benefits of CPAR are clearly evidenced throughout this insightful and powerful report as it centres the voices and lived experiences of local communities, but it is not without its challenges. This project required a substantial investment of unpaid time, additional resource and emotional labour that wasn't reflected in the funding application or original timeline. The success of the project is a testimony to the commitment of the community research team and partnership to evidence the impact on Covid-19 on BAME communities in Reading so that healthcare institutions and organisations can work with communities in Reading in the most crucial stage of this CPAR project – the development of NEXT STEPS and ACTIONS that will provide real INTERVENTION and CHANGE. We hope this report acts as a catalyst for this collective action in addressing health inequalities in Reading.

DR SALLY LLOYD-EVANS, PARTICIPATION LAB, UNIVERSITY OF READING

We are privileged to have been a partner in this community research project. The community researchers have been committed to ensuring the voices of their communities have been heard and that commitment is illustrated throughout this report. Let's ensure this marks a change in how we all work. Join us by reading the findings and recommendations, act where you can and share the results across your networks.

RACHEL SPENCER, CHIEF EXECUTIVE, READING VOLUNTARY ACTION

Tackling health inequalities: summary of recommendations

Based on the community researcher's detailed findings and recommendations, outlined in the next section of this report.

ACCESS TO MATERNAL HEALTHCARE SERVICES FOR ETHNIC MINORITY COMMUNITIES

- Streamline information and communication for better understanding.
- Ensure antenatal and postnatal classes are more accessible.
- Offer face-to-face services where possible and provide support with digital literacy when services are online.
- Provide better resources for translation and interpretation.
- Prioritise pregnant women's health, empowering them to make more individualised birth plans.
- Address staff shortages, ensuring more consistent care with the same midwife.
- Increase diversity in senior management and provide cultural awareness training to all staff working in maternal services.

ACCESS TO HEALTHCARE SERVICES FOR ETHNIC MINORITY WOMEN

- Speak to ethnic minority communities about vaccination and common medical problems in community or religious settings.
- Use a range of methods to provide information about health and wellbeing, including text messages, websites, social media and translated leaflets.
- Improve the availability and quality of translation and interpretation services – these should be available throughout a patient's journey, beginning at the moment they book a GP appointment.
- Improve GP services with longer opening hours and shorter waiting times on the phone.
- Provide translated information about helpline numbers and how to use them; support and train helpline staff to make these services more accessible and culturally sensitive.
- Reduce waiting times for hospital appointments and ensure face-to-face consultations are available for ethnic minority communities with additional barriers to accessing services online or over the phone.
- Increase awareness of regular health checks for the over 60s, NHS mental health services, and opportunities to express their views if patients have been treated unkindly or indifferently.
- Continue to provide community courses and activities which meet the needs of ethnic minority women, including IT, stress management, psychological first aid, exercise classes, visits and walks.

IMPACT OF COVID-19 ON THE MENTAL HEALTH OF ETHNIC MINORITY MEN

- Increase government funding for mental health services and make them easier to access.
- Ensure mental health issues are identified at the earliest possible stage, by increased training and awareness among all staff in public services.
- Recognise and support the role of the voluntary and community sector in providing awareness, understanding, advocacy and education around mental health issues, and responding to changing needs in communities.
- Promote mental health awareness in schools, colleges and universities.
- Develop conversation hubs offering professional and peer support.
- Support members of the community to conduct their own research and help improve services.

IMPACT OF COVID-19 ON THE NEPALESE COMMUNITY IN READING

- Provide outreach services for high-risk vulnerable households, including single parent families and those living in overcrowded conditions.
- Engage local community groups as partners in culturally-sensitive service design and delivery.
- Engage and train local community leaders and champions to mobilise for current and future public health issues, represent their communities in service design and help identify and support vulnerable households.
- Improve the availability and quality of translation and interpretation services for Nepalese and wider BAME communities.
- Identify communities experiencing language barriers and ensure ESOL classes, internet training and other support is available in community settings.
- Train public sector staff, including health care workers, in cultural, religious and ethnic diversity. Design and deliver this training in partnership with voluntary and community organisations who represent minority communities.
- Provide culturally-appropriate mental health support, going beyond medicalised treatment and fostering social interaction, physical activity and community organisations.
- Recognise and support the importance of voluntary and community organisations in building community health and wellbeing, including mental health, in the longer term.

Research overview

BACKGROUND AND AIMS

The aims of this research, set out in Public Health England and NHS Health Education England's Community Participatory Action (CPAR): Training and Mentoring Guidance Document, were to:

- Train individuals from organisations drawn from BAME communities in CPAR to tackle health issues related to Covid-19.
- Equip the BAME community researchers with the skills to later deliver CPAR to help in addressing wider inequalities.
- Share learning from CPAR across networks in the South East and beyond.

The programme was designed to support recommendation two from PHE's report Beyond the data: Understanding the impact of COVID-19 on BAME groups (2020):

> "Support community participatory research, in which researchers and community stakeholders engage as equal partners in all steps of the research process, to understand the social, cultural, structural, economic, religious, and commercial determinants of Covid-19 in BAME communities, and to develop readily implementable and scalable programmes to reduce risk and improve health outcomes."

METHODOLOGY AND ETHICAL CONSIDERATIONS

The 5 community researchers from Reading were among the 41 community researchers recruited by HEE and PHE in February 2021, through 15 voluntary organisations and social enterprises. They each received two-day training and ongoing follow-up mentoring support from the Scottish Community Development Centre. The training and mentoring were designed to equip researchers with the knowledge and skills to design, undertake and present their own community research (see Healthy Dialogues, CPAR Training and Mentoring Interim Report, October 2021). Krishna Neupane's report gives more details of the training and support received by the community researchers (see page 29).

The research carried out by the community researchers did not require formal ethical approval, but the researchers were trained and supported to carry out the research in line with the standards of accountability, ethics and reporting of the participating organisations. Researchers learned about compliance with GDPR and implementing the principles of consent, confidentiality and safe storage of information, and how to deal with issues arising when working with the public. They were supported by participating organisations to ensure their own health, safety and wellbeing during the project. The project was conducted between February 2021 and May 2022.

The Reading community researchers have presented their findings at several events and meeting, including an in-person showcase at the Museum of English Rural Life (MERL) on 4 April 2022 and an online showcase hosted by RVA on 16 June 2022. They participated in an online showcase alongside the other community researchers from across the South East on 10–12 May 2022. This was hosted by HEE SE, in partnership with the Office for Health Improvement and Disparities, NHS England and Improvement and the Scottish Community Development Centre.

FORMAT OF THIS REPORT

The following pages contain the final reports produced by the community researchers in Reading, who each set out their own research methods, findings and recommendations and acknowledgements. The final section contains profiles of the community researchers and partners, along with their reflections on the value of community-led research, including its economic value and the importance of resourcing it properly, and the project acknowledgements.

Right: CPAR team at RVA offices

Community researchers: findings and recommendations

Barriers to accessing maternal healthcare services faced by ethnic minority communities as a result of Covid-19 and digitisation

EVANGELINE KARANJA, ACRE

INTRODUCTION

The MBRRACE-UK report (2021) showed a stark disparity in the racial variations of maternal mortality rates. Black women are four times more likely to die, while Asian women were two times more likely to die than white women during pregnancy, delivery or postpartum. Apart from a slight drop in the maternal mortality rate for Black women, this bleak picture has not changed in over a decade (*Beyond the data,* 2020).

Public Health England's report, *Covid-19: understanding the impact on BAME communities,* demonstrates the widening of existing health inequalities and as a result, Health Education England South East is implementing a programme of work to support community participatory research, in which researchers and community stakeholders engage as equal partners (Beyond the data, 2020).

A key component in establishing equality in maternal healthcare provision is the examination of women's experiences of accessing these services. My involvement in voluntary community work in the past two years has allowed me to engage in community talks and hear what problems women are facing.

The topic of maternal health is one that sparked my interest in listening to many women's pregnancy journeys, the highs and the lows. I was especially interested in hearing the experiences of women who could speak English fluently. As previous research has shown, language has been a big contributing factor in the barrier to accessing maternal health care. However, what is the experience of ethnic minorities who can speak and understand the English language in accessing maternal healthcare services?

RESEARCH FOCUS

Health care services must consistently and competently strive to meet the needs of the whole population. However, past research has shown that patients from ethnic minority backgrounds have faced inequality when accessing healthcare services. Hence there is still a great deal of work to ensure that all patients, regardless of their background have equal access to healthcare services.

This study aims to explore the experiences of pregnancy, childbirth, antenatal and postnatal access, in women and healthcare professionals in the Black ethnic minority and highlight the effect of the Covid-19 pandemic and digitalisation.

1. What are the barriers to accessing maternal services?

2. What was the impact of covid-19 on maternal services?

3. What is the effect of digitalisation on maternal services?

RESEARCH METHODS

This research was qualitative, using individual interviews with open-ended interview questions so that in-depth information could be collected. This allowed me to better explain the research questions to participants, and to better understand their answers. It also enabled me to observe people's behaviour as we spoke, as this can provide extra information about how someone is feeling about an issue.

The advantage of an in-depth interview method is the rich data collected. However, the disadvantage is that it is time-intensive which limits the number of participants. I interviewed 9 respondents: 6 mothers and 3 midwives all within the Black ethnic minority with a good understanding and knowledge of the English language. Consent was given, confidentiality was agreed upon with respondents and all sessions were recorded.

Data collection occurred between November 2021 and January 2022. The analysis of data involved transcribing the recordings, reviewing the data, and taking notes of the findings that were emerging.

RESEARCH FINDINGS

1. WHAT ARE THE BARRIERS TO ACCESSING MATERNAL SERVICES?

This study focused on the lived experiences of English-speaking ethnic minority women, who were pregnant or delivered within 6 months of the Covid-19 pandemic. During the pandemic, maternal services became increasingly digitalised, and most of the women who were interviewed had to engage with online and digital services during their pregnancy and first few months after delivery.

Figure 1 shows several barriers to accessing maternal services as expressed by the participants.

1.1 INTERACTION WITH HEALTHCARE PROFESSIONALS

1.1.1 Different midwives every time.

All participants mentioned that they saw different midwives at all their antenatal appointments. They all felt that they had to re-explain their history and situation every time they met a new midwife. A common sentiment that arose in women requiring regular input from secondary care during the antenatal period was ineffective communication between their community midwives and hospital midwives or obstetricians and vice versa, sometimes resulting in the omission of crucial clinical information. The participants were not allowed to bring their partners to these appointments.

> "One of the things that I didn't like is the fact that I didn't have the same midwife throughout my pregnancy, I was always changing, so you know for one appointment I would see this midwife, next one I would see another one and she wouldn't know the history. And so yeah, I didn't like that." *Participant 4*

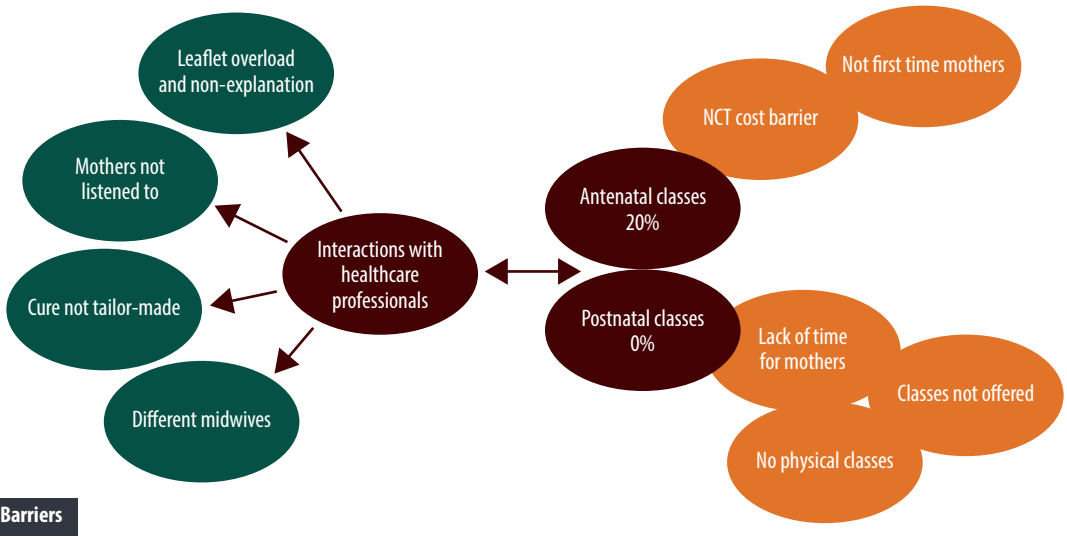


Figure 1. Barriers

> "I think it was at least three different midwives. I didn't have a consistent midwife. It wasn't good, because there was no consistency. You know, having a child when you're being faced with all of this pandemic and stuff, it's so unnerving to have so many changes as well." *Participant 2*

Two participants did mention that when they had a consistent midwife who followed up with them, it created a very good bond and person to rely on. They also mentioned that midwives from the same ethnic background did provide them more care and attention in hospitals.

> "Midwife was a good advocate. Proactive and very good in signposting where to find help." *Participant 6*

1.1.2 Leaflets

The participants all reported some level of provision from the health care professional and almost everyone agreed they would have preferred more thorough discussions. Most participants received information about their pregnancy in the form of signposting to books or websites, but they expressed that their individual information needs would have been better met by one-to-one discussions.

> "To give someone a leaflet and information and say, 'Read up about this and this and this, and these are . . . these are kind of the options'. Rather than take the time to educate the person. To say, look, we're just going to break it down to you in two sessions. This is what we want to talk about and cover here." *Participant 2*

> ". . . they just sent me leaflets for exercise." *Participant 6*

1.1.3 Not involved in decision making

Most of the participants reported feeling like they were not involved in the shared decision making with the healthcare professionals. The participants all reported some level of provision from the healthcare professional and almost everyone agreed they would have preferred more thorough discussions.

> "You were not given enough information to justify why they wanted to go the route they wanted to go." *Participant 4*

> "It was so traumatic. It was absolutely disgusting that they could have avoided a lot of things, in terms of when I was dilated, going to the hospital once. People to see where the baby's positioning was. That could have been noted down, and it could have been avoided the second time when I came in and them saying they have to do a C-section." *Participant 2*

1.1.4 Mothers not listened to by healthcare professionals

In this study, most participants spoke English fluently. Despite the high standard of English spoken, most participants felt that they were not listened to by the healthcare professionals. According to past research, the findings reflect how pregnant women are being put at greater risk due to clinicians focusing on their pregnancy, rather than the woman's own health (MBRRACE-UK report, 2021).

> "So, if you're birthing a human being, the best position to be in has always been on all fours. But there's never been that sort of an option for me. And I wonder, right, is it because of the age? Is it because of the colour?' You know, all these things pop up." *Participant 2*

> So, again, it just made me feel like this is just them saying this is just the easiest way for us to make sure we're just doing our rounds, we're meeting our checks and able to tick things off. That's how it felt." *Participant 2*

> ". . . they were not allowing me to have the time to be pregnant, to have the time to go into the full experience of having a natural birth." *Participant 2*

"The doctors were fixated on complexities; they did not listen or give enough satisfactory explanation for what and why it would be done. The care and explanation of why I couldn't have the option that I wanted, was just so blasé and tick-box and just making sure that you know, they're doing what they have to do." *Participant 6*

1.2. ANTENATAL CLASSES

Antenatal care is the care you get from health professionals during your pregnancy. Antenatal classes help you prepare for your baby's birth and give you confidence and information. They're usually informative and fun, and they're free on the NHS. You can learn how to look after and feed your baby.

Only 20% of the participants attended the antenatal classes. The participants listed several reasons why they did not attend these classes.

1.2.1 Cost of classes

The participants were offered the National Childbirth Trust (NCT) classes. The NHS only offers free antenatal classes to first-time mothers, for other follow-up pregnancies the mothers are referred to NCT classes that they have to pay for. National Childbirth Trust (NCT) classes are expensive for many people, and this is a major barrier to accessing services, as illustrated by the following quotes.

"Based on affordability you have to pay for it." *Participant 2*

"We were asked if we wanted to attend antenatal classes, we should go on the NCT Facebook page and book. The NCT Facebook page increased the pricing for the virtual antenatal classes. Yeah, they increased their pricing. So NCT antenatal classes are already expensive. They're over, I think, £100. Yeah. So, in the light of everything that was happening last year a lot of people were being made redundant, people were on furlough. Yes, you have to pay for those out of your own pocket. So, I think the pricing, when I checked, was about £180 and I decided, no, I wasn't going to spend £180." *Participant 6*

1.2.2 Not 1st-time mothers

The participants who had children already did not see any benefit in attending any prenatal classes. They felt like they already knew how to take care of new-born babies.

"It wasn't my first time." *Participant 3*

"I just thought that being online wouldn't be as beneficial as if they were in person, and because I already have two children, I thought that I would just pass." *Participant 4*

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

"The low attendance has had a very negative impact, especially on the care of the babies. The mothers, they come to the ward, and they look clueless." *Participant 9*

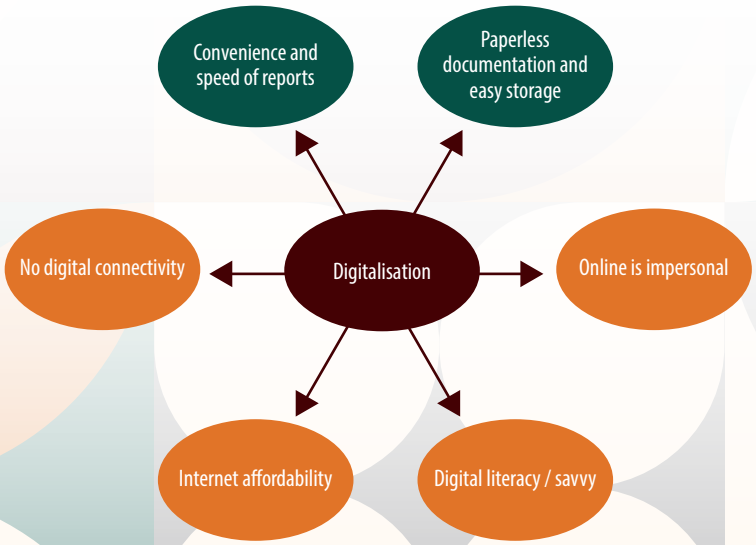
"I think that one has come across babies/mothers coming back to the hospital with babies who have not been properly fed, who have lost a lot of weight." *Participant 9*

1.3. POSTNATAL CLASSES

This is the care given to the mother and her new-born baby immediately after the birth and for the first six weeks of life. The main purpose of providing optimal postnatal care is to avert both maternal and neonatal death, as well as long-term complications (The Open University).

None of the participants attended the postnatal classes. The participants listed several reasons why they did not attend these classes.

Figure 2. Effect of digitalisation



1.3.1 Lack of time for mothers

Some of the participants cited the lack of time as a major barrier to attending postnatal classes. They felt that once they were home, they had to take care of the home and older children as well as the new-born baby, leaving very little time to attend to anything else.

> "No, no classes. There was no time. They offered me but I didn't go." *Participant 3*

> "...so you're dealing with the mental load of having an older child at home, trying to work, ordering a prescription online and then you have leaflets. It's more stuff, more mental load for you." *Participant 6*

1.3.2 Online classes were a deterrent

Several participants reported that they would have much preferred physical classes over online classes. They felt that the physical classes would be more impactful than being online.

> "I was told they would be online. I did not attend." *Participant 4*

> "COVID had just started, we didn't even have online things set up by then." *Participant 1*

> "Was online. Did not attend." *Participant 2*

1.3.3 Postnatal classes not offered

One participant was never offered postnatal classes and even enquired if it was something she was supposed to do. Two participants required postnatal physiotherapy but were told there were no classes and to just use the leaflets provided for exercise.

> "No, I haven't heard anything about that, no." *Participant 5*

> "Physio was not available. They sent leaflets for exercise." *Participant 3*

> "No, there were no antenatal classes offered." *Participant 6*

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

> "Major gap after mothers have given birth and that is after they have given birth successfully and everything works well and there are no complications, but I feel at that point in time, because of the shortage of staff they don't get one to one support. And many of them go home with lots of emotions and lots of baggage, breastfeeding ashamed that their nipples are getting cracked or they don't want to breastfeed in front of their partner. And so complex information." *Participant 7*

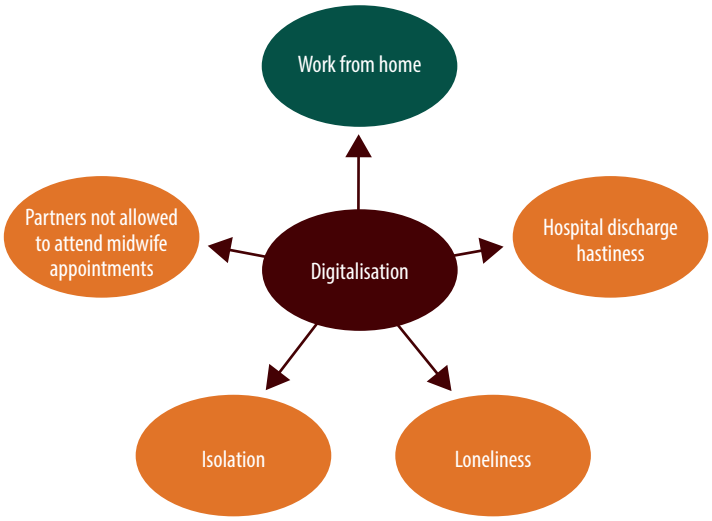
2. EFFECT OF DIGITALISATION

With the Covid-19 pandemic, there was quick adoption of digital technology in the NHS and significant changes in the delivery of services. The way that patients now access primary care has fundamentally changed. We witnessed the near-overnight restructuring of the initial method of patient contact, moving from the majority of appointments being face to face to the majority now being remote consultations. This was needed to free up space in hospitals, enable remote working and reduce the risk of infection transmission.

The maternal health care services saw a huge increase in remote appointments, especially antenatal and postnatal classes. It was important to explore the effect digitalisation had on maternal services, and there were a range of barriers that women faced as a result of these service changes, as described below. Figure 3 below shows the advantages and disadvantages of digitalisation in accessing maternal services.

Digitalisation did provide some advantages.

Figure 3. Effect of Covid-19



2.1 PROVIDES CONVENIENCE/EASE AND SPEED TO REPORT RESULTS

All participants used apps to track their pregnancy not recommended by the NHS. One of the participants had an app to report blood test results.

> "via Bluetooth monitor. You have to periodically test your blood before a meal and after a meal and it syncs to your phone, to the app on your phone and it automatically uploads the readings to your phone. I guess if you had to go in to be monitored, you had to go into hospital every time." *Participant 6*

2.2 PAPERLESS DOCUMENTATION AND EASE OF DATA STORAGE.

The digitalisation of hospital records means that midwives have to directly input data into computers as they see their patients. Midwives reported that this had reduced the amount of paper filling and resulted in ease of data storage.

> From the midwife's perspective: "...advantages of digitalisation, of course, it is good to go paperless, but it is easy to keep the notes as well." *Participant 7*

The digitalisation of maternal services also had some disadvantages.

2.3 NO DIGITAL CONNECTIVITY

To be able to participate in the online classes you would need to have a digital connection at home, a mobile device with video ability. There is an assumption that everyone is connected digitally. One participant had no internet at home and her device had no video capabilities.

> "Covid-19 had just started; we didn't even have online things set up by then." *Participant 1*

2.4 INTERNET AFFORDABILITY

Some women mentioned how the pandemic brought the loss of jobs and as a consequence, some people cannot afford to have an internet connection. Although this did not affect the participants directly, they did mention that they knew people who had been affected by this.

2.5 DIGITAL LITERACY

Digital literacy refers to an individual's ability to find, evaluate, and communicate information through typing and other media on various digital platforms (Wikipedia). Being digitally literate increases your productivity and efficiency since you can achieve more in less time.

> "Yeah, and also you have to be digitally savvy, know what you're doing because you might also have the gadget, but just know how to maybe call people using it. The Echo app, would just be the Lloyds Pharmacy, but I think now it's called the Echo app. On the Echo app and you order your prescriptions, you order the medicine, so the pre-surgery medicine, physically search for the medicines, so. . . is relying on your ability to read and to type." *Participant 6*

2.6 ONLINE IS IMPERSONAL

Most participants felt that the online classes would be impersonal and not intuitive. They would not have the same feel as you would on face-to-face classes.

> "Was online. Did not attend." *Participant 2*

> "I was told they would be online. I did not attend." *Participant 4*

The midwives concurred that digitalisation during Covid-19 was the safest way to provide some of the services. However, this created other problems as the participants could hide their identity with the camera off and you would not be able to tell if they were fully engaged.

> "How many can log in, people from BAME, how many can pull on their screen, comfortably say their problem? Seriously, unfortunately, the online has not helped because they can even hide their identity and not participate." *Participant 7*

MIDWIVES' VIEWS

> "The mothers are no longer engaging physically, antenatally, like before they deliver, so they are not...Go to antenatal classes where they will interact, which has really... has had a very negative impact, especially on the care of the babies. The mothers, come to the ward and they look clueless. You know when they meet together, all physically, everybody says their experiences, the midwife demonstrates physically, they can participate. As opposed to watching online." *Participant 9*

3. EFFECT/IMPACT OF COVID-19

The Covid-19 pandemic has had a profound impact on healthcare systems and potentially on pregnancy outcomes. The modern world has rarely been so isolated and restricted. Multiple restrictions had been imposed on public movements to contain the spread of the virus. People were forced to stay at home and social interactions were at a bare minimum. The Covid-19 pandemic has magnified the health inequalities and affected the members of Black, Asian and minority ethnic communities. The Public Health England report, *Beyond the data: Understanding the impact of Covid-19 on BAME groups* demonstrates the widening of existing health inequalities. Figure 4 below shows the findings on the effect of Covid-19.

3.1 WORK FROM HOME

Three participants were able to work from home during the pandemic. This gave them plenty of time to rest and meant they did not have to commute to work.

3.2 ISOLATION AND LONELINESS

During the pandemic, social interactions were at a bare minimum. Most participants found that they could not interact with others freely, making the participants isolated and leading to loneliness. One participant said that there were no baby group classes or other opportunities to meet up, and she felt that this affected the child as she had no interactions with other children.

> "No participation from mothers stayed home for 6 months"
> *Participant 1*

> "It was difficult in the beginning because of the sudden change of you know not being able to see friends. . . missed seeing me pregnant"
> *Participant 2*

3.3 PARTNERS NOT ALLOWED TO ATTEND MIDWIFE APPOINTMENTS

Most women reported feeling isolated during their pregnancy due to the pandemic. During Covid-19 the partners were not allowed to accompany mothers to midwife appointments. This was particularly a problem for those who felt that they would have benefitted from the presence of a companion when important information relating to their pregnancy was being relayed to them.

> "You couldn't attend them with your partner." *Participant 6*

There is a need for paternity classes for men. Most ethnic minority men tend not to attend any antenatal or postnatal classes with their partners. This becomes difficult for the mother who has to do it all on her own. During labour, the partners are not able to be helpful as they have not attended antenatal classes. This causes a lot of stress on the mother as she is alone.

3.4 HOSPITAL DISCHARGE TIME

The hospitals were under pressure during the pandemic to discharge patients quickly because they needed more bed spaces and to minimise the spread of the virus. The participants reported feeling rushed after they gave birth.

> "But they're not really explaining to you the aftermath, the after-care, what it's going to mean for you when you have a C-section." *Participant 2*

> Midwives' quote: "Too quick discharge from hospital, pressure for beds and lead to many re-admissions." *Participant 9*

3.5 DISREGARD FOR MOTHER'S PREVIOUS HISTORY

Participants felt that the health professionals did not consider previous similar occurrences in their previous pregnancies. There was a lack of consideration of women's previous conditions/situations in occurrences in previous pregnancies. The participants reported that they felt not cared for.

> "I was rated high risk for pre-eclampsia and I had gestational diabetes in my first and second pregnancy. Surprisingly discharged after 24 hours after c-section surgery. It was too premature because in my first pregnancy I had preeclampsia that resulted in me spending 10 days in the hospital. Second pregnancy I had the same conditions throughout the pregnancy but was discharged 24hours after the C-section. Within 3 hours after being discharged, I'd come back home and had to call an ambulance to go back into the hospital as I was experiencing pre-eclampsia." *Participant 6*

4. ADDITIONAL FINDINGS – MIDWIVES

I interviewed midwives and they had additional barriers/ challenges when caring for ethnic minority women as shown in Figure 4 below.

4.1 LANGUAGE BARRIER

Midwives described this as a prime feature in barriers to effective communication. Understanding the English language allows one to ask questions, understand what the mother requires and give consent. If one has limited English, the care given might not be comprehensive enough until they're able to find an interpreter.

4.2 LACK OF COMMUNICATION

The midwives' participants reported a lack of communication resulting from the language barrier among the ethnic minority women. The information being provided by the professionals to the people, they are not understanding it and they are not accessing it.

> "You can imagine it's a lot because actually in maternity it's more of communication like the 90% of the care." *Participant 9*

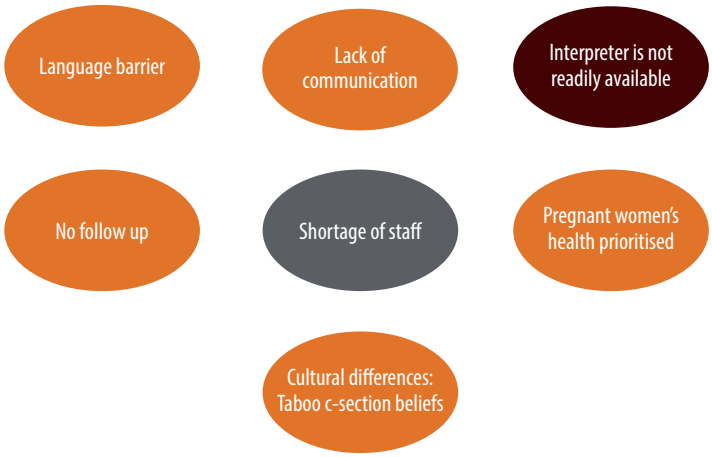
4.3 AN INTERPRETER IS NOT READILY AVAILABLE

With language barriers, an interpreter is required. However, on occasions, interpreters are not readily available at that moment.

4.4 NO FOLLOW UP WITH MOTHERS

No follow up from midwives of mothers who gave birth. Mothers do still need support after they give birth. There needs to be a follow-up, especially with postnatal classes.

Figure 4. Midwives' findings



4.5 SHORTAGE OF STAFF

The shortage of staff has put a lot of pressure on healthcare professionals therefore mothers do not get one-to-one support after they give birth. Often being given many complex leaflets to take home and read.

> "The pressure on the maternity department is high, so few staff and the birth rate has increased." *Participant 9*

4.6 PREGNANT WOMEN'S HEALTH IS IMPORTANT AND SHOULD BE PRIORITISED

Ethnic minority women need to prioritise their health when pregnant. This is usually not the case because they look after everyone else in the household and not themselves.

4.7 THE CULTURAL DIFFERENCES

Family members can be a major barrier. Some cultures deem it taboo to have a C-section. This becomes very challenging as the mother can refuse to sign the paperwork, not turn up to appointments and make it very hard to provide her with the care necessary. This puts the life of the mother and baby at risk. Partners can also be a barrier. In some cultures, the man is the spokesperson, and the woman is not allowed to speak. This makes it very hard to assess and diagnose the woman properly.

RECOMMENDATIONS AND ACTIONS

These are some recommendations from the research shown in figure 5 below.

INFORMATION AND COMMUNICATION

Good communication forms the foundation of good clinical care, and therefore, it is unsurprising that issues surrounding different aspects of communication were identified. Streamlined communication means you are not only giving infinite ways to interact but also building an effective relationship with each of them. All parties are better able to understand the information:

- More time needs to be allocated for 1-to-1 interactions.
- Information and communication are streamlined for better understanding.
- Consistency with the same midwife or better management/understanding of patient records.

ANTENATAL AND POSTNATAL CLASSES

This could be implemented in a range of ways, including the following:

- This could be arranged similar/in close timings with during midwife appointments.
- Midwives explain clearly the need for these classes.
- The cost of NCT classes needs to be addressed so that it is not a barrier.
- Paternity classes for the men and the need for partners to attend these classes.
- Follow-up of antenatal and postnatal classes attendance.

DIGITAL LITERACY

Not all mothers who took part had internet access or the skills to use online services. Online services can be impersonal and mothers can benefit from face-to-face provision. In order to improve this situation:

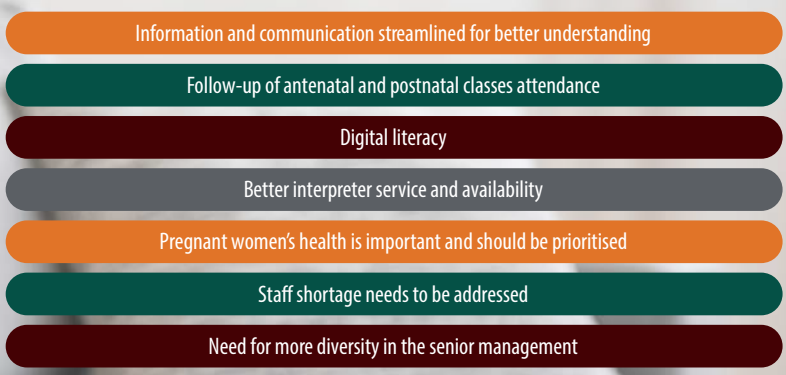
- Classes should be provided on using online services and wider digital literacy.
- Face-to-face services should be offered where appropriate and where possible.

BETTER INTERPRETER SERVICE AND AVAILABILITY

The mothers who were interviewed spoke good English. Many ethnic minority women do not speak such good English, and midwives identified language as a barrier.

- Better resources for translation should be provided, including readily available interpreters.
- Mothers' language needs are captured right at the beginning of the pregnancy and interpretation should be provided wherever needed.

Figure 5. Recommendations



PREGNANT WOMEN'S HEALTH IS IMPORTANT AND SHOULD BE PRIORITISED

- Before the woman gets pregnant, she needs to understand her anatomy, her physiology, how her body functions and how hormones will affect her when she is pregnant, how to live well, eat well and deliver safely.
- People need support to be able to prioritise and understand their own health. This will help them to present their pregnancy issues to the professional. This will help them know their body, their health issues, problems they are likely to face, and they can make an action plan, or a birth plan that is more individualised and tailor-made to the successful outcome of their pregnancy.

STAFF SHORTAGE NEEDS TO BE ADDRESSED

Midwives identified staff shortages as a key issue which had direct effects on the quality of care for pregnant women and mothers.

- More maternity health professionals are to be trained and employed to ease the burden on existing staff.

NEED FOR MORE DIVERSITY IN SENIOR MANAGEMENT

This recommendation reflects the fact that change needs to be led from the top. Diversity in management sends out an important message to the rest of an organisation. However, this is about more than symbolism, and greater diversity at the top will help to drive change at other levels.

- The working culture needs to change in the maternal healthcare profession.
- Cultural awareness training should be provided to all NHS staff working in maternal services, so that services are culturally sensitive.

We must all play a part in the solution – whether through advocacy, recognising the impacts of our own bias, validating a mother's experiences and concerns, or simply being the one person to listen and act. I chose to seek out the mothers in my community and hear what their experiences had been. I chose to get their voices heard through this research so that we can improve our maternal services, reduce the inequalities gap and save lives.

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ACKNOWLEDGEMENTS

The CPAR programme was initiated and funded by Health Education England South-East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHE England and Improvement.

Thank you to the mothers and midwives who gave such invaluable contributions to this research. I would like to express my gratitude to my facilitator Esther, the research trainer Andrew, who guided me throughout this project and helped me finalize my project. Dr Sally Lloyd-Evans of University of Reading for the support on recorders and transcribing of the interviews. Thank you to ACRE for giving me the opportunity to participate in this research. Thank you to the partners, RBC, RVA, RCLC, UoR and ACRE. I would also like to thank my friends and family who supported me during my study.

Challenges to accessing healthcare services faced by ethnic minority women in Reading during the Covid-19 pandemic

DONNA MA AND HEMAMALINI SUNDHARARAJAN, RCLC

INTRODUCTION

This survey was carried out by Reading Community Learning Centre (RCLC) as part of the Community Participatory Research Project (CPAR), initiated and funded by Health Education England South East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHE England and Improvement.

The purpose of the survey was to identify challenges encountered by ethnic minority women in Reading when accessing healthcare services during the Covid-19 pandemic, and to review how they have been affected physically and mentally. We aim to use our findings to make recommendations and check if further research will be necessary.

RCLC is a charity organisation in Reading that has the mission to reach out and empower isolated and vulnerable women to develop their skills, confidence, welfare, inclusion, social status and independence through learning, support and friendship. RCLC collaborated with other organisations in Reading on this project, some of whom pursued related areas of enquiry. Reading Borough Council (RBC) was the lead organisation in this project in partnership with Reading Community Learning Centre (RCLC), Reading Voluntary Action (RVA), Alliance for Cohesion and Racial Equality (ACRE) and University of Reading (UoR).

RESEARCH FOCUS

Currently Reading has a population of 161,780, with 35% belonging to ethnic minority communities. The aim of our research is to promote good health, education, culture and wellbeing, to make changes in accessing healthcare services and reduce inequalities.

Covid-19 has worsened existing health inequalities, with ethnic minority communities having a disproportionately high rate of serious illness and mortality from Covid-19 when compared to the wider population as a whole.

A range of economic, social and cultural factors are likely to contribute to the disproportionate impact of Covid-19 on ethnic minority communities. Our research has explored some of these factors. For instance, we have been interested in how people receive and interpret messages, including how they are affected by language barriers. Furthermore, we have investigated how much trust ethnic minority communities have in government authorities and public health information. Cultural factors may play a role here, such as cultural beliefs and values.

The two community researchers of this project are also from ethnic minorities. They both have over 6 years of working experience and social contacts with ethnic minority women in Reading.

RESEARCH METHODS

The research methods that we have adopted are a survey, phone and personal interviews. 103 women responded to our questionnaire which was distributed personally and electronically. The English questionnaire was translated into traditional Chinese, simplified Chinese, Arabic and Kurdish versions. The questionnaires were handed to learners of RCLC through staff members and the tutors. The non-learners received the questionnaires via members and leaders of social and religious communities as well as educational institutions. Those who were unable to understand the questions in English could respond with the support from somebody in their families or an interpreter arranged by RCLC in one of the following languages: Tamil, Punjabi, Hindi, Mandarin Chinese and Cantonese, Arabic, Nepalese and Kurdish.

Those with a low level of English language tended to respond better to the questions verbally in their first language. In these cases, the interpreter wrote down their answers in English either in person or over the phone. It was a challenge for the participants from countries that have a different healthcare system to understand the questions in the first place. The interpreter sometimes needed to explain the question before he/she could write down the answer for them.

PARTICIPANT PROFILE

The survey covers a wide range of women from ethnic minority communities aged from under 25 to above 75. They came from 24 different countries, including China, Nepal, Pakistan, Bangladesh, Syria, Poland, India, Russia, South Korea and Kurdistan.

- 8 respondents out of 102 (8%) said they could not communicate in English at all. 53 (52%) rated their English (on a scale of 1-10) as 2-5; 31 (30%) rated their English 6-9; and only 10 out of 102 (10%) gave their English the highest rating of 10.
- 10 out of 101 (10%) lived on their own and the rest in a household of between 2-8 people. 35 out of 102 respondents (34%) said they were living with one or two children (defined as people who were under 18), 19 (19%) lived with 3-4 children, 3 (3%) had 5-6 children and 45 (44%) lived with nobody under the age of 18.
- 26 out of 102 people (25%) have lived in the UK for under a year and 34 (33%) for over 10 years (see figure 1).
- 48% of the respondents lived in RG1, 18% in RG2 and 11% in RG6. The others spread all over the rest of Reading.

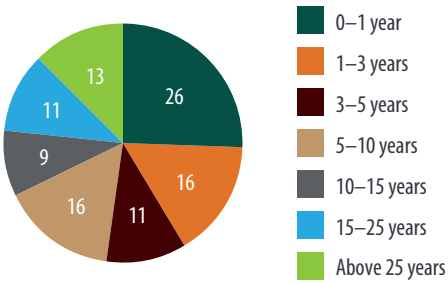


Figure 1. Number of years respondents have lived in the UK

RESEARCH FINDINGS

The key findings are presented below using charts generated from an excel spreadsheet. The total number of respondents varies slightly from question to question. This is a result of giving respondents the option of answering the questions they felt comfortable answering. Each question was answered by the majority of respondents.

5.1 COVID-19 AND ITS IMPACT

Figure 2 shows that 75 out of 103 respondents (73%) did not have anybody in the household who had tested Covid-19 positive. 16 people (15.5%) said someone in their household had tested positive. 12 people (12%) didn't answer this question.

Out of the 18 confirmed cases reported, 10 were classified as mild, 5 bad and 3 very bad. The research was conducted before the introduction of the 'booster' vaccination in the UK. Figure 3 illustrates that 85 out of 97

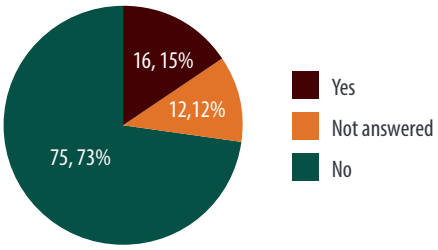


Figure 2. Whether or not anyone in the household of the respondents had tested positive for Covid-19

respondents (87%) said they had received two jabs. Only 2 (2%) had received one jab, and 6 (6%) had not yet taken any but they were planning to. 4 respondents (4%) said they didn't intend on being vaccinated at all.

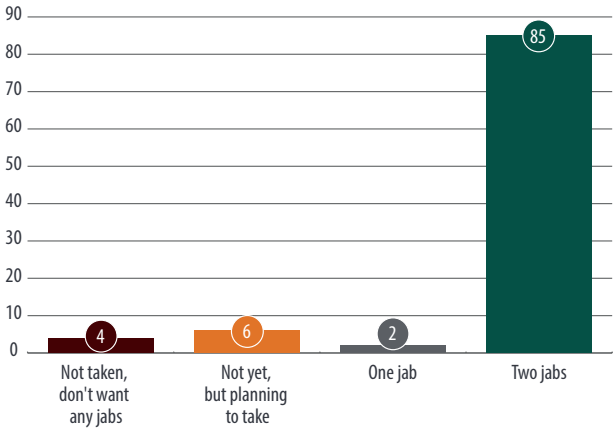


Figure 3. Covid-19 Vaccination status

A couple of respondents gave more detail on why they had chosen not be vaccinated, with one saying she avoided taking medicine in general. Normally she took it for only when it was urgent because she believed that she was fit enough to fight Covid-19. Another respondent thought she could protect herself without any jabs.

The survey asked respondents to indicate on a scale of 1-10 how well-informed they felt about the Covid-19 pandemic. Figure 4 highlights that the majority felt well informed with 85 out of 99 (86%) giving 6 or above, in contrast to 14 (14%) who gave 5 or below.

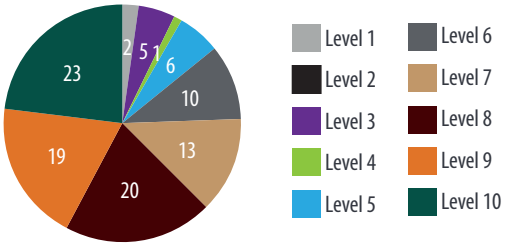


Figure 4. Knowledge level about Covid-19 pandemic (1 not informed – 10 well informed)

The health of respondents was affected by Covid-19 in other ways in addition to the direct effect of the virus. For instance, 21 out of 99 people (21%) reported that their physical health had become worse during the pandemic. 26 out of 100 people (26%) said that their mental health had become worse during the pandemic.

Statements from participants highlight some of the reasons people's physical and mental health suffered during the pandemic. For instance, some respondents found that, without their busy daily routines, it was difficult to get regular exercise, particularly in the first few months of lockdown when there were restrictions on being outdoors. As a result, some reported putting on weight and other health issues experienced by participants included stomach and skin conditions.

In terms of mental health, many found lockdown and social distancing measures difficult, with little social contact with friends and even family. This was particularly difficult for some ethnic minority women who described how they already felt isolated in the UK due to living alone or due to close family members living in other countries.

Another layer of stress and anxiety was created due to increased financial pressures. Many respondents and others in their households had been put on the UK Government's furlough scheme and had less income as a result. Some had lost their jobs, with one respondent reporting that it took 4 months to receive universal credit. Financial hardship created tension at home, made worse by being stuck indoors. One person also described how difficult it had been following the death of her father from Covid-19.

A few people mentioned positive impacts of the pandemic on health and wellbeing, including being able to find more time to exercise at home and go for walks, feeling loved and supported by family and friends and appreciating health more than before the pandemic.

5.2. CONNECTIONS OUTSIDE OF THE HOME

Many ethnic minority communities place a great importance on connections outside the home, including social, cultural and religious gatherings. In addition, ethnic minority women can find themselves particularly isolated without these activities, due to some of the factors discussed in the above section.

For this reason, the survey asked women how frequently they left their home and also about what groups they interacted with. Figure 5 shows that 49 respondents out of 100 (49%) left home daily, 34 (34%) more than once a week, 10 (10%) once a week and 7 (7%) rarely or never.

The reasons for going out included: school runs; taking children to the parks; walking for physical exercise; shopping; access to services, entertainments and restaurants; work (key worker in a supermarket); and English classes when the college was open. Some people said they only went out in their own gardens due to being vulnerable to Covid-19.

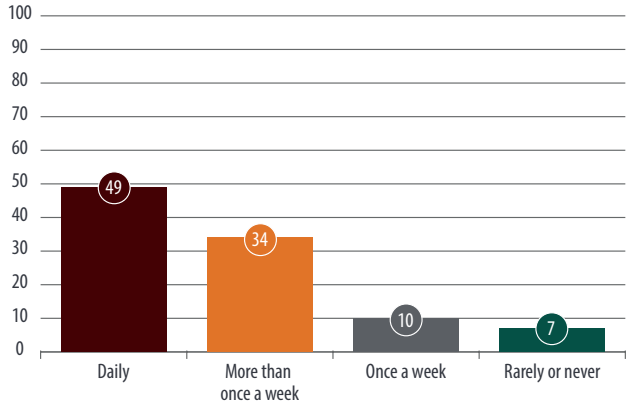


Figure 5. Frequency of leaving home

In terms of interactions with groups, figure 6 shows that 17 respondents (17%) said they belong to both religious and community groups. 28 (28%) selected community groups and 10 (10%) said religious groups. 44 people (44%) said they do not interact with any social groups.

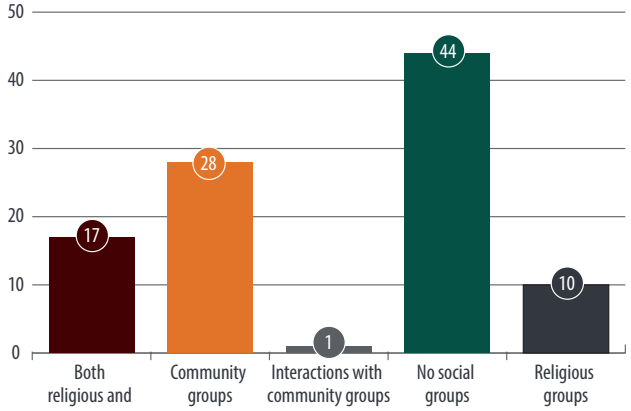


Figure 6. Interactions with groups

The data fits with what we know about many people from ethnic minority communities, and this form of group activity will have been largely missing during the Covid-19 pandemic.

The survey also asked respondents who they were able to talk with when feeling lonely, anxious or stressed. Figure 7 shows that a majority of respondents had at least one person they could talk to, with the most frequently selected options being friends and family (both local and distant). However, 9 respondents (9%) said they did not talk to anybody when feeling lonely, anxious or stressed.

Respondents were also asked what practical support they had received during the pandemic. Slightly less than 30% of the respondents said they received practical help or support during the pandemic from families, friends, community groups and social workers.

Online connectivity is another important way for people to maintain social contact, particularly during the pandemic when other forms of social contact were restricted. Figure 8 shows that 84 people out of 103 (81.5%) said they had access to the internet. 14 (13.6%) said they had no internet access, while 5 (4.9%) did not give an answer.

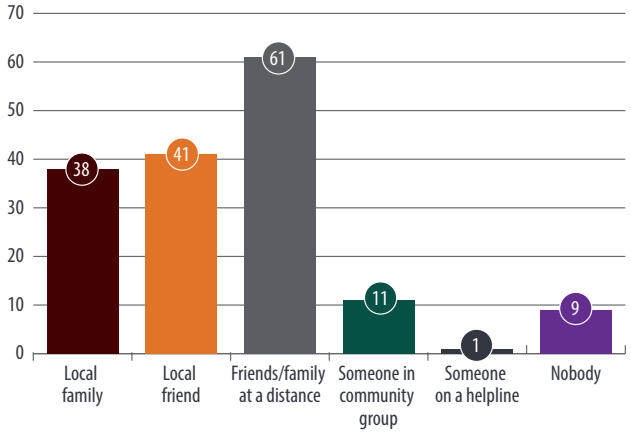


Figure 7. Who respondents talk to when feeling lonely, anxious or stressed

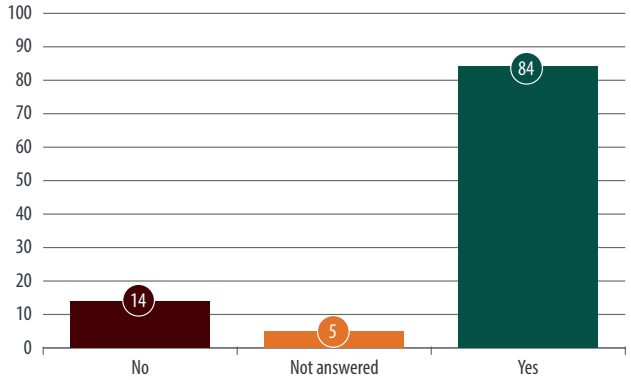


Figure 8. Internet access

5.3 BARRIERS TO ACCESSING SERVICES

Ethnic minority communities are known to face a number of barriers when accessing services, and our survey sought to establish which barriers were faced by women from ethnic minority communities in Reading.

5.3.1 Awareness of services

As illustrated in figure 9, almost everyone who responded was aware of the GP service. A majority was aware of the optician, dentist and emergency services. Online services, services to do with mental health and help with health costs were less recognised.

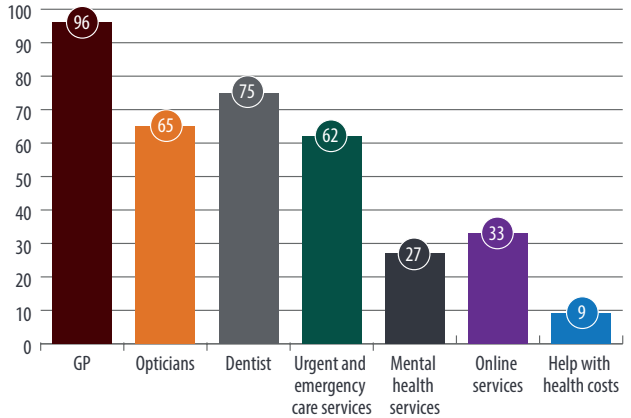


Figure 9. Awareness of NHS services

When asked which emergency numbers they were aware of, 88 respondents (85%) knew 999 and 77 (75%) knew 111, whilst only 51 (50%) knew 119.

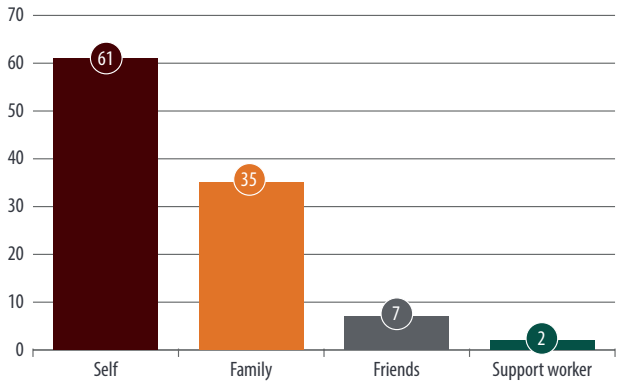


Figure 10. Booking of GP appointment

5.3.2 Challenges faced when accessing GP

Just over half the respondents had visited the GP in the last 12 months.

As shown in figure 10, more than half of the respondents, booked their doctor appointments by themselves. Around a third did it through their family members. Only 7 people said they were helped to do this by friends and 2 by social workers.

Figure 11 highlights that 30 out of 103 respondents (29%) said they had avoided going to the doctor or the hospital because of the pandemic, compared to 68 respondents (67%) who said they did not. 8 (3.9%) did not answer this question.

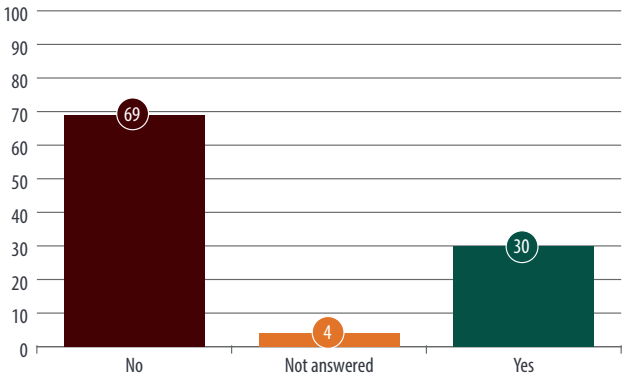


Figure 11. Whether or not respondents avoided visiting doctor/hospital due to pandemic

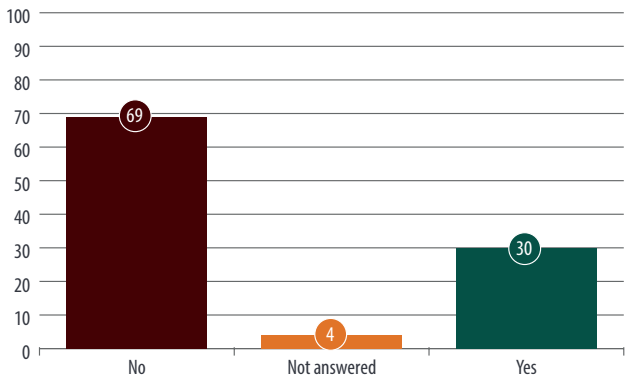


Figure 12. Whether or not respondents didn't contact GP despite having genuine requirement

Figure 12 shows that 27 out of 103 respondents (26%) stopped contacting the GP even when they had a genuine requirement whilst 68 (66%) didn't. 8 respondents (8%) did not answer this question.

5.3.3 Reasons for being reluctant to contact services

Although most respondents were able to contact health and care services during the pandemic with relatively little difficulty, the proportion of respondents choosing not to, even though they had a health-related concern, is significant and concerning. The reasons for this will be varied, but a reluctance to contact services may be tied in with uncertainty about whether to make use of services at a time of national emergency, such as during the Covid-19 pandemic. For instance, one person related that they were:

> "feeling very stressed as not easy to make appointments to see the doctor and having medical examinations at hospital" (Interview respondent)

> One person also commented that they "prefer[ed]" seeing people in person rather than online meetings" (Interview respondent)

Issues of trust and fear are also important when it comes to being confident enough to contact services. Sometimes, a lack of trust stems from prior negative experiences. For instance, one respondent was charged for using maternity services because her visa application was delayed due to the pandemic.

5.3.4 Translation and interpretation

The responses to questions around translation and interpretation may shed some more light on why people have not contacted required health and care services.

Figure 13 shows that 46 respondents out of 98 respondents (47%) didn't need an interpreter. 37 (38%) were arranged by NHS or themselves. 15 (15%) would have liked to have an interpreter. Some respondents described this issue in more detail.

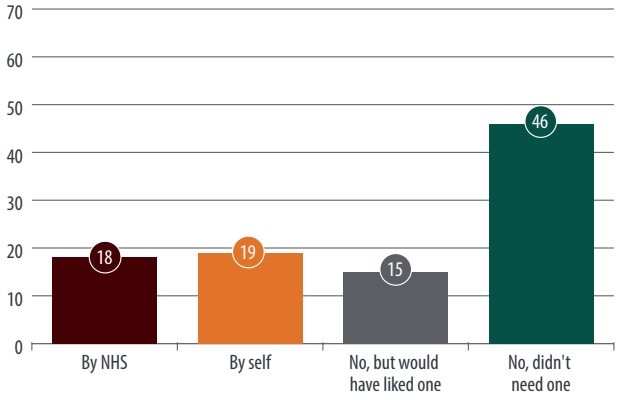


Figure 13. Whether, and how, interpretation was arranged for GP consultation

"Poor quality of translation service: imperfect and inaccurate"

"Relying on translation by a family member could cause a lot of inconvenience" [the daughter had to travel more than an hour to come to speak to the GP for a phone consultation]

The following case study, conducted as part of this research, illustrates how language barriers exacerbate other issues, including Covid-19, pre-existing health conditions and financial hardship.

5.3.5 Removing barriers

In addition to asking what barriers people faced, the survey asked respondents what could be done to help them access healthcare services. They were given a range of options to choose from, which were prioritised as follows:

- 50 people selected "translation support (face-to-face or on the phone)"
- 39 selected "longer opening hours for the health service"
- 36 selected "translated information on the services in your area"
- 33 selected "health care staff who understand your culture"
- 25 selected "better transport to the health services"
- 22 selected "reducing the cost or free travel to access health care"

The survey asked respondents how they would like to receive information about the health services they can access. The options provided were prioritised as follows:

- 69 selected "text messages"
- 48 selected "from the GP surgery"
- 22 selected "translated leaflets"
- 18 selected "websites"
- 6 selected "Facebook page"

CASE STUDY: MR

I am MR from Nepal living with my step-mum. I am a 66-year-old widow. During February 2021, I got affected by Covid, with the symptoms of digestion problems. These symptoms were very severe and I couldn't digest any food. I was admitted in Royal Berkshire hospital for one month and 26 days. I have difficulty in walking due to my ankle being operated twice in the past.

During the Covid treatment, I had the problem with understanding the English language when I was at the hospital. Sometimes a Nepali nurse talked to me but other times clinicians called my nephew to interpret on the phone. The language challenge also continued when I went for physiotherapy.

I was asked to come every day to the hospital for exercise as my lungs were severely damaged and I had to have a surgery. I was unable to travel on buses and had no one to take me to the hospital. I am on universal credit and could not afford the taxi, so I only visited 2 to 3 times a month using the taxi.

Mostly, I got help from friends and family members. Also, I received support from RCLC staff with booking GP appointments and coordinating with RVA, who provided me with a laptop for online language proficiency improvement classes. RCLC also supported me to register for Readibus (Reading Council provided bus facility) which I am using to visit the GP.

In summary, it has been very difficult due to limited mobility issues with COVID related illness and a broken ankle. I need help with shopping, transport to hospital, cooking and other household chores. Furthermore, language barriers are adding to existing difficulties of life.

RECOMMENDATIONS AND ACTIONS

For Reading Borough Council, NHS and Reading Community Learning Centre (RCLC)

ACTIONS

- Encourage vaccination by inviting someone from the NHS to speak to ethnic minority communities in community or religious settings about the facts and the consequences.
- All partners should use a range of methods to provide information about health and wellbeing, including text messages, their website, social media and translated leaflets.
- Longer opening hours at GP surgeries would be beneficial to women from ethnic minorities.
- Assign more staff to answer the phone to shorten the waiting time on the phone when making an appointment at GP surgeries.
- Translated information about helpline numbers and how to use them should be made available.
- Better support and training for helpline staff to make this service more accessible and culturally sensitive.
- Shortening waiting times of hospital appointments will be beneficial.
- Face-to-face consultation should be an option for ethnic minority communities who face additional barriers to accessing services online or over the phone.
- Patients should be made aware that there are opportunities to express their views if they have been treated unkindly or indifferently.
- Translators supplied by the agencies must be qualified to ensure high quality of service.
- Prevention is better than cure. NHS staff could be invited to go to communities and religious groups to give information about common medical problems which may affect that group e.g. diabetes and hepatitis.
- Patients aged 60 and over should be provided with regular health check-ups and be made aware of the availability of these checks and how they can increase quality of life. This will involve efforts to remove the language barrier in communicating medical information.
- Awareness of NHS mental health services should be increased by publicising that this support system is available, especially to ethnic minority women.
- Interpretation services should be available to those who don't speak English as their first language. These should be available throughout a patient's journey, beginning at the moment they book a GP appointment.
- RCLC should be supported to continue to provide courses and activities to meet with the needs of the women of ethnic minorities e.g. IT course, Mindful Stress Management course, Psychological First Aid workshop, exercise classes, visit to the Museum of English Rural Life (MERL).

RECOMMENDATIONS FOR FURTHER RESEARCH

- It would be interesting to see if attending groups makes a difference to mental health or resilience.
- Another survey targeted at men and women of non-ethnic minority backgrounds will reveal if there are any significant differences in their responses.

The impact of Covid-19 on the mental health of ethnic minority men in Reading

TARIQ GOMMA, ACRE

INTRODUCTION

This research investigates the impact of Covid-19 on the mental health of men from black and Asian minority ethnic communities (BAME) in Reading. It was carried out as part of the Community Participatory Action Research (CPAR) programme, which was initiated and funded by Health Education England South-East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHS England and Improvement.

In Reading, the research was supported by different partners such as Reading Borough Council (RBC), Reading Voluntary Action (RVA), Reading Community Learning Centre (RCLC), University of Reading (UoR) and Alliance cohesion and Racial Equality (ACRE). This research was conducted by the community local researcher from the beginning to the end through the support of training and mentoring sessions. The community played a great role in responding to the questionnaires.

RESEARCH FOCUS

Men are known to be reluctant to discuss health and wellbeing, and this can be a particular issue among ethnic minority communities. Culturally, men are often socialised into believing they have to be in control of their emotions and that to show emotion is a sign of weakness and failure. It is also known that Covid-19 has had a disproportionate impact on ethnic minority communities in terms of higher mortality and hospitalisation.

This research aims to explore how men's reluctance to talk about health and wellbeing could be a factor in increasing the likelihood of being seriously ill or dying from Covid-19. For instance, if men are reluctant to share their health and wellbeing concerns they may not seek help for Covid-19 or may avoid getting vaccinated. Alternatively, Covid-19 may be creating extra pressure on their mental health.

RESEARCH METHODS

The questionnaire focused on men from ethnic minority backgrounds. A total of 63 questionnaires were administered among different ethnic communities such as Sudanese, Nigerians, Bangladesh, Serialeon, Libyans, Eritrean Ghanaian, and Kenyans among others. A range of different ages took part in the survey with most being in the 41-59 age group (29) and the 31-40 age group (22). 9 respondents were aged 18-30 and 3 were 60 or over. 29 participants were employed, 23 self-employed, 6 were students and 5 were unemployed. More than half (34) were married, 21 were single and 8 categorised themselves as divorced. See figure 1 for a full breakdown.

The survey is anonymous, not identifying anyone's personal details. In many cases the questionnaire was administered face-to-face, whereas other questionnaires were completed by participants in their own time and returned to the researcher.

Research respondents were reached via working as a taxi driver. It was possible to talk to customers, introducing the community research, explaining what was involved and asking if they were willing to participate by filling the questionnaire. Participants who agreed were then able to complete the questionnaire during the journey. They were then thanked and given a fare discount in appreciation, which was generally welcomed.

Another way in which respondents were reached was by using the taxi base office and message system service connected to all drivers to ask fellow drivers to participate in the survey. Drivers were then able to complete the survey while in the office base during break times. A handful of additional respondents participated in the survey in this way.

Confidentiality was maintained on the data provided. All the respondents gave their consent to participate on the research. Research assistants from Reading Men's Group (We Men) supported administering of the questionnaire. The questionnaire was designed to cover four key areas:

- Impact of Covid-19
- Mental Health
- General Health
- Demographics

Figure 1. Demographic details of respondents

Age	18–30 9	31–40 22	41–59 29	60 and over 3
Ethnicity	Black African/Caribbean 37	Black/White 5	Arab/Asian 18	Others 2
Marital status	Married 34	Single 21	Divorced 8	Civil Partnership 0
Employment status	Employed 29	Self-employed 23	Student 6	Unemployed 5

RESEARCH FINDINGS

After analysing the data gathered from the questionnaires on how Covid-19 has affected BAME men's mental health, the following findings were established:

NEGATIVE EFFECTS

Most people were negatively affected either financially, mentally, psychologically or physically by Covid-19 and lockdown. 54 out of 63 respondents (86%) replied that they were affected by the pandemic. Only 9 people (14%) said they had not been affected (see figure 2).

Based on personal observation and some comments made by participants, respondents who were worst affected were people living alone and receiving social care services who had limited or no time from support or care workers, friends, and family members.

Figure 3 shows the ways in which men were affected by the pandemic and lockdown.

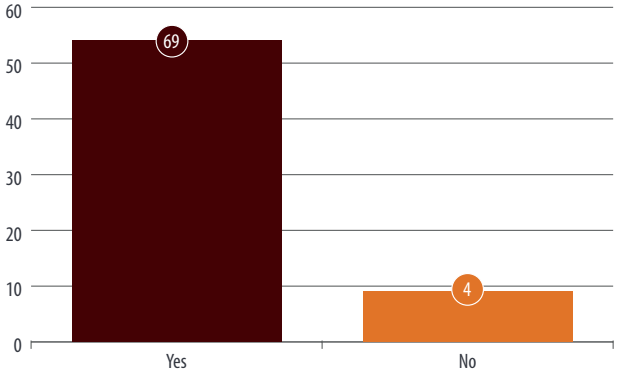


Figure 2. Whether pandemic and lockdown affected respondents

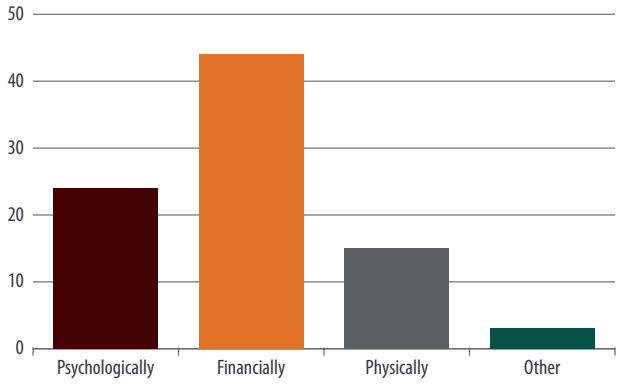


Figure 3. How Covid affected people

The survey asked people to say how they were affected by Covid-19. The most common way that people were affected by the pandemic was financially, followed by psychologically and physically.

FINANCIALLY

Many people we interviewed lost their jobs or business and or had a reduction in their earnings during the lockdown. Some people who worked on zero-hour contracts or were self-employed could not benefit from government support either. This increased the stress individuals and families experienced because of the financial difficulties.

MENTALLY

There is no doubt that the last 2 years since the pandemic began in February 2020 have been very stressful. The lockdown and the restriction of movement intensified isolation and self-isolation especially for those who were shielding. The situation was made worse about unmet needs especially those who are cared for, as a result of the lockdown, service closures and shielding rules.

Some people felt very isolated at home as individuals or as family with the caring roles largely absent or forgotten. Some people did not even have the opportunity to have someone to talk to at the time about their experiences.

At a more general level, news about the severity of the pandemic and the deaths experienced nationally and worldwide has made the last two years a worrying time for many people.

Generally, and for those with clinical symptoms, their mental health was regressing even more, because of the lack of preventative and maintenance services being withdrawn.

There is a strong correlation between mental illness and poverty. Financial worries, and living conditions such as housing and poor diet can adversely impact on mental health, while poor mental health can cause great deal of instability which will lead to people losing their jobs and poverty.

PHYSICALLY

Some people experienced a psychological barrier to going out, and restrictions to movement resulted in people having to stay home and getting less exercise.

SUPPORT

Figure 4 shows that slightly more than half of the participants (36 out of 63 responses) declared that they received help during lockdown.

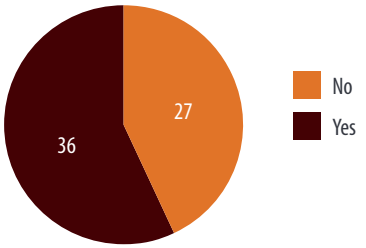


Figure 4. Whether any help was received during lockdown

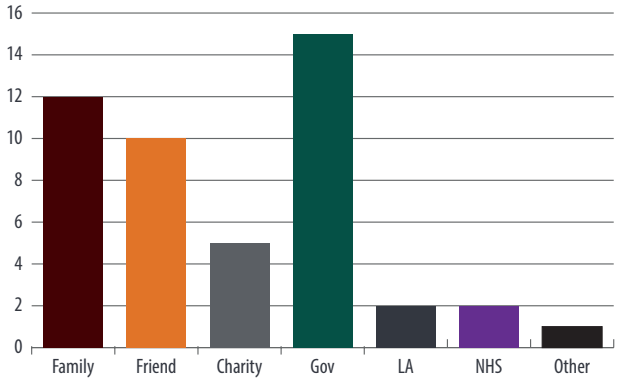


Figure 5. Sources of support

Figure 5 shows that the most common sources of support for participants were government, family, and friends. Fewer people said they received help from charities, local authorities and NHS.

Figure 6 shows that there is a low awareness of mental health services among men who took part in the research. 43 said they didn't know how to seek or access mental health services, whereas 20 said they were aware of these services and how to contact them.

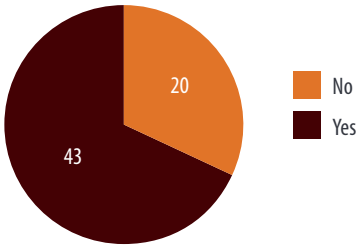


Figure 6. Whether or not respondents are aware of mental health services.

SEEKING HELP

Most respondents answered that they would seek professional help if experiencing mental health issues. Figure 7 shows that 35 out of 63 men said the were very likely to do this, which is over half of all respondents. However, 9 respondents said they were very unlikely to seek professional help, highlighting that a significant minority of men may be unwilling to get help when needed.

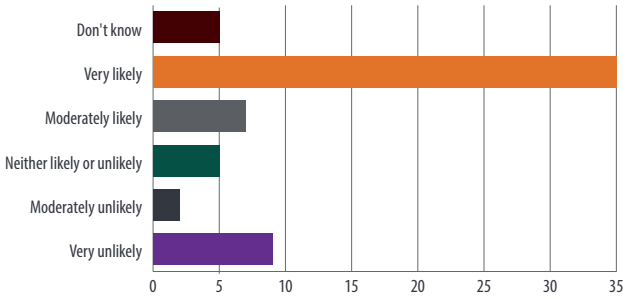


Figure 7. Likelihood of seeking professional help if experiencing mental health issues.

WHO RESPONDENTS TALK TO ABOUT PERSONAL ISSUES

The survey asked participants to indicate who they would talk to about personal issues. Figure 8 shows that 33 people said they would talk to friends and 29 said they would talk to family. This was followed by 21 who said they would talk to their doctor.

Out of the options presented, the least-selected answer was religious leader, which 8 people said they would contact. 7 people said they would prefer not to tell anyone, which reflects the earlier findings that some respondents said they would be unlikely to talk to someone about personal issues and that they would be unlikely to seek professional help if they experienced mental health issues.

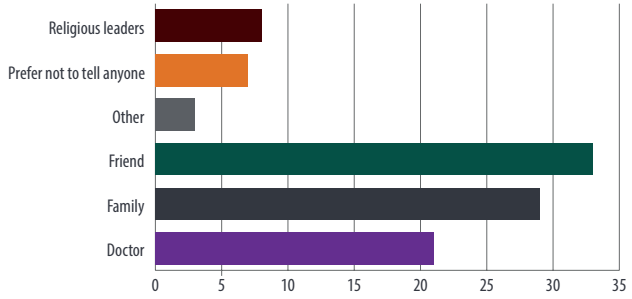


Figure 8. Who respondents talk to about personal issues

ACCESSING MENTAL HEALTH SERVICES

Respondents were asked to what extent they agreed that it is easy to access mental health services. They were also asked if they knew of any mental health services. These questions were asked in order to help understand whether or not people were aware of what support was available, whether provided by the NHS, charities or any other sector.

Figure 9 shows that 21 people either agreed or strongly agreed that mental health services are easy to access, whereas 15 disagreed or strongly disagreed. 18 out of 63 said they didn't know how much they agreed with the statement and 11 said they neither disagreed or agreed.

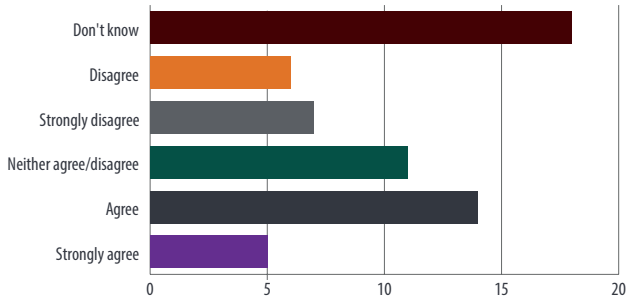


Figure 9. How much respondents agree with the statement: It is easy to access mental health services

This level of uncertainty about how easy services are to access can be explained by the finding shown in figure 10, with a large majority of respondents, 43 out of 63, saying they don't know any mental health services.

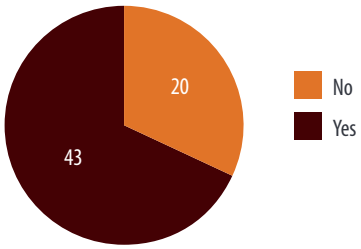


Figure 10. Whether or not respondents know any mental health services

BARRIERS TO ACCESSING MENTAL HEALTH SERVICES

The survey gave people the chance to describe any barriers that prevented them from accessing mental health services. Their answers can be categorised as follows:

LANGUAGE BARRIERS, INCLUDING APPROPRIATE ACCESS TO INTERPRETERS.

This highlights a need for translated information. Some respondents would like to see written information translated. However, others have difficulty reading or can't read at all and would prefer someone to talk to who can translated information for them or read them translated information. This could be done using videoconferencing such as Zoom or face-to-face.

DIFFICULTIES IN REGISTERING OR MAKING AN APPOINTMENT DURING THE PANDEMIC.

Some respondents expressed frustration about how difficult it was to get an appointment with psychiatric doctors or mental health practitioners. They said that it wasn't easy to get a referral and, if they managed to get referred, it took a long time to see anyone.

LACK OF UNDERSTANDING OF SOCIAL CARE SYSTEMS

The research has already established that most respondents were unaware of what mental health services were available. A few respondents mentioned that there was a lack of clear guidance and information about how to access these services.

DISCRIMINATION

BAME people often feel the colour of their skin is a reason they are not offered services. They felt that white British people would be likely to receive mental health services ahead of them. Institutional racism is another barrier, with a lack of cultural sensitivity and adequately-trained staff.

STIGMA

As this research has shown, there is a reluctance within many BAME communities to discuss the topic of mental health. A stigma around mental health exists, with people thinking it will bring shame on them, so they avoid talking about it altogether, and this may make it harder for them to access support.

CONCLUSION

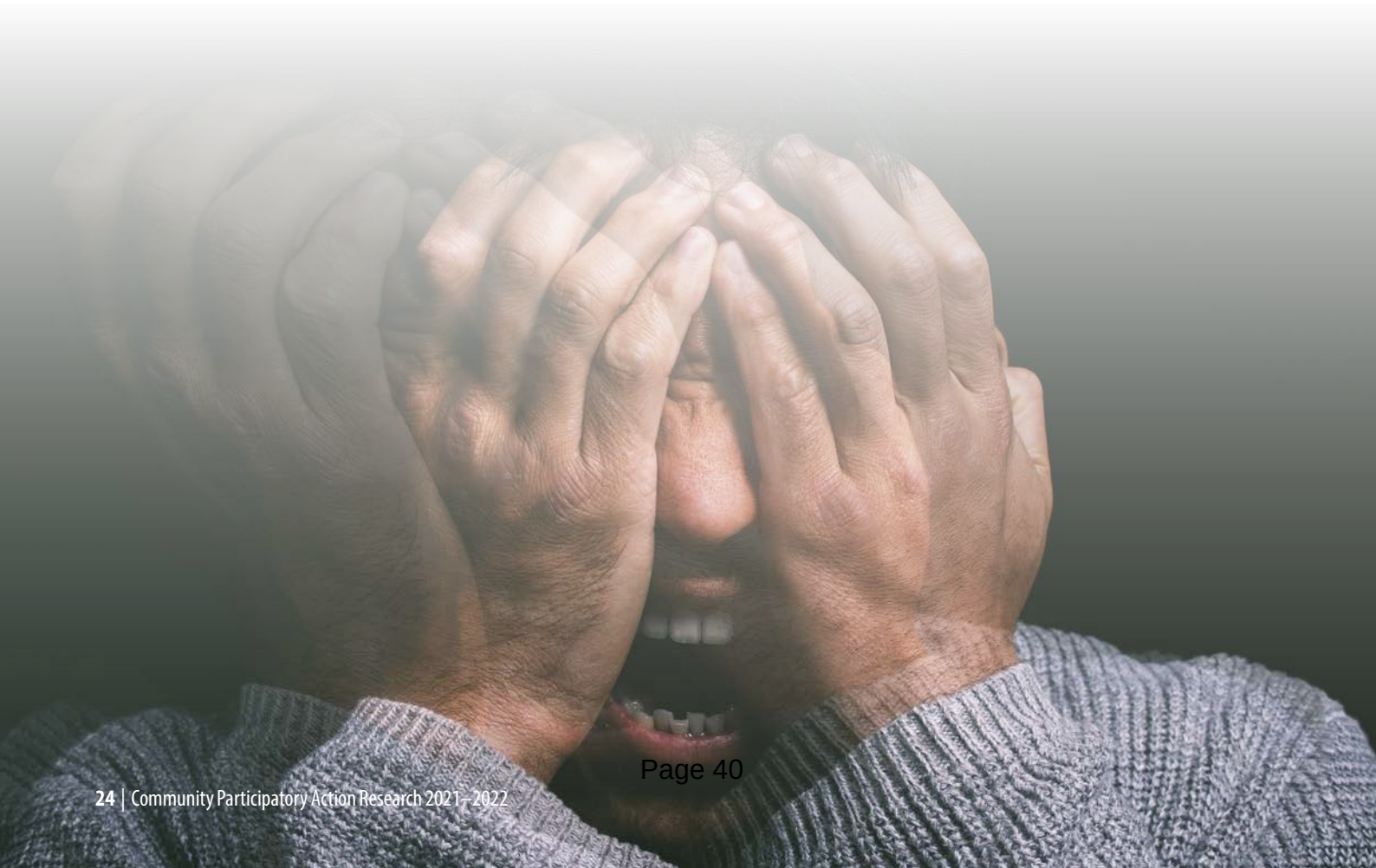
The findings of this research highlight the value of preventative approaches. They should make us think carefully about taking the early signs of mental ill-health seriously rather than only focusing on treating mental health when an individual's situation worsens.

On the 20 June 2020, a 25-year-old Libyan refugee attacked people with a knife in Forbury Gardens, Reading. Three people were killed in the incident and others injured. The young man who carried out the attack was known to mental health services in Reading. Although this example is thankfully rare, it highlights what can happen if inadequate early intervention and support for mental health is available. It is the opinion of this researcher that tragic incidents can be avoided if relevant authorities take immediate action when the signs of mental ill-health are apparent.

The research has explored the fact that BAME men are particularly likely to hide their feelings from people, even those closest to them, avoiding showing signs of weakness. This can result in them becoming increasingly isolated, leading to worsening mental health, drugs/alcohol addiction, criminality and even suicide. The research therefore sought to find out more about how BAME men Reading think about mental health and also how the Covid-19 pandemic and lockdown has impacted on men's mental health.

The research highlights the need for mental health providers and other services to offer help and support rather than simply challenging difficult behaviour. It should be easier for BAME men to get referred for mental health services, and service providers need to be aware that many BAME men will find it difficult to talk about mental health due to stigma and cultural beliefs about mental health.

At a practical level there is a need for clearer, easy-to-access information that reaches people where they are, and also for translation (both written and face-to-face). For communities, it is important to talk about mental health and to look for signs that someone is struggling. Individuals should be able to talk to someone they trust, say you they feel and ask for help.



RECOMMENDATIONS AND ACTIONS

Based on the findings of this research, the following actions and recommendations can be made:

- More funding from the UK Government, the NHS and Reading Borough Council towards mental health.
- The NHS should make it easier and simpler to access mental health services.
- The role of voluntary and community organisations in supporting people across all communities, and particularly those struggling with inequalities, should be recognised and appreciated. This sector should be supported as a key partner in terms of providing awareness, advocacy and education around mental health.
- School, colleges and universities should promote mental health and raise awareness of mental health for all students and staff.
- Support and conversation hubs, offering professional and peer support should be developed.
- People should be kept informed and updated, and systems for doing so that can adapt quickly and responsively to changing needs in communities.
- Staff in public services should be fully trained to identify mental health issues and provide immediate and appropriate intervention before the situation worsens.
- Identifying early signs of mental health issues will prevent people's mental health from worsening, and is more effective than only treating mental illness further down the line.
- Trained volunteers, with adequate screening checks, can help deliver services through local volunteer and community groups.
- Talking about mental health issues in communities will increase the understanding of mental health.
- Based on the early positive outcomes from the CPAR programme, community members should be supported to conduct their own research into the issues that affect them to help improve services and bring further benefits to communities.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to CPAR and partner organisations RBC, RVA, RCLC, UoR and ACRE, for letting me to be part of this incredible and unique research. I'm extremely grateful to Victor Koroma at ACRE who arranged for me to do this research.

I would like to express my deepest thanks to my wonderful research mentors and advisors Andrew Paterson and Esther Oenga who provided ongoing support throughout the process. This research would not have been possible without their thoughtful comments.

I am also thankful to my fellow Community Researchers participating in the CPAR programme for their considered comments and for sharing their learning. I would like to extend my deepest gratitude to Herjeet Randhawa and colleagues at RVA for all the unconditional support in this very unique and intense research.

I would also like to pay my special regards as well to Reading Men's Group (We Men) for their unlimited help and support provided during the research period. In particular, Chukwuemeka Obiora, Victor Besong and Anthony Darway from We Men were a great help in conducting the survey research.

To conclude, I cannot forget to thank all the participants who took time to complete the questionnaires and provided me with such useful comments and answers.

Appendix 1: Questionnaire

A. COVID-19 QUESTIONS

1. HAVE YOU TESTED POSITIVE FROM COVID-19?

- ☐ Yes
- ☐ No

2A. DID YOU HAVE ANY HELP DURING THE LOCKDOWN?

- ☐ Yes
- ☐ No

2B. IF YES, FROM WHOM?

- ☐ Family
- ☐ Friend
- ☐ Charity
- ☐ Government
- ☐ Local authority
- ☐ NHS
- ☐ other (please describe)

_____

_____

_____

_____

3A. HAS THE PANDEMIC AND THE LOCKDOWN AFFECTED YOU?

- ☐ Yes
- ☐ No

3B. IF YES, HOW (PLEASE TICK ALL THAT APPLY)

- ☐ Psychologically
- ☐ Financially
- ☐ Physically
- ☐ Other (please describe)

B. MENTAL HEALTH QUESTIONS

4. HAVE YOU OR SOMEONE CLOSE TO YOU EXPERIENCED EPISODES OF MENTAL HEALTH ISSUES?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

5. IF YOU HAVE A CONCERN ABOUT YOUR PERSONAL ISSUES, HOW LIKELY ARE YOU TO TALK TO SOMEONE ABOUT IT?

- ☐ Very likely
- ☐ Moderately likely
- ☐ Neither likely or unlikely
- ☐ Moderately unlikely
- ☐ Very unlikely
- ☐ Don't know

5A. WHO WOULD YOU TALK TO ABOUT PERSONAL ISSUES? (PLEASE TICK ALL THAT APPLY)

- ☐ Friend
- ☐ Family
- ☐ Doctor
- ☐ Religious Leaders
- ☐ Other (please describe)
- ☐ Prefer not to tell anyone

6. IF YOU ARE EXPERIENCING ANY SORT OF MENTAL HEALTH ISSUES, HOW LIKELY ARE YOU TO SEEK PROFESSIONAL HELP? (FOR INSTANCE, THERAPY AND TREATMENT)

- ☐ Very likely
- ☐ Moderately likely
- ☐ Neither likely or unlikely
- ☐ Moderately unlikely
- ☐ Very unlikely
- ☐ Don't know

7. WHAT HELPS YOU TO COPE IN TERMS OF YOUR MENTAL HEALTH?

- ☐ Taking part in physical exercise
- ☐ Reading
- ☐ Writing my dairies
- ☐ Going to religious congregation
- ☐ Smoking
- ☐ Drinking
- ☐ Traditional healers
- ☐ Others (please describe)

8. WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENT? "IT IS EASY TO ACCESS MENTAL HEALTH SERVICES"

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Strongly disagree
- ☐ Disagree
- ☐ I don't know

9. DO YOU KNOW ANY MENTAL HEALTH SERVICES?

- ☐ Yes
- ☐ No

10. IF APPLICABLE, WHAT BARRIERS DO YOU EXPERIENCE WHEN TRYING TO ACCESS MENTAL HEALTH SERVICES?

_____

_____

_____

_____

11. WOULD YOU TALK TO YOUR GP ABOUT ANY MENTAL HEALTH CONCERNS YOU HAVE?

- ☐ Yes
- ☐ No
- ☐ Don't know

C. GENERAL HEALTH QUESTIONS

12A. DO YOU DO ANY FORM OF EXERCISE?

- ☐ Yes
- ☐ No

12B. IF YES, HOW OFTEN? (PLEASE TICK ONE BOX)

- ☐ At least once a day
- ☐ More than once a week
- ☐ Once a week
- ☐ Once a month or less

D. DEMOGRAPHIC QUESTIONS

14. PLEASE CIRCLE WHICH ANSWERS APPLY TO YOU.

Age group	**18-30**	**31-40**	**41-59**	**60 and over**
Ethnic group	Black African/ Caribbean	Black/White	Arab/Asian	Other (please describe)
Marital status	Married	Single	Divorced/ separated	Civil partnership
Employment status	Employed	Self-employed	Student	Not employed

Thank you for completing this survey

Investigating the impact of Covid-19 on the Nepalese community in Reading

KRISHNA NEUPANE, INTEGRATED RESEARCH AND DEVELOPMENT CENTRE (IRDC), BERKSHIRE, UK CIC

INTRODUCTION

The research work was carried out between April 2021 and January 2022 as part of the CPAR programme. The CPAR programme was initiated and funded by Health Education England South-East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHS England and Improvement.

The study revealed that the Covid-19 pandemic caused health complications across the UK, and particularly within BAME communities. Some explanations put forward for this include: higher rates of poverty, other adverse impacts of inequality and increased vulnerability due to existing medical conditions within BAME communities.

In addition to experiencing higher rates of mortality and long-term illness from Covid-19, BAME communities are likely to experience a lasting legacy from Covid-19. This includes the psychological impact of fear, stress, loss of family and friends, and isolation and social distancing. Covid-19 and its economic impact are also likely to exacerbate poverty among many BAME communities.

RESEARCH FOCUS

With the above in mind, the research sought to explore the following areas of inquiry.

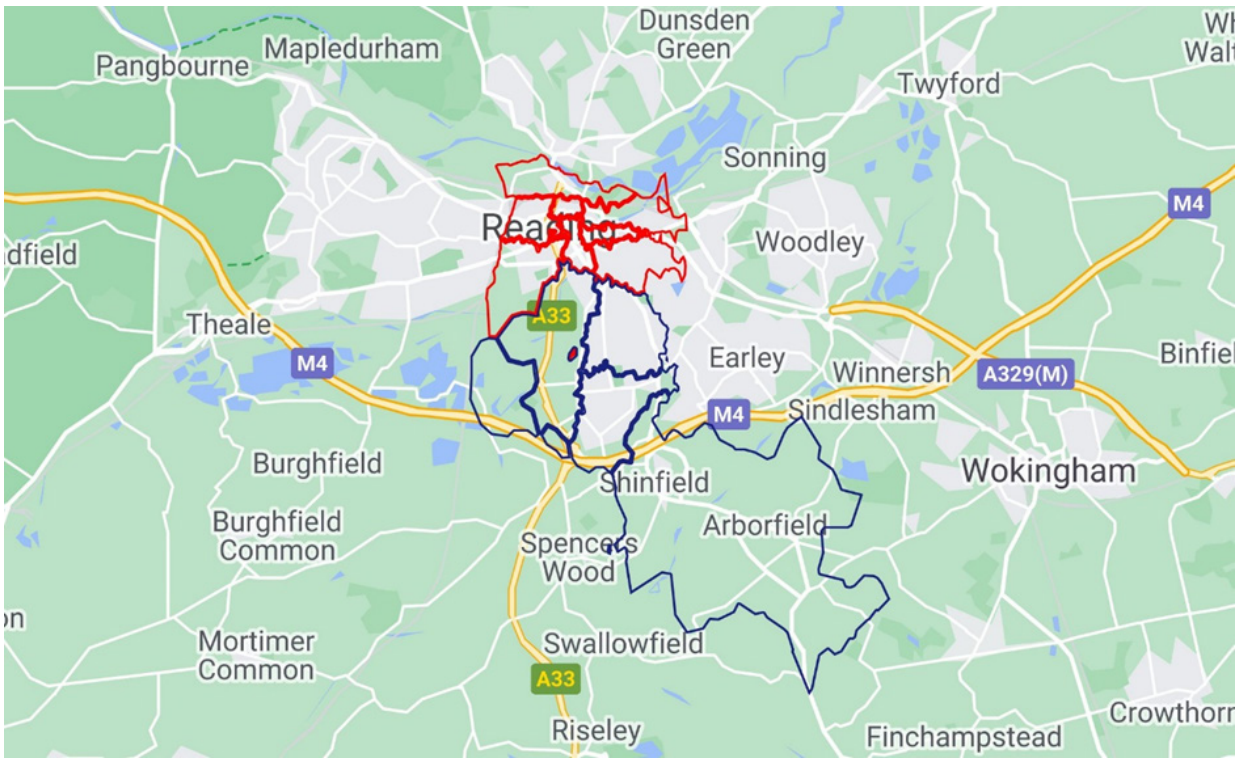
- What factors have contributed to the disproportionate impact of Covid-19 on BAME communities, specifically among Nepalese community groups residing at east and south Reading locations?
- What improvements to services can be recommended in order to address these factors and potentially improve health and wellbeing outcomes for these groups?

STUDY AREA SELECTION

Reading is the principal regional and commercial centre of the Thames Valley. The borough of Reading is home to 167,700 residents with the wider urban area of Reading reaching into the neighbouring Wokingham and West Berkshire local authority areas.

RG1 and RG2 postcode locations under Reading Borough Council territory were purposively selected for this study. In general, the east Reading location is relatively more densely populated and many mixed Nepalese groups or families reside in this area. In the RG2 area, there is evidence that more poverty and inequalities exist compared to other locations in Reading.

Map of RG1 and RG2 postcodes. Red boundaries show RG1 postcode district; blue boundaries show RG2.



RESEARCH METHODS

TRAINING AND SUPPORT

The CPAR programme provided participants with ongoing training. This included the following:

- Initial training consisted of two training sessions. Firstly, participants took part in a 2-hour online training session on community-led health. This was followed up by another 2-hour online session on community led-research. In addition to being introduced to theory and methods of this approach, the community researchers were shown the Community Participatory Action Research cycle (see figure 1). The cycle tries to show how research is an ongoing process of planning, acting and reflecting and is part of wider action in communities.

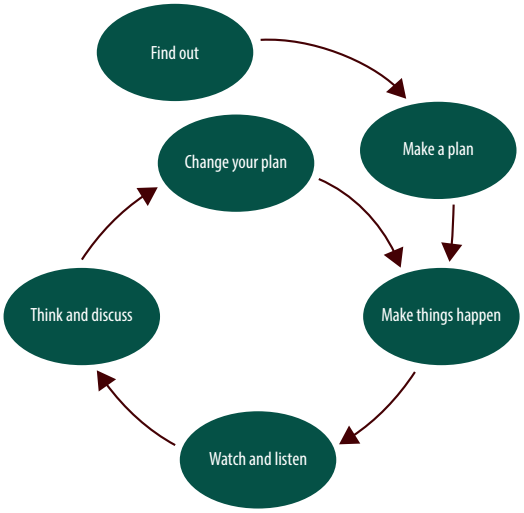


Figure 1. Community participatory action research cycle (Source: SCDC training materials, 2021)

- Continued mentoring support was then provided by Scottish Community Development Centre (SCDC) and a CPAR facilitator from Reading Voluntary Action (RVA). This included support to plan research, collect and collate information, tabulate and analyse data, and to bring findings together into a final report.
- Shared learning sessions were held at key points in the programme, and enabled community researchers to share, and learn from each other's research projects.
- A virtual session on creative research methods was provided by Dr Sally Lloyd-Evans, University of Reading. This gave an insight into a range of community participatory research tools before commencing the research work with community groups.

CONDUCTING THE RESEARCH

A total of eight face-to-face interviews were conducted; four at each location. Similarly, three focus group discussion meetings were held; one at each location and the third one was conducted with a mixed group from both locations. All interviews, except one, were conducted in Nepali language and then transcribed to English. This may have led to some inconsistencies, for instance, due to the difficulty of translating colloquial phrases.

RESEARCH TIMELINE

Timeline for research work support: The project's actual lifetime was nine months commencing from April 2021 to January 2022. The duration was break down into five different phases; training, planning-mentoring, planning-getting started, research mentoring and learning, completing research and presenting findings.

Source: SCDC training materials, 2021

IMPLICATIONS OF SELECTED RESEARCH APPROACH

This research project explored 'depth and breadth' of the actual health and wellbeing issues of local community groups. Face to face interview and focus group discussion tools are considered widely accepted, valid and reliable tools to gather community information. It explored and drew up real voices, feelings or worries of local community people. The findings and recommendation parts in the project report have been transferred as suggested programme activities or events.

This research work covered part of RG1 and RG2 of Reading Borough Council's territory (see map). Respondents for the research study represented a good range of parameters such as; age, sex, sub-group, education level, profession and residency. Likewise, the level of participants varied from those who had a low level of literacy-were limited to conversation and writing English, to fluent in speaking and writing English.

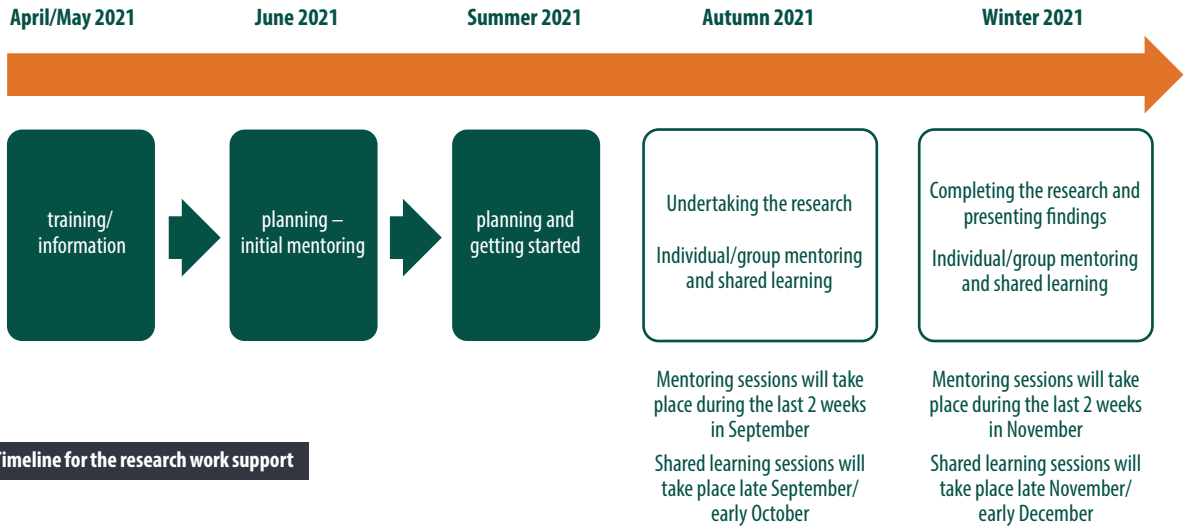


Figure 2. Timeline for the research work support

RESEARCH FINDINGS

Analysis of the interview data highlighted three major factors which could explain any disproportionate impact of Covid-19 among Nepalese community groups. These were as follows:

- Living conditions
- Communication
- Trust, fear and vaccine hesitancy

More detail on these findings is set out below. The last part of the findings section describes the impact of Covid-19 on the Nepalese community, which also came through strongly in the research.

LIVING CONDITIONS

Living conditions can be seen to have directly and indirectly increased people's vulnerability to Covid-19, including multiple families living in shared households and financial pressures. There are both cultural and material explanations for these living conditions.

SHARED HOUSING

- Respondents reported living with extended families in shared housing. This directly increases the risk of spreading and catching Covid-19. It also puts older, vulnerable, family members at risk as they are in close contact with younger family members who will, in turn, be exposed to the virus at work, school or other social contact.
- There is a cultural element here, in that the Nepalese community is tight knit with family members looking after one another.

FINANCIAL PRESSURES

- Financial pressure also increases the likelihood of having to share accommodation. It also puts more members of households to work pressure. For instance, a person who worked as a Nepali – English translator said they had to go to work during the pandemic in order to afford everyday household costs and to pay bills.
- Some people who were interviewed said they prioritised saving money over maintaining a healthy diet. An unhealthy diet contributed to reduce immunity and a person's ability to fight infection, and therefore indirectly increases a person's likelihood of experiencing severe symptoms.
- Another respondent pointed out that older people found it difficult to pay to top up their mobile phone credit, which prevented them from contacting the GP. It is possible that financial circumstances are therefore leaving people more vulnerable, as it may prevent them from seeking help immediately.
- Among the Nepalese community, there is a cultural orientation to save money for supporting grandchildren, grandparents and other family members.

COMMUNICATION

The two key dimensions of communication that emerged from the research were language and internet use. Barriers in both these areas made it difficult for Nepalese community members to receive and understand information and advice related to Covid-19 that could help keep them safe.

LANGUAGE BARRIERS

Respondents said that not being able to communicate in English made it difficult to access services and receive advice and support regarding health and wellbeing related issues. In relation to Covid-19, this was expressed as one of the major barriers to receiving medical advice on symptoms, staying safe and keeping healthy.

Those who received the information found it difficult to interpret and understand. Language and communication barriers make it harder to distinguish accurate information from information from untrustworthy sources.

People interviewed in the research said there were not enough interpreters available when needed which made it difficult for them to access required health care services and access medical advice.

ONLINE COMMUNICATION

Another communication barrier people experienced during the Covid-19 pandemic was around connecting with online services. Some people had limited access to technology that would enable them to go online, whereas others did not have the required digital skills.

In general, where there was a regular flow of information either online, through e-newsletters or video clips, this was appreciated. Telephone conversations were also helpful for those who could communicate considered positive.

However, most community members who took part in the research preferred to have face-to-face interactions as, otherwise, they felt they could not adequately explain their conditions to service providers.

SOURCES OF SUPPORT

One participant described how a Nepalese doctor at their local GP was able to translate guidance for them.

> "Nepali doctor who worked in local GP helped to interpret medical information in this sense we are happy with GP services" (Interview respondent)

Instead of relying on formal sources of information, some families relied on informal networks for advice. Participants described how an inter-family support service had emerged which helped people to hear the latest information and advice. More generally, family members often interpreted for each other.

Voluntary and community groups were also identified as a source of support. In addition to supplying healthy food and other groceries, these organisations ran Covid-19 awareness sessions where translation was offered. Some also helped book GP appointments.

> "Provided voluntary services by local charities at Covid vaccination centres was helpful for interpretation, fill out forms." (Interview respondent)

FEAR, TRUST AND VACCINE HESITANCY

The issues of fear and trust were prominent throughout the interviews. These issues are clearly linked to communication, since people are more likely to be fearful and mistrusting when they have little access to good quality information and advice. Combined, these issues can be seen to increase people's vulnerability to Covid-19 as they result in vaccine hesitancy and other beliefs or actions that go against main-stream public health advice.

FEAR

People who were interviewed recounted stories they had heard during the pandemic, which had been circulating around the Nepalese community in Reading. Examples of local stories included hospital staff fleeing from hospitals due to the virus and news of people dying in Royal Berkshire Hospital, including young people and teachers. Respondents said that stories like these had spread fear and negative rumours in the local community.

TRUST

Respondents tended to have negative perceptions of local NHS services during the pandemic. For instance, one view was that hospitals were overloaded because GPs weren't doing their jobs properly in terms of providing good advice and services for everyday health concerns. It was felt that people had to make recurring visits to the GP before they received the correct diagnosis, leaving them suffering for longer and with worse health outcomes. This negativity towards GPs appeared to be connected to a feeling that GPs should have remained open during the pandemic.

> "Our entire family members got corona symptoms however, we never got GP advice and services at this very difficult time and GP never bothered about our life." (Interview respondent).

> "I am one of the extremely vulnerable and shielded patients and it is now 24 months' time I haven't seen my GP face to face, I have experienced extremely difficult to make phone contact to GP, as it took me one hour and fifty-nine minutes to get contacted, I had recorded this, made it screenshot and produced to the GP receptionist but still did not trust for this. No one did contact me in its second phase." (Interview respondent).

More positively, the participant who had been provided with interpretation by their Nepalese GP added that their overall experience with this GP had been favourable.

> "I rate GP's services very good as they made follow up calls to monitor my personal health condition and provide necessary advice whether I need any further support. I really received required services, support and help from my GP."

Another statutory service which was viewed positively in the research was Reading Borough Council's online information which was helpful in terms of finding information on vaccination centres, emergency contact numbers, interpretation and advice (including via video clips). The council's provision of food and other supplies to shielding families was also appreciated.

Respondents often talked about their experiences and perceptions of what they saw as the delayed government response to the pandemic. Referring back to the initial days of the pandemic, some thought that the decision to introduce restrictions as part of a national lockdown came too late. Others thought that public health policies and messages had been confused and incoherent.

> "NHS local hospitals were confused whether staff members who got positive symptoms must stay in isolation or continue working. It was somehow like a research study whether this is ok or that is ok, with no precise policy introduced or decision made at decision making level."

It is well understood that mistrust of health services and other public institutions among BAME communities is often rooted in racism. A small number of respondents expressed concerns about being treated differently due to their ethnicity. For instance, one view was that that health services prioritised check-ups and other services for some groups over others, due to discrimination.

> "In policy documents there seem to have equal rights for all however in real practice it is different, looking at service seekers' skins, language, culture they never give us equal treatment"

Ethnic minority communities also have negative experiences due to cultural insensitivity. This can be as simple as not providing food that people are used to eating. One participant described a how the food on offer in hospital can make a tragic situation even harder.

> "As the hospitalised patients were not allowed to have homemade foods and drinks and some of the admitted patients didn't like the taste of foods in hospital, they were not allowed to make visit by their family members. One corona patient in hospital requested to have some homemade rice but did not get it and sadly she died, it's extremely a shame case."

FOLLOWING GUIDELINES

Research participants described how ineffective decision making had impacted on their ability to stay safe and follow health protection guidelines.

> "In my home my close relatives visited us, we did not refuse them coming in my house, sadly we got corona positive by then as there was no strict rules applied by the local Government including hospital, it was only very late social distancing, using protective device like face masks strictly applied by local government." (Interview respondent)

PERCEPTIONS OF COVID-19 AND VACCINE HESITANCY

For some, mistrust and fear extended to Covid-19 and the vaccination programme. One view expressed in the research was that Covid-19 was a simple flu and that we should not worry much about it. Some other people were 'vaccine hesitant' due to believing that negative side effects included infertility and becoming more vulnerable to other diseases.

Other beliefs which came through in the research included that traditional herbal remedies used in Nepal were effective for Covid-19, and that had they been used the disease could have been eradicated by now. There was also some uncertainty and confusion about how Covid-19 could be transmitted. This ranged from doubts over some very plausible transmission routes, such as via traffic light buttons, to belief in less scientific means of transmission, such as that the virus 'spears' could stick to the bottom of shoes.

> "Back in Nepal, a range of herbs are available that are not found in Reading. Otherwise, we could have eradicated Covid-19 using them" (Interview respondent)

THE IMPACT OF COVID-19 ON THE NEPALESE COMMUNITY

Covid-19 had a significant impact on both the physical and mental health of research participants. People had lost loved ones, had been seriously ill themselves and, in some cases, the impact would be felt for the rest of people's lives.

In terms of physical health, Covid-19 had had a direct impact on people's families, with many losing loved ones. Some participants described how the impact of Covid-19 on them and their family's physical health had also impacted on their mental wellbeing.

> "In school where my children study found positive symptoms to teachers, I have to take my children to school regularly, I started getting stress and felt panicking. After few days my son's teacher died because of Coronavirus, and I started thinking there might be a high risk in my family members, I started worrying too much as my old age mum lives with me."

> "Suddenly, Covid-19 invaded in the area beginning in 2020, my entire family at home was affected and got ill. It was a shocking situation, and we could not call an ambulance and to go to hospital, neither get help from relatives, friends and neighbouring families. My wife got severely ill, I started thinking she will not live for long. I had to manage this terrible family crisis. I controlled myself, did not lose my patience and kept helping them by my level and capacity providing foods and other support, gradually days turned to better, but this is one of the most bitters experiences I have ever had, now our days turning to a full moon." (Interview respondent)

People's mental health also suffered as a result of lockdown and social distancing measures. Participants highlighted how living in isolation without having any face-to-face contact, in combination with being unable to exercise and travel, had increased their stress and anxiety levels.

Moreover, this was something which was seen to have lasting implications for individuals and communities. Social gatherings and celebrations are an important part of Nepalese culture, so having such limited social interaction would have been very difficult for many people. One research participant was concerned that the local Nepalese community might struggle to fully recover.

> "We are gradually losing cultural knowledge, rich family ties, social life and inter family and inter -community interactions, which are vital to live a healthy and happy life. We are human being, therefore need to have regular interactions, support and sharing feelings with one another. Connecting to nature is very important."

RECOMMENDATIONS AND ACTIONS

Based on the above findings, the following recommendations can be made.

OUTREACH AND ENGAGEMENT

Outreach services are required for high-risk vulnerable households, including single parent households and those living in overcrowded conditions.

Local community groups need to be engaged with as partners in service design and delivery. This will ensure that services are culturally sensitive and will help to achieve some of the other recommendations below concerning interpretation and mental health.

In addition, local community leaders, or champions, need to be engaged with so they can help mobilise for current and future public health issues. Volunteers and groups should be provided with proper training to prepare them as champions. They would have a varied role that recognises their rich information about their local communities. This could include representing their communities in the design of services and also helping in the community to identify and support vulnerable households.

As part of this outreach, there should be a public health awareness programme for communities to provide accurate information on public health issues and services. This should include practical support for vulnerable households and individuals, including those living in isolation, single-parent families and those with multiple health conditions

INTERPRETATION AND LANGUAGE SUPPORT

Interpreting services need to be readily available for Nepalese and wider BAME communities who require this.

Translation should be provided by community representatives who are trusted members of their own community.

Translated versions of important public health information and other advice should be available.

More widely, public agencies should work together to identify communities experiencing language barriers and ensure ESOL classes, internet training and other support is available.

Training and support needs to be participant-centred and tailored in order to be culturally appropriate and so that it delivered in a location and time that people can attend.

CULTURAL, RELIGIOUS AND ETHNIC DIVERSITY TRAINING

Public sector staff, including health care workers should be provided with training in cultural, religious and ethnic diversity. Again, this should be designed and delivered with voluntary and community organisations who represent minority communities. Therefore, this training should not be considered in isolation of the other recommendations in this report. It should be developed in tandem with community engagement outreach programmes as well as interpretation services and mental health provision.

CULTURALLY APPROPRIATE MENTAL HEALTH SUPPORT

Covid-19 and the resulting health protection measures have had a significant impact on the mental health of people in the Nepalese community. As part of outreach work, it is important to identify households in need of such support and to design culturally appropriate services with the people affected, including community organisations representing them.

Support should go beyond medicalised treatment for mental health, and focus on fostering social interaction, building community organisations and providing physical activity. Community and voluntary organisations need to be central to this provision and should be engaged with and supported to contribute their expertise based on lived-experience. It is this kind of community support that will build community health and wellbeing, including mental health, in the longer term.

LEARNINGS REFLECTION FROM THE CPAR PROJECT

Plan your research carefully: In order to be successful, it is important to plan your research carefully. To do this well you will need to review existing evidence and speak to a range of people from the community and service providers, which will help you to explore and identify your research queries.

Formulation of research questions: Based on your initial planning, you will need to think about what it is you want to find out and why, including what you will do with the research findings. It is advisable to do this prior to conducting your research. It will be helpful to get feedback from others and to pilot your methods and questions with a test group before using them to conduct your research.

Make sure you have the required time and other resources: Prior to proceeding with your research, there may be useful to estimate the time it will take, as well as what material and funding you will require to complete your project. It is important not to underestimate what is required or to take it lightly as even the best research can be hampered by a lack of time and resources.

Seek endorsement of your research queries with community groups: Your research will be more relevant and proceed more smoothly if you speak to people from the community you are researching beforehand. This will help ensure there is a common understanding of the project within the community. To do this, you could organise informal meetings to share your research queries and aims. It may be useful to explain how it is funded and why it is being conducted. This will help to avoid confusion and misunderstanding between community groups and the researcher, and is key to progressing and completing the research as planned.

Prepare well for your interviews: According to a common saying, 'to hunt a cat you have to prepare as if you are going to hunt a tiger'. A research interview may look like a straightforward undertaking. However, in order to adequately prepare your interview and focus group meetings, you have to be confident, get organised and well prepared. You should prepare an interview checklist on a piece of paper or in your diary, and arrange necessary equipment (such as recording devices) accordingly. Doing so will not only save you time and but also help to ensure no mistakes are made.

It is important to establish a suitable interview time and venue with respondents in advance. One-off communication with respondents may not work and, ideally, you should have a phone chat to reiterate the aims and format of your interview, as well as take people through consent forms for the interview. This may also be a good opportunity to establish the approximate time required to take part in an interview and to discuss a suitable venue. If you can arrange these small but important details in advance you should be able to conduct your research effectively with a degree of confidence and peace of mind.

Greet and say 'thank you' to respondents: Greeting and thanking respondents at the time of interview and in all email and phone communication will help maintain a good connection and build strong and lasting research relationships. A small gift, if you have anything to give, will also help to build an effective relationship and show your appreciation for the time participants have given you.

FUTURE RESEARCH AREAS

Based on the findings and recommendations of this research, two potential areas for future research are:

- Investigating the role of youth to help address the language and technological barriers faced by older generations and transfer good culture and family relationships to new generations.
- Exploring how to improve English language courses for people who do not speak English as a first language, including ways to make these more interactive, accessible and engaging

ACKNOWLEDGEMENTS

I would like to give my heartfelt thanks to all respondents who willingly took part in face-to-face interviews and focus groups. Without their willingness and meaningful participation, the community participatory action research (CPAR) project work would not have been completed successfully. I am thankful to Herjeet Randhawa at Reading Voluntary Action (RVA) who encouraged me to engage in CPAR work as a local researcher and provided support as and when deemed necessary in its initial phase.

Similarly, I am very grateful to Dr Andrew Paterson from Scottish Community Development Centre (SCDC) for providing necessary training, mentoring and report development support. I am very proud of having such a wonderful facilitator, Dr Esther Oenga, RVA who continually encouraged me to progress the research work according to the planned timeline, and ensured access to audio recording equipment in order to carry out interviews. Her role in supporting the development of this research report cannot be ignored, and I would therefore like to express my deepest appreciation to her. Also, I am grateful to Dr Sally Lloyd-Evans, University of Reading who shared the CPAR creative methods with the community researchers prior to commencement of the interviews and focus groups. I found the tips and methods that she provided helpful.

I enjoyed attending shared meetings as part of the CPAR project and working together with the other participating community researchers. In general, the support provided by Michelle Berry and Nisa Unis from Reading Borough Council (RBC) was helpful and I am thankful to both of them. Finally, I would like to recognise the support provided by all others those directly or indirectly connected to this piece of work to get the research to where it is now.

Profiles and reflections: community researchers and partners

EVANGELINE KARANJA, COMMUNITY RESEARCHER

I am a mother to twin girls, with a passion for community work and service. I am a Master's graduate from the University of Reading and previously worked as a Mortgage Advisor at NatWest. During the pandemic, I volunteered my time with grassroots community organisations ACRE and Utulivu Women's group. Volunteering offers me the opportunity to extend my knowledge base, network with other professionals, work meaningfully in the community, and most importantly, have a positive impact now and on the next generation.

I believe that community-based research empowers local communities creating a constructive relationship between communities and the institutions. Community engagement is necessary, and viable, as it is likely to lead to more equitable, sustainable public decisions and improve the liveability of local communities. The research was an opportunity to pursue an in-depth study on access to maternal services for ethnic minority English-speaking women and midwives in Reading, Berkshire.

Through this research, I learned to use qualitative research methods and data analysis. This helped me gain sound technical knowledge, perfect my soft skills, and gain confidence and credibility to make a good professional impact. I hope the recommendations in the report can be used and adapted to make a change to maternal healthcare and access. I feel confident and empowered to carry out more community research in the future.

DONNA MA, COMMUNITY RESEARCHER

During my 24 years in England, after moving from Hong Kong, I have always had a mission to serve ethnic minority communities particularly Chinese immigrants. The opportunity came in April 2021 through RCLC which is one of the three charity organisations in this CPAR project. Becoming a CPAR researcher has enabled me to go beyond the religious, social and educational sectors.

My working experience as a qualified ESOL tutor has given me knowledge about different ethnic minority cultures. The trust and respect that I have gained from ethnic minorities helped the respondents feel more comfortable to share their views and life experiences. When I started my first online training session in April 2021, I was anxious and not sure whether I would be able to do a good job. The support which I have received in this CPAR programme has provided me the skills to design the questionnaire, do the data entry and data analysis as well as compiling the final report. After taking part actively in this programme for a year I am feeling empowered and confident. Working with a colleague and other people in this project, I have learnt to be more patient and open-minded and also picked up some IT skills.

I am glad that through this research the women respondents had the chance to speak their mind in spite of language barriers and lack of IT knowledge and social contacts. The findings of this research will inform future communication plans for all health and wellbeing issues within Reading's diverse communities, and facilitate the development of accessible health care services.

I also participated in the Town Centre Strategy Community Engagement led by Reading Voluntary Action and hosted a focus group online. I would like to continue my learning journey to become a competent community researcher and contribute more to the ethnic minority community.

HEMAMALINI SUNDHARARAJAN, COMMUNITY RESEARCHER

With a deep sense of commitment to do something for society, I have taken up different voluntary and paid roles at Reading Community Learning Centre (RCLC) over the last 8 years. This has enabled close interactions with ethnic minority women.

As an Outreach Support Worker, I was able to establish a level of trust with ethnic minority women, wherein open conversations could be had about their day-to-day challenges. Some of these challenges were generic and systemic in nature, especially regarding education and healthcare support, with deeper impacts due to Covid.

When the CPAR research initiative was talked about at RCLC, I enrolled as CPAR Researcher. Even though I had no prior experience of conducting research, the CPAR programme team ensured that appropriate guidance was provided through all the phases of the research. This research provided me the opportunity to take a structured approach in summarising the challenges faced by ethnic minority women and formulating an action plan for implementation. Personally, this has helped me to improve my social and IT skills and my research skills, including formulating questions, data collection, data analysis and reporting.

The eagerness with which the research team, RCLC and external respondents offered their time and support for this research initiative, indicated the collective spirit and a sense of togetherness for the common objective of community development. The research findings and recommendations have highlighted the need for additional focus on education and steps to improve the reach of healthcare services. I hope that the research findings would be looked at as the voice of Reading Ethnic Minority Women and the recommendations taken in earnest for their improvement.

I am thankful for this opportunity and look forward to more such engagements to contribute to the society.

TARIQ GOMMA, COMMUNITY RESEARCHER

This CPAR research has been a great wake-up call for me during Covid-19 and lockdowns. It has opened doors and provided great opportunities for me to discover myself and my potential. It started when Victor Koroma at ACRE gave me the opportunity to be a part of this research. At first, I was very nervous and many questions went through my head such as: was I the right person to do this research? what am I going to investigate? how am I going to do that? and can I really do that? There were many questions and worries, but the biggest worry was that I wasn't equipped enough with knowledge to do this. My self-esteem was quite low, my confidence was zero, my motivation and self-belief were not there due to what I had gone through during the pandemic.

One day, hope came along from someone believing in me, who told me that everything is possible and nothing impossible under the sun. That person is Dr Esther Oenga the CPAR Advisor and facilitator, who motivated me to take the first step, she reassured me that support and guidance was available throughout the research process. That was a big step for me. Then Dr Andrew Paterson, the CPAR mentor, stepped in alongside Esther in the mission to guide me along the way. They were the real driving force and the brains behind it all. These two wonderful people made it very easy for me, guided me, advised me, lifted me up and motivated me along the way. They helped me from the beginning until the end, from designing the questionnaire to writing this report. Their support at each stage gave me more confidence to move on to the next step.

I cannot describe the magnitude of experience I gained from doing this research. It taught me so many things and important lessons in life, including working according to your values and objectives. It taught me to always look ahead not back, look up not down, feel positive not negative. Nothing is impossible and there is always light and hope at the end of the tunnel. This research taught me to be strong and motivated and always look and think ahead. Because of that I decided to learn more about the subject of mental health and the need to create awareness of mental health in BAME communities.

CPAR research gave me all the confidence I needed, and I decided to join West Lancashire College's online course, Mental Health and First Aid. I have learned so much that people in my community have started getting advice from me about the subject. For example, a friend of mine is so inspired by me doing the research, he decided that he will be more involved with volunteering with ACRE. Furthermore, a woman at a local café which I regularly visit told me she had been through a tough time and had recently experienced depression. When I had a chat with her regarding mental health research, she was touched by my experience and the useful information I shared. She decided to take the flyer that was developed during the CPAR research and put it in the staff room to encourage other staff members to learn and seek help when needed. Finally, a group of Sudanese asylum seekers started feeling better and confident when I introduced them to the Mental Health Hub sessions that are taking place at ACRE's office every Tuesday.

CPAR research has made me realize the value of self-motivation and I'm hungry to learn more about mental health to be a better person for myself, my community and people in need. There is no shame in seeking help and it's never too late to take action. Small positive steps may change your life or someone's life.

KRISHNA NEUPANE, COMMUNITY RESEARCHER

Krishna has a Master's degree in Forestry from the University of the Philippines and a Bachelor's degree in Agriculture from India. Krishna is trained in development-oriented research in agriculture, instructional development foundations, project management and programme administration in developing countries. He has worked in the technical and vocational training institute managed by the Council for Technical Education and Vocational Training in Nepal and as Senior Programme Manager for the Nepal Agroforestry Foundation he conducted various field research projects and coordinated externally-funded projects such as AusAid watershed projects, a Danish-funded private forestry project and a University of Reading funded livestock livelihood project.

Krishna entered the UK in 2005 under the highly-skilled migrant programme scheme. He worked as a chair of trustees for Greater Reading Nepalese Community Association and during his tenure launched various programmes and activities with funding and support from Berkshire West Clinical Commissioning Group and RBC.

In 2016, he founded the Integrated Research and Development Centre (IRDC), Berkshire, UK CIC, which aims to contribute to reducing poverty and inequality (one of the strategic plans of Reading Borough Council), and supporting primarily south Asian BAME community groups by providing training in basic IT and computers, English conversation, gardening, and health, wellbeing and nutrition.

For the last few years, Krishna has been actively engaged in community research works such as community needs assessments, community surveys and community participatory action research initiatives.

DR DEMELZA HOOKWAY, RVA COMMUNICATIONS MANAGER

The CPAR project has been inspiring to work on in so many respects. From an RVA perspective, it has built on previous participatory action research with community partners and the University and highlighted once again the importance of foregrounding community voices. One of the highlights has been Eva, Donna, Hema, Krishna and Tariq presenting their findings at regional and national showcases and seeing their research become part of the evidence base for all stakeholders committed to reducing health inequalities in Reading. As well as the community researchers' findings, this report aims to document the collective effort it has taken to accomplish the CPAR project by people who are committed to listening, learning and taking social action. Sally, Esther and Aisha write so eloquently about the vital importance of funding and resourcing this work properly, so that we can hang on to the 'action' in participatory action research.

DR ESTHER OENGA, PROJECT FACILITATOR

Community participatory action research (CPAR)-Reading is described by many stakeholders as a unique and successful research project conducted between February 2021 and May 2022. Five CPAR-Reading researchers were among the 41 community researchers recruited by Health Education England, South East (HEE SE) to undertake research. The aims of the programme were to equip community researchers from Black, Asian and Minority Ethnic (BAME) communities without research skills to undertake research within their communities.

A great achievement of the CPAR project was the ownership taken by the CPAR researchers for the duration of the project and participation from the beginning until the end. They engaged in the research processes, decided the research topics in consultation with their communities and prepared a final report sharing their findings in different showcasing events. This achievement was inconceivable to the researchers at the offset because they had little or no prior research experience, they were nervous, fearful and not ready to engage in research. A significant contributor to their success was the existing relationship and trust they had within their communities.

It was evident that, the additional research projects, the Town Centre and Southcote digital research projects provided practical experiences for the researchers in terms of engaging the communities in meaningful conversations and presenting the research progress in different showcase events. This further enhanced their confidence. One researcher, who was initially nervous to take part in the research project said, ***"I am now a competent researcher, I now have full appetite for research and want to turn my research career upside down. We have been supported and nurtured every step of the process by our mentor".*** The researchers have been empowered and become great assets in the Reading community.

The CPAR partners tirelessly supported the research project all through up to the end, with the researchers being grateful to the community partners for their commitment and sacrifices. In an informal meeting, the researchers had the following to say about the community partners: ***"the community partners have been fantastic, they provided solutions to all the research challenges such as transcribing recorded interviews, translating questionnaires into different languages, they provided recorders, laptops, and even the use of physical space where we have met real people in a real room with snacks away from the Zoom screen".***

One noticeable success factor of CPAR-Reading as noted by all the stakeholders was the role of a part time CPAR facilitator to support the researchers, partners and wider collaborations. The facilitator role was unique to CPAR Reading and no project within the South-East region had a similar role supporting their research projects. The stakeholders said, "the role was unique, essential, and a great asset as it was most needed in the CPAR research". The CPAR partners regarded the facilitator as a "bridge", "glue", "connector" that supported the smooth running of the CPAR project. In addition, the local support provided by Michelle Berry, Nisa Unis from RBC, and Lorna Zischka and Sonia Duval from the University of Reading was highly appreciated by the researchers.

A key aspect highlighted during the CPAR project was the required time and need for the stakeholders to be flexible. The part-time facilitator had to be flexible to accommodate the researchers needs, often working on off days beyond the contracted hours. The facilitator went far and beyond her role not only to support the local project but also support the South East region research as a whole. In addition, many CPAR partners and researchers worked more hours beyond the initial hours allocated to the project. The facilitator observed great commitment from different researchers. **At one time, one researcher attended a physical meeting during his work break while another researcher made a zoom presentation while on a break at work.** These are really sacrifices, commitments and efforts that go unnoticed but contribute to overall success of the project.

The success of the CPAR-Reading project was as a result of strong partnerships with the five partners that depended on existing relationship and collaborations. The five partners: Reading Community Learning Centre (RCLC), Reading Borough Council (RBC), Alliance for Cohesion and Racial Equality (ACRE), Reading Voluntary Action (RVA) and University of Reading Participation Lab worked as a team and supported the project passionately. Each partner contributed uniquely beyond their initial commitments. The CPAR-Reading project partners created several opportunities for the researchers to showcase the many benefits their research produced. This enhanced the researcher's confidence, presentations skills, and widened networks locally, nationally and internationally.

At the end of the CPAR-Reading project, events were organised to present the researcher's work. This was carried out both online and in person with the objective of presenting the research findings and recommendations. The events enhanced the relationship the researchers had with the partners and created a broader trust within the community as they felt valued. It is hoped that this CPAR report will not only be shared widely to different organisations but also to the diverse communities represented in the research undertaken. One community participant in the final showcase event asked ***"CPAR recommendations, what next?".*** Such questions were shared with organisations, policy makers and service providers tasked with taking forward the CPAR project recommendations and address the **ACTION** points in order to make the necessary interventions. **As the CPAR projects comes to an end, there is need to support the researchers post research. This will be different for all researchers. In the short term, this includes their emotional wellbeing, as they may have become more vulnerable during the research process. Additionally, there are practical needs relating to any further community work they undertake that will need support, including making presentations without adequate resources.**

It is important to note that two other CPAR projects were conducted in Reading by Jacquah Foundation who focused on Covid-hesitancy and Utulivu Women's Group that focused on mental health among young people. Their reports will be published independently.

CPAR project is a great model, however, there is a need for researchers to be recognised, valued and rewarded. Partnership and collaboration are key to addressing the local issues identified and the coordination of any efforts made is essential and most needed. This utilises the underlying strength when the community works together. In order to achieve good outcomes, adequate time allocation and funding are required. The implementation of recommendations at the actions stage needs to be taken seriously, or else, relationships built over time are broken. Finally, despite the CPAR project being conducted during the pandemic, I can truly say that participating in research that focused on a bottom up approach and equal partnership has been remarkable in all ways.

AISHA MALIK, CENTRE MANAGER, READING COMMUNITY LEARNING CENTRE

It has been widely reported that the COVID-19 pandemic has disproportionately impacted Black and Ethnic Minority (BAME) communities across the UK, which have suffered higher rates of hospitalisation and mortality. While the causes of this outsized impact are yet to be fully untangled, it is consistent with longstanding disparities in health outcomes and access to medical treatment between BAME communities and the white majority. The pandemic has, in effect, brought pre-existing health inequities to the fore.

Reading Community Learning Centre (RCLC) has over 20 years of experience in delivering services to support traditionally 'hard-to-reach' refugee and migrant ethnic minority women. Our mission is to empower and support refugee and migrant women by creating a space for learning, and advocating for equal treatment, equal rights, and a life free from violence and discrimination. When the opportunity arose for us to be involved in a project which would not only investigate and assess why some of these disparities exist within the ethnic minority groups locally but also train and support women from the community to undertake this research, we were thrilled to be part of it. Especially as it meant that this would increase the diversity of community researchers locally.

The role of RCLC was to work collaboratively in partnership with RBC, Reading Voluntary Action, the University of Reading Participation Lab and ACRE (Alliance for Cohesion and Racial Equality) to recruit, train and produce a research report for CPAR funded by SCDC and HEE. A key strength of this project has been in bringing together the skills from each of these organisations culminating in research which has engaged with a much richer and diverse group of ethnic minorities. Another great strength has been the funding provided by RBC to employ a facilitator to oversee the project and bring it all together. Without this funding for the role, it would have been extremely difficult to coordinate the four research projects, complete them within the time frame but also provide much needed support to the five community researchers on this project. The facilitator was crucial in spreading the word about the project and was invited to speak at various steering groups to talk about the project.

Due to the Covid-19 pandemic although the project was due to start in April 2021, we were not able to really get the ball rolling until June 2021. We were always adamant that our research must be completed in person as we had already experienced 3 lockdowns with the women we supported and knew that we would not be able to get the detailed research and information unless it was in person with the interviewees in their first language. This in person contact was also vital to build trust and support so that women could feel safe and free to express their experiences of accessing healthcare in their first language during the pandemic and how it affected them at their own pace.

RCLC recruited two female community bilingual researchers from the centre, who between them had lived experience of coming to this country as a migrant, a background in teaching ESOL, volunteering and providing outreach support to migrant and refugee women in Reading. Our researchers were passionate and excited to be part of this research but also to have the opportunity to receive mentoring and training.

RCLC would like to thank SCDC for the mentoring and training which equipped and prepared the researchers with research techniques as well provided an opportunity to meet other researchers, share and reflect on their work. Our project benefitted hugely from having the expertise and support from the University especially in the collection of data, data analysis and the inputting stages. The facilitator who also had experience in carrying out research was also a great strength during these stages to support the community researchers who were doing this for the first time. This additional support helped to give the community researchers confidence in their research, build their research skills at their own pace and have a support network.

Another great strength of this research project was that we were able to investigate and research the topics and areas which mattered to each of the partner organisations rather than being dictated by funding. Moreover, the existing links, trusted relationships, and connections the partners had to each of the diverse ethnic minority families and communities meant that the project was able to engage with, identify and question those communities who are often overlooked or not included in this type of research.

This research was incredibly important to us in not only making the voices of the women we were talking to heard but also in using this research to bring about changes and improvements. As a charity we pooled all our resources and connections which were not funded by the project such as translation, volunteer support, administration and management and outreach support.

An important recommendation for me for any research which engages with communities who don't have English as a first language is to include a budget for translation work but also to budget in the real time costs for the additional support mechanisms to see this project come to fruition, such as the management time, outreach work, translation support and volunteer costs. The cost of the project was far more than just the few paid hours for the researchers for their time in attending trainings. I would advise that for future projects a realistic budget which includes these elements is budgeted for.

Being a part of this CPAR Project has truly been a great experience not only for us as a partner organisation but also for the researchers. Not only were we able to carry out research in an area that was hugely important locally and nationally, but it has also equipped the community researchers with new skills which they could utilise in working in this field in the future. The fact that we as a small grass roots charity can use this funding and platform to carry out research and hopefully bring change to the forefront is immensely rewarding and exciting. I hope that there is more funding for this type of research empowering communities to be active, vocal participants in brining local change by getting the decision makers to listen and take note. RCLC are really proud of all the researchers and looking forward to seeing the social changes the report will influence.

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DAYNA WHITE, NEIGHBOURHOOD AND PARTNERSHIPS MANAGER AT READING BOROUGH COUNCIL

The CPAR project has been an incredible opportunity to build a strong partnership between Reading Borough Council, University of Reading Participation Lab and the community organisations hosting and supporting the community researchers – Reading Voluntary Action, Alliance for Cohesion and Racial Equality and Reading Community Learning Centre. The project has enabled us to build this partnership, supporting members of the community to upskill as researchers and provide a supportive platform for this vital research to take place.

The community researchers have been able to collect such valuable insights from communities that so often go unheard, by exploring the experiences of these groups around these important topics and collating them into formal research the project has amplified these voices and experiences in such a crucial way. The interest from wider partners in this research shows how much this work is needed and how significant the work of the community researchers and all the organisations involved is. As a local authority we really see the value in using the community researcher approach and this is something we're keen to explore moving forwards.

The support from the partners involved and the work of the researchers themselves is what has made this project so successful. The support from the CPAR facilitator both to the researchers, but also to the partners has been impeccable and a key foundational block to the realisation of the project. The role of facilitator has been a vital one and is something to consider when thinking about community research projects like this. The resourcing of the project is an area to consider moving forwards as much of the success has been a result of unpaid hours worked and goodwill given by partners and researchers – this work must be properly resourced moving forwards to create a sustainable and ethically sound approach. Locally we will be looking, as a partnership, at potential routes to do this.

The final reports and recommendations from the community researchers are essential reading and something we as a local authority are taking forward via a task and finish group. We're also keen to continue to develop the strong partnership of the CPAR project group and together, find a sustainable way to build on the success of the project.

VICTOR KOROMA, CHIEF EXECUTIVE, ACRE

Alliance for cohesion and racial equality (ACRE) in its previous and present establishments has been advocating on issues affecting, and supporting ethnic minority communities in Reading for over 50 years. The incidence of Covid-19 took everyone by surprise and the rate at which it impacted particularly people from minoritised communities was devastating. Investigative reports which summarised the effect of the pandemic on BAMER communities only served to confuse people further. However, what was clear was that at the heart of the problem was poor access to health services, leading to equally poor health outcomes.

ACRE and our community support partners in Reading, including Utulivu Women's Group, have in recent times been highlighting the fact that health services were not meeting the needs of ethnic minority communities. Said services were designed on a one-size-fits-all model, and when it came to ethnic minority groups, it further compounded their unequal access to services leading to many who deserved to be helped not getting the help they needed.

The CPAR project was a welcome opportunity for us to put some of the questions we had to the test. Our two researchers, Tariq Gomma and Eva Karanja investigated areas of Men's Mental Health, and access to Maternity Services respectively and the results speak for themselves. However, taken in context of the other researchers' reports is easy to surmise that there are many more areas of glaring health inequalities experienced by people from minoritised communities. This type of work should not be a one off.

The other challenges this piece of work brings are: how are we going to meet the expectations raised within the various communities that were investigated; what service development approaches would the NHS/Health Education England and local public health planners take to address issues raised in this report; and what help and support would be provided to voluntary sector organisations [Reading CPAR Partners] to enable us to carry out further investigations on health inequalities in Reading.

That said, sincere thanks to NHS/HEE & SCDC for the opportunity; to all our CPAR partners, especially Dr Esther Oenga for the support provided to all the researchers; Dr Sally Lloyd- Evans for her support and especial thanks and gratitude to Eva and Tariq for their commitment to the task.

DR ANDREW PATERSON, POLICY AND RESEARCH OFFICER, SCOTTISH COMMUNITY DEVELOPMENT CENTRE

CPAR was an amazing learning experience for me. I think it's important to say this, since my role was to offer mentoring support to the community researchers, guiding them through the different stages of their research with their communities. But even though the community researchers were having to learn a lot, I felt that I was also learning a huge amount in my mentoring role. In part, this was because there was a lot that was new for me – I'm relatively new to supporting people to do research as my normal job is more traditional policy and research work, and I've only recently started supporting groups to do their own research, although this is something SCDC has been doing for many years. The Covid-19 pandemic and lockdown meant we had to support people online rather than face-to-face, so everyone had to adapt quickly.

But the main learning for me was to see how much enthusiasm, bravery, insight and commitment the community researchers have in taking forward their research. Leading on your own research can of course appear extremely daunting, and I don't mind admitting that the thought of supporting numerous community research projects from start to finish seemed like it would be a huge undertaking for me too. And in many ways, it was a huge undertaking for everyone, but importantly, it was achievable. Donna, Eva, Hema, Krishna and Tariq showed that, given the right support, people who have little or no experience of research can design, carry out and take forward their own research that benefits them as individuals and has valuable insights for improving services for their communities. I've learned a huge amount about what 'right support' means – including the role of peers and making sure emotional and mental wellbeing is considered carefully. Having someone as dedicated and as dexterous as Esther in a local support role has been invaluable, and it's fair to say the success of the Reading CPAR project has a lot to do with her.

It's good to think that, one year on since the programme began, CPAR will have a lasting legacy for local services as well as everyone involved in the programme.

CPAR Acknowledgements

The idea for the CPAR project came from Public Health England's report that recommended a bottom-up approach to support local community researchers to investigate the issues that mattered to the community as a result of the impact of Covid-19. The project took over a year: to design the research, for the data to be collected, for analysis to be done and for the final report to be written. The whole process was a journey of dedication and commitment from many different people and organisations.

Thanks to Public Health England for first recognising and recommending the engagement of community researchers without which the community researchers will have not gotten the opportunity. Thanks to the Health Education England team and especially Joanne McEwan for working so hard until the end with the showcase event that celebrated the researchers. To all our partners in the South East region. We are deeply grateful for your support. We are grateful to the Scottish Community Development Centre especially Dr Andrew Paterson for supporting the researchers and giving valuable feedback on their reports.

Thanks to the Reading Borough Council team who supported the CPAR research: Unis Nisa who designed and printed the researchers' ID badges, Amanda Nyeke for supporting the project in many ways, and Michelle Berry for making the grant application and seeing the project take off, and providing the researchers opportunities to showcase the research at RBC meetings. Thanks to RBC for funding the part-time facilitator role and the researchers' laptops. Thanks to Dayna White for her support towards the end of the project and for spearheading the CPAR recommendations.

Thanks to the University of Reading Participation Lab for all the support in creative research methods, and for recording devices, transcribing services, conference costs, and additional contributions from Dr Lorna Zischka and Sonia Duval with quantitative analysis. To Dr Sally-Lloyd-Evans, thanks for being there for the researchers, facilitator, and other partners with all your advice and guidance. Thanks to Professor Adrian Bell for participating in the showcase event at MERL and presenting the certificates to the researchers.

Our gratitude goes to Reading Voluntary Action for its enormous contributions including conference rooms and covering printing and costs for flyers and the final report. Thanks to Rachel Spencer who worked tirelessly for the project to succeed, to Herjeet Randhawa for her supervisions and close monitoring, Dr Demelza Hookway, working powerfully behind the scene editing the final report and to William Westwood who supported the CPAR research from day one.

We are thankful to RCLC for supporting the researchers throughout, facilitating payments, solving issues and to Aisha Malik for attending partner's meetings and ensuring CPAR was a success. Thanks to the Alliance for Cohesion for Racial Equality for working with the researchers and other partners directly to ensure that research processes went on smoothly. Thanks to Victor Koroma for all the hard work and the We Men group who assisted with data collection. Thanks to the facilitator, Dr Esther Oenga for being flexible and working beyond her hours to support the researchers.

Thanks to the diverse Reading COMMUNITIES that participated in the research in different ways without which no research will have been accomplished. Last, but not least, thanks to the community researchers for successfully participating in the research from start to the end. A considerable amount of time was invested in this research and we want to say thanks to ALL that contributed in one way or the other.

Notes

Notes

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Together

healthwatch Reading

We're laying the foundations for making health and social care better

Annual Report April 2022 – March 2023

Contents

"In the last ten years, the health and social care landscape has changed dramatically, but the dedication of local Healthwatch hasn't. Your local Healthwatch has worked tirelessly to make sure the views of local people are heard, and NHS and social care leaders use your feedback to make care better."

Louise Ansari, Healthwatch National Director

Message from Lead Officer

Welcome to the first Annual Report since Healthwatch Reading has been hosted by The Advocacy People. The ten months since the transfer have been busy, with lots of change so this year's report will look a little different.

Much of our time has been about building up the team - our first task was to recruit a dedicated team of employed staff and volunteers. We have been pleased to welcome people from a diverse mix of backgrounds with a variety of skills and experience to help us reach across Reading communities.

Having got our team in place, as well as recognising and championing the work of the previous Healthwatch Reading provider, our focus has been to make Healthwatch Reading even more relevant and responsive to the needs of the Reading community, validating the trust that has been placed in us.

Our team has been out and about on a Reading 'roadshow', raising awareness of who we are and what we do and getting insight into the experiences of people using local health and social care services. We have also made sure our print materials can be found and our digital information is up to date.

At the same time as reaching out to the public, we knew we needed to raise awareness of Healthwatch Reading as an independent public voice by being present at meetings to make sure the public voice is being listened to when decisions are being made.

A key part of this work has been to ensure Healthwatch, and therefore local people. are fully represented in the new Integrated Care System for Buckinghamshire, Oxfordshire and Berkshire West where Berkshire West covers Reading, West Berkshire and Wokingham Borough. You'll find more about what this means on page 14.

I am grateful to the Advisory Group who supports the team to deliver a quality service that is realistic about what we can take on with our finite resources and increasing demand.

This report has helped us take stock, reflect on what we have achieved in our first 10 months and plan our priorities for next year. Hence why we have called our report 'Laying the Foundations' - we have laid the groundwork to be a powerful voice for Reading residents in decisions about health and social care and ask you to join us on the next phase by responding to our calls for feedback, following us on social media and signing up to our newsletter.

Alice Kunjappy-Clifton
Lead Officer, Healthwatch Reading

About us

Healthwatch Reading is your local health and social care champion.

We make sure NHS leaders and decision makers hear your voice and use your feedback to improve care. We can also help you to find reliable and trustworthy information and advice.

Our vision

A world where we can all get the health and care we need.

Our mission

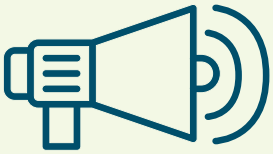
To make sure people's experiences help make health and care better.

Our values are:

- **Listening** to people and making sure their voices are heard.
- **Including** everyone in the conversation – especially those who don't always have their voice heard.
- **Analysing** different people's experiences to learn how to improve care.
- **Acting** on feedback and driving change.
- **Partnering** with care providers, Government, and the voluntary sector – serving as the public's independent advocate.

Year in review

Reaching out



We have been out and about in the community meeting local people and the organisations who work in the Borough through being out and about in the community on our roadshow.

Local people have contacted us in different ways to directly share their experiences of health and social care services and/or for advice and information. We have heard lots about important topics such GP access and dentistry

Making a difference to health

We have continued to speak up on behalf of asylum seekers in the Home Office Contracted Accommodation in Reading. We heard about the experience of women and children. As a result, the NHS Safeguarding team is planning safeguarding assurance visits to check on the residents' health and wellbeing.

Health and care that works for you

We're lucky to have

6 outstanding volunteers with a range of different experiences and background who form our Advisory Group.

We're funded by our local authority. From 1 June 2022 (when The Advocacy People took over the contract) to 31 March 2023 we received

£80,988.

We currently employ

6 staff who help us carry out our work on a part-time basis.

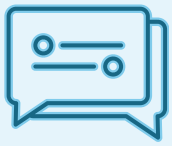
Our year in brief

Spring

During March, April and May 2022, The Advocacy People worked with the outgoing provider to get ready for the transfer.

Summer

On 1 June 2022, The Advocacy People took over the Healthwatch Reading contract. We advertised for new staff and volunteers.



We reached out to local health and social care providers to build relationships and make sure we were invited to the right meetings to bring the voice of Reading residents to people making decisions.

Autumn

A new team was established. We started awareness of Healthwatch in the community, starting with voluntary sector organisations.

Women locally were asked about maternal mental health as part of the Healthwatch England campaign.

Winter

We heard how asylum seekers living in Reading, particularly women and babies, were having difficulties with getting nutritional food and access to Healthcare. We talked to Reading Borough Council and the NHS about our concerns. You can read more about this further down..

We championed the use of accessible language and the need to provide interpreters through Alliance for Cohesion and Racial Equality's Community Champions.

10 years of improving care

This year marks a special milestone for Healthwatch. Over the last ten years, people have shared their experiences, good and bad, to help improve health and social care. As well as informing local decision-making, feedback from Reading residents has contributed to Healthwatch England's evidence so they have been able to make care better at a national level. Here are a few of the highlights :

How have we made care better, together?

Vaccine Confidence

Public health received valuable information around vaccine confidence with people from different backgrounds, which provided vital lessons for subsequent campaigns

Discharge from hospital

Healthwatch heard from patients and carers that discharge from hospital can be difficult and confusing. The Government listened to our recommendations and updated key guidance to put patient safety first.

Healthcare information

Your feedback helped inform our 'your care, your way' campaign to make sure everyone gets healthcare information in a way they understand. Our work helped lead to a review of the Accessible Information Standard.

NHS Waitlist

Healthwatch joined with other organisations to request an urgent response to hospital waiting lists, to include better communication and support without overloading primary care. The NHS set out a recovery plan to address the backlog.

NHS Dentistry

We have continued to express concerns about dentistry, which has helped to secure changes which the NHS will be introducing soon.

Listening to your experiences

Services can't make improvements without hearing your views. That's why over the last year we have made listening to feedback from all areas of the community a priority. This allows us to understand the full picture, and feed this back to services and help them improve.

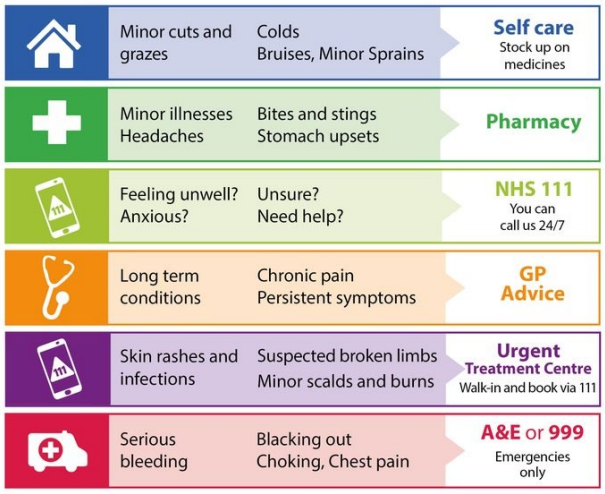
This year we have reached different communities by:

- Attending events and community centres locally
- Attending weekly community conversations and groups
- Ensuring our marketing materials are appropriate to ensure easy engagement with communities, online and in print.

Laying the foundations: making Healthwatch Reading visible

As we are building the foundation of the new team of Healthwatch Reading to be the organisation to go to for advice and information on health and social care, we have had to look at how we can improve our visibility.

We have been out and about in the Borough attending events and holding pop-up clinics in different places. We have been asking communities what we can do to make more people aware of Healthwatch Reading.



We have been sharing frequently asked questions to support the Reading public with the challenges of dentistry and GP access.

We've been supporting residents to understand the new way in which GP surgeries in particular are now providing services.

Our Lead Officer, Alice Kunjappy-Clifton, spoke at The Advocacy People's all staff away day to make sure everyone knows about Healthwatch, wherever they work.

Asylum Seekers living in Reading

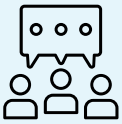
Throughout our work we gather information about health inequalities by speaking to people whose experiences aren't often heard.

Through building relationships with other organisations in the community, we have heard a lot of concerns about the conditions in which asylum seekers placed in Home Office contracted accommodation are living in Reading.

Examples include lack of:

- appropriate facilities to prepare baby food
- suitable food to meet different dietary requirements, including for children
- communal space where people can spend time away from their room
- transport to medical appointments
- access to dental treatment.

Healthwatch Reading has taken the following action:



- Raised safeguarding concerns with the NHS (Buckingham, Oxfordshire and Berkshire West ICB) who are now conducting safeguarding assurance visits.
- Met with Reading Borough Council, the Home Office, Clearsprings (part of Ready Homes who run the accommodation where asylum seekers are housed – see below) and local voluntary organisations.
- Ensured the West of Berkshire Safeguarding Adults Board are aware of the issues and asked for joined up working between the three local authorities in Berkshire West (Reading, West Berkshire and Wokingham Borough).

Context

Whilst awaiting an initial decision, emergency support is provided by the Home Office in Initial Accommodation, which could be a hotel, flat, house, hostel or bed and breakfast. Whilst these might previously have had guest facilities, these have been suspended. Asylum seekers in this position have a right to NHS healthcare; local authorities have no statutory responsibilities.

How will Healthwatch Reading make a difference?

- We will follow up with the NHS to check that recommendations leading from their visits will be acted upon to ensure issues such as lack of access to healthcare are addressed.
- We will continue to share information with Clearsprings and ask what action they are taking.
- Whilst we know that local authorities are limited in what they can do, there are examples of good practice. We would like to see the three Berkshire West councils joining together to share work together.

Maternal mental health

This year Healthwatch England worked to find out about the experiences of mothers and birthing parents of mental health care.

As part of their project, Healthwatch England conducted a national survey from October to December 2022. At the same time, the three Healthwatch in Berkshire West (Reading, West Berkshire and Wokingham Borough) felt it was important to understand the local picture and how it compares to the national situation.

We therefore did the same survey, adding a question so people could tell us which of the three areas they lived in.

We found that people in Reading were experiencing the same issues as people across the country:

- Care and support provided is having an impact on mental health. 37% of people we heard from experienced negative impacts on their mental health due to the care and support they received during labour and childbirth. This compares to 42% nationally (HWE 2023).
- Mental health is not routinely discussed at postnatal checks. Nearly half (46%) of the people we heard from said that mental health was either not mentioned or not discussed enough at their postnatal check. At nearly half, this compares with the national findings of 22% (HWE 2023)
- Care is inconsistent for pre and postnatal mental health difficulties. Over half the people we heard from experienced mental health difficulties. One third of these people were not offered information or a referral.

What has happened since the report?

NHS England have published their plan for improving experiences for mothers and birthing parents. Their commitments reflect the findings of the Healthwatch England report – this shows that the NHS are listening to what people are saying.

What will Healthwatch Reading do next?

We will continue to work 'behind the scenes' to see how the plan is rolled out locally and how this is impacting local people. If we hear concerns from local people we will ask questions of the people making the decisions.

If you've recently given birth, we'd like to hear from you about your experiences of maternal and birthing parent care:

healthwatchreading.co.uk

t: 0118 214 5579

e: info@healthwatchreading.co.uk

Healthwatch Hero

Utulivu Women's Group supports the voice of ethnically diverse communities. They are our beacon to ensure ethnically diverse communities, especially women, get important information, support, advice and give feedback.

Since the change in provider to The Advocacy People in June 2022, they have supported Healthwatch Reading by:

- Spreading the Healthwatch message, helping to increase our visibility amongst the ethnically diverse communities in Reading.
- Sharing what they have heard ethnic minority women say about maternity services in Reading and the experiences of the asylum seekers in Home Office Contracted Accommodation.

> *Working with Healthwatch Reading team has been a great help to Utulivu Women's Group and the Community Hub. They helped us to highlight some of these issues at all levels and we feel that change is starting, and the voices of the grassroots communities are being heard. Healthwatch has been instrumental in supporting our health Champions to find volunteering and training opportunities in their organisation. We will continue to work closely, make our voices heard and achieve positive change in our communities.*
>
> *Eva Karanja, Manager, Utulivu Women's Group*

Working in partnership

Healthwatch isn't just about getting feedback from local people and passing this on ourselves.

We promote and support organisations to make sure they involve local people when they are making decisions.

Our approach as 'critical friend' is to work constructively and collaboratively, looking for solutions to make health and social care better.

We do this by:

- Making sure we are involved, and asking questions, in committees/boards/programmes where decisions about health and social care are being made
- Advising organisations on what they should do to involve people, including reviewing surveys suggesting how views can be collected from across our communities.

Working in the new Integrated Care System

This year has seen a big change to the way in which the NHS is organised locally so that services are more joined up and can provide the care we need, when and where we need it.

This means that NHS services in Wokingham Borough are now part of an Integrated Care Board (ICB) which covers Buckinghamshire, Oxfordshire and Berkshire West, known as **BOB.** Berkshire West is made up of Reading, West Berkshire and Wokingham Borough.

The ICB decides how the budget is spent and develops plans to improve people's health. Locally, Berkshire West (a 'place' in the ICS) there is a partnership which makes sure local services meet the needs of local people.
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What does this mean for Healthwatch Reading?

The Advocacy People host the three Healthwatch in Berkshire West. This makes it very easy to work together to be in more places at once – on the ground in Reading and ensuring Reading residents are represented when decisions are being made. This is very important as we have limited resources.

As well as working together in Berkshire West, we have been working with Healthwatch Bucks and Healthwatch Oxfordshire and getting to know the people who work in the new system.

For next year, we have been given some extra money so that we can increase our capacity to attend different meetings and talk to residents of Reading about what's being planned across BOB.

"BOB ICB recognises Healthwatch as a key partner in our Integrated Care System as we continue to develop our mission and deliver better care for our residents. In Berkshire West place we value the role of Healthwatch as a patient-centred advocate and as a critical friend. We look forward to our continued joint working in 2023-24."

Eiliis McCarthy
Programme Manager and Locality Lead (Reading)
Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

NHS
Buckinghamshire, Oxfordshire and Berkshire West
Integrated Care Board

Working with BOB Integrated Care Board: an example

Transforming continuing healthcare

Some people with long-term complex health needs qualify for free social care arranged and funded by the NHS. This is called NHS continuing healthcare. Buckinghamshire, Oxfordshire and Berkshire West (BOB) ICB is working to make sure that people across BOB get fair and equitable access to continuing healthcare and, if eligible, get consistently good quality care.

The programme of work for making this happen is called the All Age Continuing Care (AACC) Transformation Board.

Healthwatch Reading, alongside our colleagues from the other four Healthwatch in the BOB area, have been part of the Hearing People's Voices Task and Finish Group.

We are there to make sure the experiences of people who have applied for and those who receive continuing healthcare are listened to when decisions to change the way services are delivered are being made.

In order to understand more about people's experience of continuing care, we helped design a survey of people receiving continuing healthcare. This survey will be sent out in July 2023 and then twice a year thereafter.

We are planning to speak to people who have applied for but not been eligible for continuing healthcare. The findings from this research, together with the results of the surveys, will help BOB ICB understand how people experience its services and contribute to the design and delivery of services in the future.

We will continue to work with the Board in the coming months.

"BOB ICB is keen to obtain constructive feedback from service users on their experience of continuing healthcare. All five Healthwatch have made an important contribution to this work and we hope that they will continue to support efforts to improve access to these services and the quality of care provided by obtaining and interpreting service-user feedback. This is essential input to achieve continuous improvement across BOB based on evidence derived directly from those people who have experienced the continuing healthcare pathway."

Dr Paul Pettigrew
External Consultant
Waite Atkins Limited

Ensuring language is accessible and easy to understand

Throughout our work we gather information about health inequalities by speaking to people whose experiences aren't often heard.

We also make sure that other organisations take the same approach to sharing and gathering information about their services.

Healthwatch Reading were involved in chairing an online meeting for the public in Berkshire West where the NHS shared their draft strategy for working as part of the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB).

Healthwatch Reading, with Healthwatch West Berkshire and Healthwatch Wokingham Borough, asked BOB ICB if the meeting would have British Sign Language interpretation. As a result of asking this question, BSL interpretation was arranged.

As part of the new hospital development of Royal Berkshire Hospital, the Building Berkshire Together team created a survey to ask local people for their views. We worked with the team to make sure the language used in the survey was easy to understand and would reach people who don't use the internet. We will continue to ensure that the public are properly consulted on the plans.

Our goal at Building Berkshire Together, the new hospital programme for Royal Berkshire NHS Foundation Trust is to build a new, purpose-built hospital which meets the needs of the diverse communities we serve. Working with Healthwatch has given us invaluable insight, support and opportunities to engage with our local communities to develop healthcare facilities which helps us tackle accessibility and health inequalities.

Alison Foster, Programme Director, Building Berkshire Together

Advice and information

If you feel lost and don't know where to turn, Healthwatch is here for you. In times of worry or stress, we can provide confidential support and free information to help you understand your options and get the help you need. Whether it's finding an NHS dentist, how to make a complaint or choosing a good care home for a loved one – you can count on us.

This year we've helped people by:

- Providing up to date information on access to NHS dentistry and GP-led services.
- Linking people to reliable information and services they need.
- Supporting the COVID-19 vaccination and booster programme.
- Helping people to access the services they need.
- Creating a new website which is accessible and easy to use.

Case study: support to access a local pharmacy

What happened: Mrs A told us about her bad experience when she went into her local pharmacy to pick up her and her daughter's medication.

She was given a sealed medication bag and asked whether both items were in the same bag as she had been expecting the items in 2 separate bags, as before.

The member of staff became angry and accused Mrs A of time wasting. Mrs A's first language isn't English, so she didn't fully understand what was being said and this raised her anxiety. She did however pick up that she was being asked to leave and that if she didn't then force would be used.

As a result of this, Mrs A did not feel able to return to the same pharmacy.

What Healthwatch did:

Healthwatch Reading contacted the Thames Valley Local Pharmaceutical Committee (LPC) member who looked at ways to support Mrs A. He had a conversation with the lead pharmacist where this happened who then looked at the CCTV from that day. The lead pharmacist wanted to continue to serve Mrs A and advised that they have a member of staff who speaks Mrs A's first language.

Healthwatch Reading spoke to Mrs A again and explained that she has two options: to choose another pharmacy or stay where she was.

Mrs A decided she wanted to stay with the pharmacy as there wasn't another one near where she lives.

How this has made a difference:

Mrs A told us that she felt heard and feels she now understands the options open to her. She knows that if she has further difficulties at the same pharmacy, she can come back to Healthwatch Reading.

The lead pharmacist was able to speak to the staff at the pharmacy about what had happened so the staff are more informed about working with people who do not have English as their first language.

"I have always admired the work that Healthwatch provides but over the last 3 years that I have worked with them, I have found Healthwatch to be professional, understandable, and extremely approachable. It is great that we have the same goal of satisfying a customer's needs."

Kevin Barnes
Thames Valley Local Pharmaceutical Committee member

Volunteering

It continues to be a challenging time in volunteer recruitment; however, we are now supported by a team of fantastic volunteers who make up our newly created Advisory Group. The group works alongside the paid staff team to:

- Agree the strategy and priorities for our yearly work plan.
- Ensure Healthwatch Reading adheres to its principles and purpose.
- Support management, staff and other volunteers.
- Ensure accountability for quality and delivery of the strategy and workplan to local people.
- Represent Healthwatch and the voice of local people at strategic meetings with health and social care partners.
- Be ambassadors for Healthwatch Reading and to use every opportunity to promote our work, share our successes, raise our profile and listen to local voices and help make change

Luke Howarth is one of our Volunteer Advisory Group members who brings vast experience working in local government, housing and homelessness.

Here he talks about why he has joined Healthwatch Reading.

"I am proud to be from Reading, so when I saw that Healthwatch were looking for new Advisory Board Members, I wanted to offer my experience from working in local government and housing and homelessness services.
By listening to experiences, enhancing our understanding of barriers and working together, we can improve access to and the quality of health services. We can improve local healthcare and outcomes.
I look forward to hearing from patients about their experiences."

Do you feel inspired?

We are still on the lookout for new volunteers, from across our community. As well as our Advisory Group, we have roles in Community Engagement and Enter and View (where we visit services to see them in action).

For more information and to get in touch:

Healthwatchreading.co.uk
0118 214 5579
info@healthwatchreading.co.uk

Finance and future priorities

To help us carry out our work we receive funding from our local authority under the Health and Social Care Act 2012.

Our income and expenditure

Income		Expenditure	
Reading Borough Council (core funding)	£80,988	Employment costs	£69,045
Healthwatch England for local database development	£1,500	Other operating costs	£12,219
Additional income	£360	Support and administration costs	£8,834
Total income	**£82,848**	**Total expenditure**	**£90,098**

Next steps

In the ten years since Healthwatch was launched, we've demonstrated the power of public feedback in helping the health and care system understand what is working, spot issues and think about how things can be better in the future.

Services are currently facing unprecedented challenges and tackling the backlog needs to be a key priority for the NHS to ensure everyone gets the care they need. Over the next year we will continue our role in collecting feedback from everyone in our local community and giving them a voice to help shape improvements to services.

We will also continue our work to tackling inequalities that exist and work to reduce the barriers you face when accessing care, regardless whether that is because of where you live, income or race.

Top three priorities for 2023-24

- GP access and quality – looking at people's understanding of how GP-led services are structured and self-care options.
- Maternal mental health – see page 10.
- Dentistry – focus on: pregnant women; women who have had a baby in the last 12 months; and people with learning disabilities.

Statutory statements

Healthwatch Reading, Dept 77, 105 London Street, Reading, Berkshire, RG1 4QD

Contract held by The Advocacy People, Rock House, 49-51 Cambridge Road, Hastings, East Sussex, TN34 1DT

Healthwatch Reading uses the Healthwatch Trademark when undertaking our statutory activities as covered by the licence agreement.

The way we work

Involvement of volunteers and lay people in our governance and decision-making

Our newly created Healthwatch Advisory Group consists of 5 members who work on a voluntary basis to provide direction, oversight and scrutiny to our activities. Our Board ensures that decisions about priority areas of work reflect the concerns and interests of our diverse local community. As a new Advisory Group, they have met once to discuss progress to date and our forward plans.

We also ensure wider public involvement in deciding our work priorities. Our top priority for the year ahead was determined through a public survey.

Methods and systems used across the year to obtain local people's experiences

We use a wide range of approaches to ensure that as many people as possible have the opportunity to provide us with insight about their experience of using services. During 2022/23 we have been available for local residents to contact us by phone, email, provided a webform on our website and through social media, as well as attending events and meetings of community groups and forums.

We ensure that this annual report is made available to as many members of the public and partner organisations as possible. We will publish it on our website www.healthwatchreading.co.uk.

Responses from recommendations

We had no providers who did not respond to requests for information or comment on observations and recommendations.

Taking people's experiences to decision makers

We ensure that people who can make decisions about services hear about the insight and experiences that have been shared with us.

In Reading we take this information to the Reading Integration Board and the Health and Wellbeing Board so it is heard by decision makers at local authority level.

We also take insight and experiences to decision makers in the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care System and work with the other Healthwatch within this area to ensure voices are heard from all parts of the community. For example, we are part of a Hearing People's Voices strand of the All Age Continuing Care Transformation Board and have a seat at the System Quality Group.

We also share our data with Healthwatch England to help address health and care issues at a national level.

Enter and view

This year, we made 0 Enter and View visits as we did not receive feedback about any one particular service that warranted such a visit.

Healthwatch representatives

Healthwatch Reading is represented on the Reading Health and Wellbeing Board by Alice Kunjappy-Clifton, Lead Officer. During 2022/23 our representative has effectively carried out this role by sharing how we work and our future workplans and, asking questions from the public perspective and ensuring the public voice is considered in decision-making.

Healthwatch Reading works in collaboration with the other 4 Healthwatch in the Buckinghamshire, Oxfordshire and Berkshire West (BOB) to ensure Reading residents are represented at Place level (Berkshire West) and Integrated Care Board level. With the three Berkshire West Healthwatch delivered by The Advocacy People, representation for Place is shared between Alice Kunjappy-Clifton (Lead Officer, Healthwatch Reading and Wokingham Borough), Fiona Worby (Lead Officer, Healthwatch West Berkshire) and Sarah Deason (Area Director, Healthwatch in Berkshire West).

Representation at BOB Level is in conjunction with Zoe McIntosh and Veronica Barry, Chief Officers in Healthwatch Bucks and Oxfordshire respectively. We look forward to continue our partnership in 2023/24.

healthwatch Reading

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READING HEALTH AND WELLBEING BOARD

Date of Meeting	14 July 2023
Title	Health and Wellbeing Strategy Quarterly Implementation Plan Narrative and Dashboard Report
Purpose of the report	To note the report for information
Report author	Amanda Nyeke
Job title	Public Health and Wellbeing Manager
Organisation	Reading Borough Council
Recommendations	1. That the Health and Wellbeing Board notes the following updates contained in the report: **Priority 1** – Tasks supporting Actions 1 - 8 within this priority area including partnership working, proposing projects to support provision of a range of services to support people to be healthy, reduce health inequalities. **Priority 2** – Tasks supporting Actions 1 - 6, focusing on identifying health and care needs of individuals at risk of poor outcomes and actions for supporting them. Including engaging with and funding projects that enable people to access information and support at a time and in a way that meets their needs. **Priority 3** – Tasks supporting Actions 1 - 7 have been updated, focusing on the development of evidence-based parenting programmes, multi-agency working and rolling out a revised parenting offer including fathers and parents to be. There continues to be progress in all priorities. **Priority 4** – Tasks supporting Actions 1 - 7 have been updated with a focus on addressing inequalities in mental health, training, the work of the Mental Health Support Teams (MHSTs) and Primary Mental Health Team (PMHT). **Priority 5** – Tasks supporting Actions 1 - 8 have been updated with progress in awareness raising of local mental health support, strengthening partnership working and training.

1. Executive Summary

1.1. This report presents an overview on the implementation of the Berkshire West Health and Wellbeing Strategy 2021-2030 in Reading and, in Appendices A and B, detailed information on performance and progress towards achieving the local goals and actions set out in the both the overarching strategy and the locally agreed implementation plans.

1.2. The Health & Wellbeing Implementation Plans and dashboard report update (Appendix A) contain a detailed update on actions agreed for each implementation plan and the most recent update of key indicators in each priority area. Full data for key indicators for each priority is provided in the full Health & Wellbeing Dashboard Report (Appendix B).

2. Policy Context

2.1. The Health and Social Care Act 2012 sets out the requirement on Health and Wellbeing Boards to use a Joint Strategic Needs Assessment (JSNA) and a Joint Health and Wellbeing Strategy (JHWS) to develop plans which:

- improve the health and wellbeing of the people in their area;
- reduce health inequalities; and
- promote the integration of services.

2.2. In 2021 The Berkshire West Health and Wellbeing Strategy for 2021-2030 was jointly developed and published on behalf of Health and Wellbeing Boards in Reading, West Berkshire and Wokingham. The strategy contains five priority areas:

- Reduce the differences in health between different groups of people
- Support individuals at high risk of bad health outcomes to live healthy lives
- Help families and children in early years
- Promote good mental health and wellbeing for all children and young people
- Promote good mental health and wellbeing for all adults

2.3. In Reading the strategy was supplemented by the development of implementation plans for each priority area. These were presented to the Health and Wellbeing Board and approved in March 2022.

2.4. In 2016 the board had previously agreed to introduce regular performance updates, including a Health and Wellbeing Dashboard Report, at each meeting to ensure that members of the board are kept informed about the Partnership's performance in its priority areas. The current Health and Wellbeing Dashboard Report has been developed to reflect the new priorities set out in the Berkshire West Health and Wellbeing Strategy 2021-2030 and the associated implementation plans.

2.5. The Health and Wellbeing Dashboard provides the latest data available to support the Board to scrutinise and evaluate the performance of the Partnership against the agreed priorities set out in the Health and Wellbeing Strategy. Some of the national data used to measure public health outcomes, particularly for those indicators based on annual national survey and hospital data, goes through a process of checking and validation before publication, which can mean that it is published sometime after it was collected. Other data contained in this report is reported directly from local health service providers, including primary care providers, and, as these data are not validated or processed before publication, there may therefore be some minor discrepancies and corrections between reports.

2.6. At each Health & Wellbeing Board meeting Health & Wellbeing Strategy Priority Leads for Reading Borough Council will provide a narrative update against selected tasks and priority items that have been actioned during that period. Statistical data will be refreshed every six months. The reporting schedule for 2023/24 is therefore as follows:

Health and Wellbeing Board	Narrative updates – selected tasks and priorities	Data refresh
July 2023	✓	✓
October 2023	✓	✗
January 2024	✓	✓
March 2024	✓	✗

3. The Proposal

3.1. Overview

Priority 1 – Reduce the differences in health between different groups of people

The Reading Integration Board (RIB) continue to work with our partners in health and the voluntary sector to ensure that a good range of services are provided to support people to stay healthy and well, and that these are communicated to people who may be more at risk of experiencing poor health or long-term health conditions. Members of the Integration Board are involved with community groups and services and can propose projects that support these groups that are culturally sensitive.

Priority 2 – Support individuals at high risk of bad health outcomes to live healthy lives

The Dementia Friendly Reading Steering Group have submitted a funding application to resource a Dementia Friendly Reading Coordinator post who can support with developing a training programme to support organisations.

There are several groups for gentle exercise and health awareness, mini health MOTs being run within our community by voluntary sector organisations.

Work to develop a Joint All Ages Unpaid Carer Strategy for Reading are underway with a Carers Survey launching during Carers Week in early June. This process will enable us to build a picture of the needs of carers in Reading and inform a strategy and action plan to improve the experience of carers in Reading.

We have invested in Technology Enabled Care (TEC) to support people to remain safe and well in their home and to live as independently as possible.

Our Multi-Disciplinary Team meetings that are operated through three clusters of our Primary Care Network, covering all Reading areas, are continuing and have been successful in supporting people with complex needs and long-term conditions to effectively manage these and to improve health outcomes.

Priority 3 – Help families and children in early years

The under 5s workstream of the One Reading partnership continue to lead on priority 3 to help families in early years in Reading. There are seven key priority areas, and we are working across the partnership including maternity services, health visitors, paediatricians, education, and the voluntary sector to drive forward priority areas. Universal and targeted health services have returned to face-to-face delivery at Children Centres improving accessibility and enabling families to connect with a wider range of services. The multi-agency work focused on speech, language and communication has made significant progress against the agreed aims including increasing early years practitioner confidence and reducing referrals to specialist speech and language therapy. A revised parenting offer has been established and is now being provided on a rolling programme. This includes parents to be and fathers.

Priority 4 - Promote good mental health and wellbeing for all children and young people

The Consistent Approaches to the Mental Health and Emotional Wellbeing for Children and Young People Group has focused on the following: inequalities in mental health, whole school approaches to emotional wellbeing, provision of the Mental Health Support Teams, Primary Mental Health Team and Educational Psychology Service in schools, support and interventions for children and young people, and training for professionals and parent/carers.

We have a good mental health and emotional wellbeing offer for children and young people in Reading, from getting advice through to specialist services. The BFfC school based mental health support offer is provided by two Mental Health Support Teams, the Primary Mental Health Team, the Emotionally Based School Avoidance Service, and the Educational Psychology Service. These services offer a range of interventions for mild to moderate mental health needs, working with schools, families, and practitioners across Early Help and Social Care. The work of these mental

health services sits in the context of our Therapeutic Thinking Schools and our Autism Growth Approach, both of which offer tools for understanding and implementing the trauma informed approach. We work systemically with partners using the THRIVE model, a stepped-care needs led approach that encourages partnership working

Priority 5 – Promote good mental health for all adults

This quarter saw the Annual Mental Health Inequalities Conference take place, led by Berkshire Healthcare Foundation Trust and the Community Wellbeing Hub, with presentations from health partners, voluntary sector organisations and the sharing of lived experiences from service users. This conference was well attended and supported the implementation plan action around raising awareness of mental health in a culturally competent way with some of our communities where there is a real presence of stigma around mental health.

May was also Mental Health Month and a full communications campaign took place on RBC social media channels including video content capturing some of the mental health and wellbeing support available across the borough. The campaign focused on highlighting the importance of physical activity and green spaces; the link between debt or money with anxiety; and crisis support. Local support was highlighted through this campaign and local organisations were able to raise awareness for the support they offer residents.

In April, the Mental Wellbeing Group heard from the Adult Social Care team leading the Mental Health Reablement programme which has been very successful. This led to forging more links with the voluntary sector, including social prescribers and wider voluntary sector groups who can support the people under the reablement programme.

There continues to be a focus on training including a team member training to deliver the Suicide First Aid Lite sessions, with an initial trial session running with RBC staff this month. Work on the Mental Health Needs Assessment for Adults in Reading continues, with focus groups booked in over the summer.

4. Contribution to Reading's Health and Wellbeing Strategic Aims

4.1. This proposal supports Corporate Plan priorities by ensuring that Health and Wellbeing Board members are kept informed of performance and progress against key indicators, including those that support corporate strategies. It contributes to all the Berkshire West Joint Health & Wellbeing Strategy 2021-30 priorities.

5. Environmental and Climate Implications

5.1. The recommended action will have no impact on the Council's ability to respond to the Climate Emergency.

6. Community Engagement

6.1. A wide range of voluntary and public sector partners and members of the public were encouraged to participate in the development of the Health and Wellbeing Strategy. The indicators included in this report reflect those areas highlighted during the development of the strategy and included in the final version. Key engage will continue to be a part of the process of implementing, reviewing and updating actions within the strategy to ensure it continues to address local need.

7. Equality Implications

7.1. Not applicable - an Equality Impact Assessment is not required in relation to the specific proposal to present an update to the Board in this format.

8. Other Relevant Considerations

8.1. Not applicable.

9. Legal Implications

9.1. Not applicable.

10. Financial Implications

10.1. The proposal to update the board on performance and progress in implementing the Berkshire West Health and Wellbeing Strategy in Reading offers improved efficiency and value for money by ensuring Board members are better able to determine how effort and resources are most likely to be invested beneficially on behalf of the local community.

11. Timetable for Implementation

11.1. The Berkshire West Health and Wellbeing Strategy is a 10-year strategy (2021-2030). Implementation plans are for three years however will continue to be reviewed on an annual basis.

12. Background Papers

12.1. There are none

Appendices

1. Health & Wellbeing Implementation Plans and Dashboard Report Update

2. Health & Wellbeing Dashboard Report

APPENDIX 1 - HEALTH AND WELLBEING IMPLEMENTATION PLANS NARRATIVE AND DASHBOARD REPORT UPDATE

PRIORITY 1: Reduce the differences in health between different groups of people, Implementation Plan narrative update

Action name	Status	Commentary (100 word max)
1. Take a 'Health in All Policies' approach that embeds health and wellbeing across policies and services.	Green	All policy reviews and development of new policies are assessed to ensure there is a reflection of the health and wellbeing of our residents and staff where appropriate.
2. Address the challenge of funding in all areas and ensure that decisions on changing services, to improve outcomes, does not adversely affect people with poorer health.	Green	The Better Care Fund supports delivery of Adult Social Care services and projects to address health and social care concerns that are aligned with the Better Care Fund objectives: BCF Objective 1: Enable people to stay well, safe and independent at home for longer BCF Objective 2: Provide the right care in the right place at the right time
3. Use information and intelligence to identify the communities and groups who experience poorer outcomes and ensure the right services and support are available to them while measuring the impact of our work.	Green	An annual inequalities report has been developed that looks into the impact on life expectancy of people from different backgrounds and compares across deprivation deciles. Where specific inequalities in health outcomes are identified we will work with our system partners to identify appropriate measures to address these inequalities. We have worked with partners to build a Hoarding Protocol and pathway, installed Technology Enabled Care devices and equipment to reduce risk of falls and are developing a Falls service, and we are developing a bariatric support pathway to enable timely discharges from hospital and to enable respite care, as well as developing dementia friendly services.
4. Ensure an effective programme of NHS Health Checks and follow up support services that are designed to meet the needs of all people in the community, ensuring appropriate communication and engagement methods that are culturally sensitive.	Amber	The Integration Board membership includes representatives from Primary Networks - GPs, and the national Health Checks are promoted through their practices and information campaigns within surgeries, as well as being promoted through community groups. Mini health checks that include blood pressure checks, are methods used to encourage people to contact their GPs where necessary. Translation of materials to support awareness is available. Monitoring data shows an increase in the percentage of people having completed Health Checks who have cardiovascular diseases, diabetes asthma and other long-term conditions.
5. Continue to develop the ways we work with ethnically diverse community leaders, voluntary sector, unpaid carers, and self-help groups that sit within Local Authorities.	Green	We have good connections with our voluntary care sector and representatives that attend the Reading Integration Board as members. We have active participation within ethnically diverse communities such as supporting digital literacy and health and wellbeing activities.
6. Ensure fairer access to services and support for	Green	One of our voluntary care sector partners has implemented a referral platform to enable effective social prescribing (i.e. referral to support services in voluntary sector, such as bereavement or walking groups, as well as mental health services, such as talking therapies). Residents are also able to self-refer

those in most need through effective signposting, targeted health education and promoting digital inclusion, all in a way that empowers communities to take ownership of their own health.		through this route, and there were in excess of 400 effective referrals within the first two months of operation. The platform enables people to reach the right support for them at the time they need it and residents also have the opportunity to self-refer. A full report on the effectiveness of this platform is to be presented to the Integration Board in July 2023.
7. Increase the visibility and signposting of existing services and improve access to services for people at higher risk of bad health outcomes, whilst also providing pastoral support through faith-based organisations linked to health and social care services.	Green	A number of voluntary sector and faith-based services are funded to deliver key information and advice services for Reading residents, as well as offering local exercise groups in church halls and other activities that promote wellbeing in the community, such as a Parish Nurse funded through a small grant from the Better Care Fund, who runs exercise and awareness sessions and actively engages with their community, signposting people to services where needed.
8. Monitor and assess how Covid-19 has differentially impacted our local populations, including through the displacement or disruption of usual services. Ensure health inequalities exacerbated by COVID-19 are addressed as we recover and ensure access to services.	Green	Our primary care networks and voluntary care sectors continue to be key participants in identifying any health inequalities exacerbated by COVID-19 and referring to appropriate support services.

Priority 1 – Key indicators

Population Health Management (PHM) Dashboard

This table shows the most recent data from the PHM dashboard showing the risk ratio for a range of conditions linked with early mortality and disability. Details about how PCNs and GP practices in the most deprived communities in Reading are affected are provided in the narrative.

Condition	Reading overall relative risk compared to ICS - baseline (March 22)	Target	Q2 Sept 22	Most recent Q1 June 23	Reading overall relative risk compared to ICS - this quarter	Narrative
Cancer	0.76	0.76	0.73	1.01	Above target (greater risk)	Relative risk in Reading is has increased since September 2022
Cardiovascular	0.85	0.85	0.84	0.80	Below target (lower risk)	Relative risk is below the target
Diabetes	0.95	0.95	0.94	0.95	Choose an item.	Relative risk has remained at the same level
Mental Health	1.05	0.95	1.01	1.24	Above target (greater risk)	The relative risk in Reading is higher compared to the ICS/target and has increased since September 2022
Obesity	0.87	0.87	0.88	0.95	Above target (greater risk)	Above target, increase since September 2022
Respiratory	0.97	0.97	0.95	0.93	Below target (lower risk)	Below target - slight decrease since September 2022

ICS Insights Evaluation Dashboard

This table shows the proportion of people living in Reading with each condition who have received all of the statutory health checks recommended for the condition within the recommended time period.

Condition	Level at start date/ BASELINE (31/03/2021)	Target	Level at end date MOST RECENT COMPLETE MONTH (09/06/2023)	Change	Narrative
Cardiovascular					
Hypertension	43.44%	80%	57.0%	13.6	There has been a significant improvement in the uptake
Heart failure	42.71%	80%	47.0%	4.3	There has been some improvement in the uptake
Stroke/TIA	66.02%	80%	77.65	11.6	There has been a significant improvement in the uptake
Coronary Heart Disease	72.31%	80%	80.0%	7.7	There has been a significant improvement in the uptake
Peripheral artery disease	62.13%	80%	66.5%	4.4	There has been some improvement in the uptake
Atrial fibrillation	16.54%	80%	18.5%	2.0	There has been an increase in prevalence
Dementia	41.13%	70%	64.9%	23.8	There has been a significant improvement in the uptake
Mental Health	54.50%	80%	63.5%	9.0	There has been a significant improvement in the uptake
Asthma	58.20%	80%	57.1%	-1.1	There has been a small decrease in the uptake
Learning disability	43.23%	80%	60.0%	16.8	There has been a significant improvement in the uptake
Cervical screening	58.40%	80%	62.0%	3.6	There has been some improvement in the uptake
Diabetes	62.37%	80%	65.9%	3.5	There has been some improvement in the uptake
TOTAL	54.46%	79%	57.2%	2.7	Overall, there has been some improvement in the uptake

PRIORITY 2: Support individuals at high risk of bad health outcomes to live healthy lives, Implementation Plan narrative update

Action name	Status	Commentary (100 word max)
1. Identify people at risk of poor health outcomes, using Population Health Management data and local data sources, as well as increase visibility of existing services, and signposting to those services, as well as improving access for people at risk of poor health outcomes.	Green	There are a number of activities that support the identification of people at risk of poor health outcomes that are active within the borough; NHS health checks through GPs, mini health checks in community settings, complex and long-term condition multi-disciplinary teams to review cases and ensure there are care plans in place, community exercise and information groups as well as advice and wellbeing services.
2. To raise awareness and understanding of dementia. Working in partnership with other sectors, we can introduce an integrated programme ensuring the Dementia Pathway is robust and extended to include pre diagnosis support, and improve early diagnosis rates, rehabilitation and support for people affected by dementia and their unpaid carers.	Green	The Dementia Friendly Reading Steering Group is currently undertaking a self-assessment exercise ahead of applying for Dementia Friendly Community status with Alzheimer's Society before the national closure of this scheme in December. The group have also submitted a funding application to resource a Dementia Friendly Reading Coordinator post who can support with this work, including coordinating a borough wide Dementia Friends training programme and supporting organisations (including RBC) with Dementia queries and advice.
3. Improve identification and support for unpaid carers of all ages. Work with unpaid carers and partner agencies to promote the health and wellbeing of unpaid carers by giving them a break from their caring responsibilities, whilst allowing them to fulfil their caring role.	Green	Work to develop a Joint All Ages Unpaid Carer Strategy for Reading are underway with a Carers Survey launching during Carers Week in early June. The engagement period runs until the end of June including focus groups with different groups of unpaid carers. This work is driven by the Carers Steering Group, with active membership from the Reading & West Berkshire Carers Partnership, the Carer Leads for Royal Berkshire Healthcare Foundation Trust and Berkshire Healthcare Foundation Trust, Brighter Futures for Children, wider voluntary sector partners and unpaid carers themselves. This process will enable us to build a picture of the needs of carers in Reading and inform a strategy and action plan to improve the experience of carers in Reading.
4. We will work together to reduce the number of rough sleepers and improve their mental and physical health through improved access to local services.	Green	We have commissioned a joint review across our six local authority areas using Rough Sleeping Initiative (RSI) grant funding to strategically look at prison releases, hospital discharges and issues/disputes around local connection and rough sleeping. Where there are, for example, several prisons that serve the six authorities. They are working on a pilot with HMP Bullingdon re: pre-work in, and a protocol with, prisons so that people are identified and referred to the local authority prior to release, so that the most suitable accommodation can be explored. Across Berkshire West we are keen for this scope to cover Prospect Park, Royal Berkshire Foundation Hospital, and other hospitals across the region, which ties into the work that is underway with our Housing team. A proposal has been put forward to develop a Homelessness Pathway for Reading that is aligned with other neighbouring local authorities and supported by Housing.
5. Prevent, promote awareness, and provide support to people affected by domestic abuse in line with proposals outlined in the Domestic Abuse Bill.	Green	We work closely with our Voluntary Care Sector Partners, Adult Social Care, Housing and Thames Valley Police to ensure safeguarding concerns are reported to enable action to be taken to support people at risk of domestic abuse, and a Tackling Domestic Abuse Strategy has been developed and implemented.
6. Support people with learning disabilities through working with voluntary organisations in order to concentrate on issues that matter most to them.	Green	We are working with our Voluntary Care Sector partners, some of whom are specialists in supporting people with Learning Disabilities, who are involved in a range of forums to enable engagement and feedback to support commissioning and priorities across Reading and the wider Berkshire West "Place". We have funded a part-time Autism Outreach worker post and have contributed to the Autism Strategy for Berkshire West. We also have the Compass Recovery College which provided free training and information for people with both low-level mental illness and long-term conditions affecting their mental health.

Priority 2 – Key indicators

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	England
Inequality in life expectancy at birth (male)	OHID Fingertips	Published	Annual	7.0 (2017-19)	7.0 (lower is better)	**6.8** (2018-20)	1/12/2022	9.7
Inequality in life expectancy at birth (female)	OHID fingertips	Published	Annual	8.3 (2017-19)	8.3 (lower is better)	**7.8** (2018-20)	1/12/2022	7.9
Rate of diagnosis of dementia in people aged 65+ estimated to have dementia	NHS digital	Published	Monthly	61.5% (February 2022)	66% (higher is better)	**63.5%** (September 2022)	1/12/2022	62.2%
Number of people sleeping rough (snapshot)	DLUHC	Published	Annual	22 (November 2021)	NA (lower is better)	Data due February 2023 (provisional)	1/12/2022	36
Proportion of working adults with learning disabilities in paid employment	OHID Fingertips	Published	Annual	5.9% (2019/20)	At least in line with national average (higher is better)	**5.9%** (2019/20) (no update)	1/12/2022	5.6%

PRIORITY 3: Help families and children in early years, Implementation Plan narrative update

Action name	Status	Commentary (100 word max)
1. Explore a more integrated universal approach that combines children's centres, midwifery, health visiting as outlined in the Best Start for Life report. This will aim to improve the health, wellbeing, development, and educational outcomes of children in Reading	Green	Health Visiting service lead Well Baby Clinics are back being delivered face to face in Children's Centres. Drop-in clinics have been re-introduced for breastfeeding support and BHCFT are in the process of commissioning peer support. A multi-disciplinary approach at Whitley Children's Centre is up and running supporting families.
2. Work to provide evidence-based support for mothers, fathers, and other carers to help prepare them for parenthood and improve their personal and collective resilience during pregnancy and throughout the early years.	Green	Evidence based, trauma informed, parenting programmes (Mellow Parenting) are now established and being delivered on a rolling programme for families. This includes Mellow Bumps, Babies and Toddlers. The fathers to be support is also now established, good links through the infant hub established with maternity services that is seeing consistent signposting of father and now self-referrals.
3. Increase the number of 2-year-olds (who experience disadvantage) accessing nursery places across Reading	Green	Whilst the number of 2rys olds accessing funded nursery places dipped in Spring term 2023 (65%) it remains above our target baseline. Work to promote the scheme continues with the Family Information Service (FIS) providing childcare brokerage support to 358 Reading families eligible for a 2-year funded place between 1 Jan 2023 and 3 July 2023. The 2-year funding page on the FIS directory is in the top 10 most visited between 1 January 2023 – 8 July 2023 with 4,161 page views and 2,908 unique page views. Parent Champions have been recruited and visiting community venues to promote take up to parents/carers.
4. We will ensure that early year's settings staff are trained in trauma-informed practice and care, know where to find information or help, and can signpost families	Green	Early years settings continue to have access to level 1 trauma informed, and level 2 trauma skilled training provided online. The Brighter Futures for Children (BFfC) Early Years team offer 'Child at the Heart – A Trauma Informed Approach' which is delivered face to face in two parts. It incorporates the videos from Level 1, guided discussion, ACES, healthy brain development, self/co - regulation, attachment, communication styles/behaviour. This will be repeated in September 2023. In addition, 12 practitioners (9 settings) have benefited from therapeutic play session and 53 practitioners (30 settings) have benefited from guided discussions to implement learning.
5. We will publish clear guidelines on how to	Green	The Reading Job Centre Employment Advisor, co-located with BFfC, works closely with Children's Centre to provide parents/carers with informal opportunities to discuss benefits and work. This includes one off benefit checks and 1-2-1 tailored support. 16 families have been provided with tailored

Action name	Status	Commentary (100 word max)
access financial help; tackle stigma around this issue where it occurs.		support with two parents being supported to return to work. The Employment Advisor also acts as a link with Job Coaches ensuring they are up to date with information on funded childcare provision. FIS has dedicated sections for childcare and family money. These sections include information on funded childcare, debt management and universal credit.
6. Develop a speech, language, and communication pathway to support the early identification and low-level intervention to prevent later higher cost services	Green	There has been an overall 38% reduction in referral to speech and language therapy, contributing to a reduced waiting list and time for children. The Speech and Language Champions scheme is now in its second year with 43 champions enrolled in the programme. There has been an overall improvement in champions confidence levels including 90% reporting an increase in confidence in creating communication friendly environments. The Wellcomm speech and language tool has been piloted and reviewed by the Best Start for Speech, Language, and Communication multiagency working group. 45% of children who had a review using the Wellcomm tool made progress.
7. Explore the systems for identification of need for ante natal and post-natal care of pregnant women and unborn/new-born babies to reduce non-accidental injuries	Green	BFfC Children's Social Care and Health completed joint work on pre-birth assessments for those children were there are safeguarding concerns. In addition, the work completed by BWSCP. There is close working established with Children's Centres, maternity services, and health visiting. BFfC has two staff focused on supporting families pre-and post-birth (Infant Coordinator and Infant Family Support Worker). They work closing with midwifery both in the hospital and the community.

Priority 3 – Key indicators (*No new updates*)

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	Benchmark
School readiness % <u>not</u> achieving good level of development	OHID Fingertips	Published	Annual	30.8% (2018/19)	Due to covid 19 pandemic expected national % will increase significantly so local target to be set in line with national when released	**30.8%** (2018/19) (no update)	1/12/2022	28.2% (currently)
Hospital admissions caused by deliberate and non-intentional injuries)0-14 years)	OHID Fingertips	Published	Annual	69.74 per 10,000 (2020-21)	Maintain rate below national benchmark	**69.74** per 10,000 (2020-21) (no update)	1/12/2022	75.65

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	Benchmark
% aged 2-2 ½ receiving ASQ3	OHID Fingertips	Published	Annual	97.4% (2020/21)	Maintain rate above national benchmark	**99.2%** (2021/22)	30/11/2022	90.3%
% 2-year-olds achieving at least expected in communication and language in the Early Years Foundation Stage Profile	DFE EY foundation profile	Published	Annual	79.1% (2018/19)	Due to covid 19 pandemic expected national % will increase significantly so local target to be set in line with national when released	**89.7%** (2021/22)	30/11/2022	86.2%
Number attending parenting groups in quarter, including NCT hospital-based groups and English for pregnant women who do not speak English	Brighter Futures for Children and Maternity Services	Local	Quarterly		50	50	30/11/2022 (*No new updates*)	NA
Uptake of trauma-informed training by Early Years practitioners in quarter	Brighter Futures for Children	Local	Quarterly		100	204	16/06/2023	NA

PRIORITY 4: Promote good mental health and wellbeing for all children and young people, Implementation Plan narrative update

Action name	Status	Commentary (100 word max)
1. Provide early intervention for children and young people with the right help and support at the right time	Green	Whole School approach, provided by the following teams: 2 Mental Health Support Teams offering early intervention and training for mild to moderate needs. Primary Mental Health Team offers consultation, training and more intense therapeutic work with CYP with mild to moderate needs.
2. Support settings and communities in being trauma informed and using a restorative approach	Green	Reading schools are supported in using the Therapeutic Thinking Schools approach. Regular network meetings are held to help support trauma informed and Therapeutic Thinking in practice.
3. Coproduction and collaboration with children and young people, families, communities and faith groups to shape future mental health services and in delivering transformation of mental health and emotional wellbeing services	Amber	Inequalities in mental health work is continuing, with focus groups with CYP and meetings with community and faith leaders. We have explored how racially diverse communities may experience barriers to accessing mental health services. Through participatory research over the past year, we have been able to identify some areas for improvement, and provide advisory documents to BFfC partners, schools and the wider community about how to support individuals from racially diverse backgrounds within their organisations/the community. There are also several projects that are being developed to help address health inequalities. For example, a Racial Equity Agreement that schools in Reading can sign up to, and a centralised area of on the BFfC website, designed to support racially diverse families and CYP. Over the coming year, this work will extend to focus on school exclusions as this has been identified as a key area disproportionately impacting on CYP from an ethnically diverse background. CYP who identify as LGBTQ+ are also at increased risk of a wide range of mental health challenges, including depression and anxiety (Just Like Us, 2021). Work is also planned to explore how organisations and services (such as the MHST) can develop to further support the LGBTQ+ community and to develop and create similar resources and links with the LGBTQ+ community to those developed for CYP from a racially diverse background and help to provide clarity for those supporting vulnerable groups such as these.
4. Develop an easy to navigate local mental health and emotional wellbeing offer for children, young people, parents, carers and professionals/practitioners.	Amber	Berkshire West/ BOB project feedback is being analysed.
5. Identify and provide services for targeted populations i.e. the most vulnerable children and young people to ensure equality of access to support and services	Green	Reading is an Autism Education Trust training hub, and the training is being rolled out across schools. See inequalities project above.
6. Recovery after Covid-19/ adolescent mental health	Green	The Emotionally Based School Avoidance (EBSA) project is being well received by schools and families, with some data on progress indicating the success of CYP and families in using this support.
7. Local transformation plan	Green	Priorities in place and monitored.

Priority 4 - Key Indicators

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	Benchmark
% school aged children with social, emotional and mental health needs	OHID Fingertips	Published	Annual	3.24% (2021)	Due to covid 19 pandemic expected national % will increase significantly so local target to be set in line with national when released (Lower is better)	3.5% (2022)	April 2022	3.0% (England)
Children in care	OHID Fingertips	Published	Annual	72 per 10,000 (2021)	Due to covid 19 pandemic expected national % will increase significantly so local target to be set in line with national when released (Lower is better)	64 per 10,000 (2021)	April 2022	70 per 10,000 (England)
% children looked after whose emotional wellbeing is a cause of concern	OHID Fingertips	Published	Annual	40.8% (2021)	Due to covid 19 pandemic expected national % will increase significantly so local target to be set in line with national when released (Lower is better)	40.8%	April 2021	36.8% (England)
Referrals to Mental Health Service Team (MHST) 1 of children and young people and their parents across project schools	Brighter Futures for Children	Local	Quarterly	150 (2021/22 Q4) MHST teams 1 & 2 = 189 referrals (2022/23 Q1)	80-100 referrals per quarter (higher is better)	**132** (2022/23 Q2)	September 2022	NA
% of children and young people engaged with MHST 1 who report they have moved closer to their goals (Goal Based Outcomes) or Outcomes Rating Scale	Brighter Futures for Children	Local	Quarterly	83% (2021/22 Q4) Goals = 100%; RCADS = 72% (2022/23 Q1)	80% (higher is better)	Goals = **89%**; RCADS = **65%** (2022/23 Q2)	September 2022	NA
% of children and young people working with Primary Mental Health Team who report they have moved closer to their goals (Goal Based Outcomes) or Outcomes Rating Scale	Brighter Futures for Children	Local	Quarterly	90% (2021/22 Q4) 90% (2022/23 Q1)	80% (higher is better)	**90%** (2022/23 Q2)	September 2022	NA

PRIORITY 5: Promote good mental health and wellbeing for all adults, Implementation Plan narrative update

Action name	Status	Commentary (100 word max)
1. Raise mental health awareness and promote wellbeing	Amber	May is Mental Health Awareness Week, we ran a month long communications campaign focusing on local support available to residents across a range of different themes including: physical activity, green spaces, debt, anxiety, mental health crisis support. The crisis support content in particular, saw good engagement, highlighting the need for this provision. The Annual Mental Health Inequalities Conference hosted by the Community Wellbeing Hub and Berkshire Healthcare Foundation Trust was well attended and featured stories of lived experience as well as the promotion of available support.
2. Address social factors that create risks to mental health and wellbeing, including social isolation and loneliness	Amber	Some key needs have been identified by members of the Mental Wellbeing Group that are relevant for this action, including a gap in provision around targeted support for adult males at risk of offending who may also have mental health conditions, substance misuse, multiple disadvantage and trauma. The mental health need for refugees and asylum seekers is also an area that has become increasingly prevalent with a business case proposal for a targeted mental health specialist team developed by Berkshire Healthcare Foundation Trust, but funding is yet to be identified. The refugee and asylum seeker housing support team at RBC have also now coordinated a regular refugee support panel meeting for partners working with this cohort (including voluntary sector) to work together at casework level to ensure individuals are accessing necessary and appropriate support, including mental health support.
3. Focus targeted support on groups at greater risk of experiencing mental health challenges, loneliness and social isolation and health inequalities in order to support early identification and intervention	Amber	Work continues in supporting groups identified as at greater risk of experiencing mental health challenges and inequalities with voluntary sector groups offering more support around early identification and intervention including the Community Wellbeing Hub (CWH) launching a new weekly support session for women to support with wellbeing which is largely attended by women from ethnically diverse backgrounds and with refugee or asylum seeker status. Reading Community Outreach Service has also launched their mental health support offer which now includes group support sessions and referral pathways have improved, with the services manager connecting with groups such as the one at the CWH, raising awareness of this service.
4. Foster more collaborative working across health, care and third sector services to recognise and address mental health support needs	Green	The Social Prescribing Forum continues to be delivered by Reading Voluntary Action with the next event in July. This is an opportunity for health, adult social care, wider local authority departments and voluntary sector colleagues to come together, including a 'speed networking' style event which will foster new relationships. The Adult Social Care Mental Health Reablement team presented at the last Mental Wellbeing Group and were well received with lots of interest and support from members of the group, and this has led to new partnerships and links forming.
5. Develop and support peer support initiatives, befriending and volunteer schemes, particularly recognising the impact of Covid-19 on smaller voluntary sector groups	Amber	Reading Voluntary Action continue to deliver their Chat, Connect Befriend programme promoting volunteering and befriending across the borough. They also continue to lead the Befriending Forum which most recently had presentations from NHS Check In and Chat service which offers one- off and short term telephone befriending.
6. Build the capacity and capability across the health and social care workforce to prevent mental health problems and promote good mental health	Amber	Mental Health First Aider training and broader Mental Health Awareness training was completed by a range of partners including internal RBC colleagues and broader voluntary and community sector partners as part of the Physical Activity for Mental Health (PAMH) Partnership project. This funding has now finished and new funding must be sought to continue this training programme. A team member is gaining accreditation to deliver the Suicide First Aid Lite training with the first trial session taking place this month with internal RBC colleagues. Making Every Contact Count training continues to be delivered in partnership with BOB ICB colleagues with recent sessions delivered to Cancer Champions and RBC colleagues.

Action name	Status	Commentary (100 word max)
7. Support people affected by Covid-19 with their mental wellbeing and associated loneliness and isolation	Amber	This priority continues to be delivered through training programmes delivered by members of the Mental Wellbeing Group including Berkshire Healthcare Foundation Trust, Wellbeing Matters team (NHS), Reading Voluntary Action, Community Wellbeing Hub and the Public Health and Wellbeing Team.
8. Develop local metrics to measure progress linked to Reading Mental Health Needs Assessment	Amber	The Mental Health Needs Assessment continues to develop, a data report has recently been drafted and focus groups will take place in the next 6 weeks alongside 3 surveys for people with lived experience of mental health problem(s), people caring for someone with mental health problem(s) and professionals supporting people with mental health problem(s).

Priority 5 – Key indicators

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	Benchmark
% people in Reading diagnosed with a SMI	Connected Care (via ICS Insights Evaluation Dashboard)	Local	Quarterly	1.0% (5th May 2022)	NA	0.9%	June 2023	
% people in Reading diagnosed with depression	Connected Care (via ICS Insights Evaluation Dashboard)	Local	Quarterly	9.8% (5th May 2022)	NA	10.1%	June 2023	
Drug and alcohol outreach performance - % accessing treatment	Public Health	Local	Quarterly	Q1 – 75.00%	To be agreed (higher is better)	**64%**	15/6/2023	
Drug and alcohol outreach performance - % retained in treatment	Public Health	Local	Quarterly	Q1 – 83.00%	To be agreed (higher is better)	**86%**	15/6/2023	
Drug and alcohol outreach performance - % receiving a health intervention	Public Health	Local	Quarterly	Q1 – 83.00%	To be agreed (higher is better)	**86%**	15/6/2023	

Indicator name	Source	Published/Local	Frequency	Baseline	Target	Most recent	Date reported	Benchmark
Self-reported wellbeing – % people with high anxiety	OHID	Published	Annual	24.49% (20/21)	24.15% by 22/23 (lower is better	22.6% (21/22)	1/12/2022	22.6% (21/22) England
Self-reported wellbeing – % people with low happiness	OHID	Published	Annual	8.47% (20/21)	Maintain current performance level – to be reviewed (lower is better)	4.2% (21/22)	1/12/2022	8.4% (21/22) England
Self-reported wellbeing – % people with low satisfaction	OHID	Published	Annual	5.3% (21/22)	Review when updated by OHID (lower is better)	5.3% (21/22)	1/12/2022	5.0% (21/22) England
Self-reported wellbeing – % people with low worthwhile	OHID	Published	Annual	5.3% (21/22)	Review when updated by OHID (lower is better)	5.3% (21/22)	1/12/2022	4.0% (21/22) England
Loneliness - % of people who feel lonely often, always or some of the time	OHID	Published	Annual	20.39% (2019/20)	Maintain current performance level – to be reviewed (lower is better)	20.39% (2019/20) (no update)	1/12/2022	22.26% (19/20) England

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PRIORITY 1: Reduce the differences in health between different groups of people

Condition	Reading overall relative risk compared to ICS – baseline (March 22)	Target			Reading overall relative risk compared to ICS – this quarter (Lower is better: Red = above target, Green = below target)											
		2022	2023	2024	2022				2023				2024			
					Q1 June	Q2 Sept	Q3 Dec	Q4 March	Q1 June	Q2 Sept	Q3 Dec	Q4 March	Q1 June	Q2 Sept	Q3 Dec	Q4 March
Cancer	0.76	0.75	0.74	0.73	0.75	0.73	0.84	N/A	1.01							
Cardiovascular	0.85	0.84	0.82	0.81	0.85	0.84	0.84	N/A	0.8							
Diabetes	0.95	0.94	0.92	0.91	0.95	0.94	0.95	N/A	0.95							
Mental Health	1.05	1.03	1.02	1.00	1.04	1.01	1.18	N/A	1.24							
Obesity	0.87	0.86	0.84	0.83	0.88	0.88	0.92	N/A	0.95							
Respiratory (COPD)	0.97	0.96	0.94	0.93	0.97	0.95	0.99	N/A	0.93							

From Reading's Population Health Management Dashboard (access restricted)
https://app.powerbi.com/links/VdsDusSs0C?ctid=7b6a45a6-474e-42c0-9bcf-f2585d9f1b30&pbi_source=linkShare

Dashboard: Health Checks Evaluation Dashboard

Total Reading population

Reading population in deciles 1-4 (or quintiles 1&2) - with 1 being most deprived areas

Condition	Level at start date (BASELINE Baseline 31/03/2021	Level at checkpoint checkpoint 31/05/2022	DOT	Target 2022	Target 2023	Target 2024	2022/23 Q1 June	2022/23 Q2 Sept	2022/23 Q3 Dec	2022/23 Q4 March	2023/24 Q1 June
Cardiovascular											
Hypertension	43.44%	46.55%	↑	80%	80%	80%	46.55%	47.74%	49.46%	57.00%	56.77%
Heart failure	42.71%	47.32%	↑	80%	80%	80%	47.32%	46.24%	47.30%	47.00%	47.83%
Stroke/TIA	66.02%	72.25%	↑	80%	80%	80%	72.25%	73.90%	75.55%	77.60%	78.40%
Coronary Heart Disease	72.31%	77.17%	↑	80%	80%	80%	77.17%	78.26%	79.58%	80.00%	80.12%
Peripheral artery disease	62.13%	64.00%	↑	80%	80%	80%	64.00%	62.99%	62.95%	66.50%	66.86%
Atrial fibrillation	16.54%	16.59%	↑	80%	80%	80%	16.59%	16.98%	17.82%	17.80%	17.80%
Dementia	41.13%	39.84%	↓	70%	70%	70%	39.84%	48.32%	51.63%	64.90%	64.94%
Mental health	54.50%	62.91%	↑	80%	80%	80%	62.91%	64.06%	65.23%	63.50%	64.33%
Asthma	58.20%	53.76%	↓	80%	80%	80%	53.76%	54.84%	57.44%	57.10%	59.05%
Learning disability	43.23%	50.88%	↑	80%	80%	80%	50.88%	55.09%	52.71%	60.00%	59.05%
Cervical screening	58.40%	61.24%	↑	80%	80%	80%	61.24%	63.08%	63.27%	62.00%	60.59%
Diabetes	62.37%	63.72%	↑	80%	80%	80%	63.72%	60.99%	63.86%	65.90%	65.89%
Total	54.46%	56.91%	↑	79%	79%	79%	56.91%	61.19%	63.38%	59.9%	60.1%

Condition	Level at start date Baseline 31/03/2021	Level at checkpoint checkpoint 31/05/2022	DOT	2022/23 Q1 June	2022/23 Q2 Sept	2022/23 Q3 Dec	2022/23 Q4 March	2023/24 Q1 June
Cardiovascular								
Hypertension	40.42%	43.89%	↑	44.00%	46.06%	47.25%	54.20%	56.77%
Heart failure	38.47%	44.23%	↑	44.65%	46.05%	47.85%	47.70%	47.83%
Stroke/TIA	62.55%	69.79%	↑	70.42%	71.38%	73.22%	76.70%	78.40%
Coronary Hea	71.67%	77.34%	↑	77.88%	78.54%	78.72%	78.50%	80.12%
Peripheral art	58.17%	59.08%	↑	59.72%	60.74%	60.68%	67.00%	66.86%
Atrial fibrillati	18.08%	17.35%	↑	17.22%	16.91%	16.91%	18.50%	18.50%
Dementia	42.29%	49.01%	↑	50.00%	58.90%	59.15%	58.90%	64.94%
Mental health	58.51%	63.31%	↑	64.07%	65.17%	64.81%	64.30%	64.33%
Asthma	57.64%	54.14%	↓	54.37%	56.93%	58.62%	57.50%	58.50%
Learning disabi	44.42%	50.58%	↑	51.13%	54.38%	49.07%	54.20%	59.05%
Cervical screeni	57.42%	59.18%	↑	59.16%	58.90%	59.15%	57.40%	60.59%
Diabetes	56.66%	57.71%	↑	57.61%	59.60%	63.15%	65.20%	65.89%
Total	56.79%	58.05%	↑	58.03%	59.59%	62.18%	58.3%	60.15%

Note: Total figure as it appears does not include CVD

From Frimley ICS Insights Health Checks Evaluation Dashboard (access restricted)
Evaluation Dashboard - Power BI

NB: Q1 2023- Atrial fibrillation data is the same as in March because it has not been refreshed in the system

PRIORITY 2: Reduce the differences in health between different groups of people

Difference in life expectancy at birth (years)

Year	England		Reading		
	Female	Male	Female	Male	
2010 - 12	6.8	9.1	6.7	9.6	
2011 - 13	6.9	9	5.8	10.5	
2012 - 14	7	9.1	7.3	9.2	
2013 - 15	7.1	9.2	6.7	8	
2014 - 16	7.3	9.4	7.7	7.8	
2015 - 17	7.4	9.4	6.3	8.8	
2016 - 18	7.5	9.5	7.2	8	
2017 - 19	7.6	9.4	8.3	7	
2018 - 20	7.9	9.7	7.8	6.8	No updated data (as at July 2023)

Source OHID Public Health Profiles https://fingertips.phe.org.uk/search/life%20expectancy#page/4/gid/1000049/pat/6/par/E12000008/ati/102/are/E06000038/iid/92901/age/1/sex/1/cat/-1/ctp/-1/yrr/3/cid/4/tbm/1

Dementia diagnosis rate amongst people aged 65+ estimated to have dementia (% of those estimated to have dementia to be diagnosed)

Month	Reading	England	
31/05/2021	62.5	61.8	
30/06/2021	62.4	61.9	
31/07/2021	62.5	62.1	
31/08/2021	64.2	62.0	
30/09/2021	63.7	62.0	
31/10/2021	62.1	61.9	
30/11/2021	62.3	62.0	
31/12/2021	63.1	61.8	
31/01/2022	62.5	61.6	
28/02/2022	61.5	61.7	
31/03/2022	61.5	62.0	
30/04/2022	62.0	61.8	
30/09/2022	63.5	62.2	Some improvement in diagnosis rate

Source NHS Digital Recorded Dementia Diagnoses - NHS Digital
Also available on OHID - Fingertips

Number of people rough sleeping (annual snapshot)

Year	Reading	England	
2010	6	1770	
2011	5	2180	
2012	---	2310	
2013	8	2410	
2014	12	2740	
2015	16	3570	
2016	22	4130	
2017	31	4750	
2018	25	4680	
2019	28	4270	
2020	19	2690	
2021	22	2440	
2022	36	3,069	Increase from 2021

Source: Department for Levelling Up, Housing and Communities https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1063903/rs_statistics2021.xlsx

Proportion of supported working age adults with learning disability in paid employment (%)

Year	Reading	England	
2014/15	6.6	6.0	
2015/16	6.9	5.8	
2016/17	7.1	5.7	
2017/18	6.0	6.0	
2018/19	6.0	5.9	
2019/20	5.9	5.6	No updated data Nov 22

Source: OHID Fingertips Learning Disability Profiles - Data - OHID (phe.org.uk)

PRIORITY 3: Help families and children in early years

School readiness

Not achieving GLD	Time period								
FSM status	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21
All								Statistics release cancelled	Statistics release cancelled
England	48.3	39.6	33.7	30.7	29.3	28.5	28.2	-	-
Reading	49	36.3	32.9	29	29.6	28.9	30.8	-	-
Free school meals									
England	63.8	55.2	48.8	45.6	44	43.4	43.5	-	-
Reading	59.7	47.9	46.9	42.8	45	40	43.5	-	-
Non free school meals									
England	44.8	36.3	31.1	28.3	27	26.2	25.7	-	-
Reading	46.7	34.1	30.4	26.6	26.9	27.2	28.4	-	-

Source https://www.gov.uk/government/statistics/early-years-foundation-stage-profile-results-2018-to-2019

Hospital admissions caused by unintentional and deliberate injuries in children (0-14 years)

	England		Reading		
Time period	Rate per 10,000	Number of admi	Rate per 10,000	Number o	
2010/11	115.22	107429.00	91.77	256.00	
2011/12	118.25	110996.00	106.27	303.00	
2012/13	103.86	98511.00	85.34	250.00	
2013/14	112.20	107473.00	82.53	249.00	
2014/15	109.63	106082.00	85.85	266.00	
2015/16	104.20	102036.00	84.57	267.00	
2016/17	101.46	100728.00	84.98	270.00	
2017/18	96.44	96910.00	82.16	265.00	
2018/19	96.09	97479.00	72.89	235.00	
2019/20	91.17	92926.00	73.05	235.00	
2020/21	75.65	77273.00	69.74	225.00	No updated data (as at July 2023)

Source Public health profiles - OHID (phe.org.uk)

% aged 2-2 1/2 receiving ASQ3

	England		Reading		
Time period	%	Number	%	Number	
2015/16	81.3	372053	99.8	1973	
2016/17	89.4	461514	98.0	1821	
2017/18	90.2	454992	78.9	1758	
2018/19	90.3	479887	92.8	1742	
2019/20	92.6	471802	97.4	1753	
2020/21	85.2	391683	97.4	801	
2021/22	85.2	391683	97.4	801	
2021/22	90.3	414767	99.2	1286	Increasing and getting better (as at July 2023)

Source Public health profiles - OHID (phe.org.uk)

% 2-year-olds achieving at least expected in communication and language in the Early Years Foundation Stage Profile

Time period	England		Reading		
	% achieving at least expected	% exceeding expected	% achieving at least expected	% exceeding expected	
2012/13	72.2	10.5	72.6	12.7	
2013/14	77.1	12.9	78.5	11.0	
2014/15	80.3	14.2	79.2	12.2	
2015/16	81.6	14.4	81.9	15.2	
2016/17	82.1	14.8	80.8	12.8	
2017/18	82.4	15.3	80.2	12.8	
2018/19	82.2	15.6	79.1	13.8	
2021/22	86.2	-	89.7	-	Increasing and getting better (as at July 2023)

Source https://www.gov.uk/government/statistics/early-years-foundation-stage-profile-results-2018-to-2019

PRIORITY 4: Promote good mental health and wellbeing for all children and young people

% school aged children with social, emotional and mental health needs

Time period	England		Reading		
	%	Number of pupils	%	Number of pupils	
2015	2.0	169110	3.0	701	
2016	2.3	184930	2.8	599	
2017	2.3	186793	3.0	647	
2018	2.4	193657	3.0	659	
2019	2.5	205673	3.1	686	
2020	2.7	222595	3.1	710	
2021	2.8	231463	3.2	748	
2022	3	250272	3.5	823	Rate is increasing (as at July 2023)

Source Public health profiles - OHID (phe.org.uk)

Children in care

Time period	England		Reading		
	Rate per 10,000	Number of pupils	Rate per 10,000	Number of pupils	
2011	59	65520	69	215	
2012	59	67050	71	240	
2013	60	68110	67	225	
2014	59.82731	68840	59.87	210	
2015	59.9912	69540	57.18271	205	
2016	60.31929	70440	60.38482	220	
2017	62	72670	72	260	
2018	64	75370	75	277	
2019	65	78140	73	271	
2020	67	80000	75	277	
2021	67	80850	72	270	
2022	70.0	82,170	64.0	234	Rate is improving (as at July 2023)

Source Public health profiles - OHID (phe.org.uk)

% children looked after whose emotional wellbeing is a cause for concern

Time period	England		Reading		
	%	Number of pupils	%	Number of pupils	
2014/15	37.0		56.0		
2015/16	37.8	10434	43.5	27	
2016/17	38.1	10980	48.1	51	
2017/18	38.6	11850	43.4	53	
2018/19	38.6	12390	37.8	54	
2019/20	37.9	13000	32.0	48	
2020/21	36.8	12850	40.8	60	No updated data (as at July 2023)

Source Public health profiles - OHID (phe.org.uk)

Number of referrals to Mental Health Service Team (MHST)

Time period	Referrals to Mental Health Service Team (MHST) 1 of children and young people and their parents across project schools	Target	
2022/23 Q1	MHST teams 1 & 2 = 189 referrals	80-100	
2022/23 Q2	MHST teams 1 & 2 = 132 referrals	80-100	
2022/23 Q3	MHST teams 1 & 2 = 217 referrals	80-100	
2022/23 Q4	MHST teams 1& 2 = 360 referrals	80-100	
2023/24 Q1		80-100	
2023/24 Q2		80-100	
2023/24 Q3		80-100	
2023/24 Q4		80-101	As reported in July 2023

% of children and young people engaged with MHST who have moved towards their goals

Time period	% of children and young people engaged with MHST 1 who report they have moved closer to their goals (Goal Based Outcomes) or Outcomes Rating Scale	Target	
2022/23 Q1	Trailblazer MHST 1 Goals = 100%; RCADS =	80%	
2022/23 Q2	Trailblazer MHST 1 Goals = 89%; RCADS = 6	80%	
2022/23 Q3	Trailblazer(MHST 1) **Goals =95% RCADS = 6**	80%	
2022/23 Q4	Trailblazer(MHST 1) **Goals =90% RCADS = 8**	80%	
2023/24 Q1		80%	
2023/24 Q2		80%	
2023/24 Q3		80%	
2023/24 Q4		80%	As reported in July 2023

% of children and young people working with Primary Mental Health Team who have moved towards their goals

Time period	% of children and young people engaged with MHST 1 who report they have moved closer to their goals (Goal Based Outcomes) or Outcomes Rating Scale	Target	
2022/23 Q1	90%	80%	
2022/23 Q2	90%	80%	
2022/23 Q3	90%	80%	
2022/23 Q4	90%	80%	
2023/24 Q1		80%	
2023/24 Q2		80%	
2023/24 Q3		80%	
2023/24 Q4		80%	As reported in July 2023

Source: Brighter Futures for Children - Locally reported

PRIORITY 5: Promote good mental health and wellbeing for all adults

Number of people diagnosed with SMI (QOF)

Total Reading population

Year	Quarter	Number diagnosed with SMI	% of Reading residents	Relative risk Reading residents	% meeting statutory health checks		Date (QOF, Connected Care)
					Baseline (Mar 22)	This quarter	
2022/23	Q1	1997	1.0%	1.31	*59.4%*	62.91%	14/06/2022
	Q2	N/A	N/A	N/A	N/A	N/A	N/A
	Q3	2,508	0.9%	1.18		65.23%	12/01/2023
	Q4	N/A	N/A	N/A	N/A	N/A	N/A
2023/24	Q1	2317.00	0.90%	1.24		64.30%	06/01/2023
	Q2						
	Q3						
	Q4						
2024/25	Q1						
	Q2						
	Q3						
	Q4						

Unable to get data for Q2 at time of writing

Source

Home Page - Power BI

Reading population in deciles 1-4 (or quintiles 1&2) - with 1 being most deprived areas

Year	Quarter	Number diagnosed with SMI	% of Reading residents	Relative risk Reading residents	% meeting statutory health checks		Date (QOF, Connected Care)
					Baseline (Mar 22)	This quarter	
2022/23	Q1	N/A	N/A	N/A	N/A	N/A	N/A
	Q2	N/A	N/A	N/A	N/A	N/A	N/A
	Q3	1,023	1.1%	1.45	*62.80%*	64.81%	12/01/2023
	Q4	N/A	N/A	N/A	N/A	N/A	N/A
2023/24	Q1	5,156	5.90%	1.46		64.50%	06/01/2023
	Q2						
	Q3						
	Q4						
2024/25	Q1						
	Q2						
	Q3						
	Q4						

Number of people diagnosed with depression (QOF)

Total Reading population

Year	Quarter	Number diagnosed with depression	% of Reading residents	Relative risk Reading residents	Date (QOF, Connected Care)
2022/23	Q1	19,853	10.0%	1	14/06/2022
	Q2	N/A	N/A	N/A	N/A
	Q3	28,401	10.4%	1.02	12/01/2023
	Q4	N/A	N/A	N/A	N/A
2023/24	Q1	26,323	10.10%	1	06/01/2023
	Q2				
	Q3				
	Q4				
2024/25	Q1				
	Q2				
	Q3				
	Q4				

Source

Home Page - Power BI

Reading population in deciles 1-4 (or quintiles 1&2) - with 1 being most deprived areas

Year	Quarter	Number diagnosed with depression	% of Reading residents	Relative risk Reading residents	Date (QOF, Connected Care)
2022/23	Q1	N/A	N/A	N/A	N/A
	Q2	N/A	N/A	N/A	N/A
	Q3	10,241	11.4%	1.11	12/01/2023
	Q4	N/A	N/A	N/A	N/A
2023/24	Q1	9,606	11.2%	1.1	06/01/2023
	Q2				
	Q3				
	Q4				
2024/25	Q1				
	Q2				
	Q3				
	Q4				

Drug and alcohol outreach support to street homeless population

Year	Quarter	Number known to be street homeless	Number engaged in care planned treatment with drug and alcohol outreach team	% engaged in care planned treatment with the drug and alcohol outreach team	% of those engaged in care planned treatment who remain in treatment for at least 3 months	% of those engaged in care planned treatment who receive a health intervention	
2022/23	Q1	8	6	75%	83%	83%	
	Q2	9	6	67%	89%	89%	
	Q3	13	8	62%	88%	88%	
	Q4	11	7	64%	86%	86%	
2023/24	Q1						
	Q2						
	Q3						
	Q4						
2024/25	Q1						
	Q2						
	Q3						
	Q4						Latest data provided (as at July 2023)

Source
Locally reported

Self-reported wellbeing

	Self-reported wellbeing							
	High anxiety score		Low happiness score		Low satisfaction score		Low worthwhile score	
Year	Reading	England	Reading	England	Reading	England	Reading	England
2011/12	18.99	21.74	9.08	10.72	5.57	6.53	4.33	4.76
2012/13	22.13	20.97	7.7	10.29	4.5	5.74	4.13	4.3
2013/14	18.43	19.96	5.99	9.63	3.57	5.58		4.2
2014/15	21.46	19.33	5.23	8.9	4.97	4.74		3.78
2015/16	17.21	19.37	7.69	8.75	3.83	4.55		3.55
2016/17	21.89	19.87	8.77	8.54	3.83	4.5		3.64
2017/18	18.58	20.01	7.55	8.2		4.41		3.57
2018/19	20.47	19.72	5.99	7.81	4.47	4.29	4.16	3.61
2019/20	18.85	21.94		8.72		4.68		3.81
2020/21	24.49	24.15	8.47	9.21	-	6.06	-	4.38
2021/22	22.6	22.6	4.2	8.4	5.3	5.0	5.3	4.0

Source Common Mental Health Disorders - OHID (phe.org.uk) No further update to date (as at July 2023)

Loneliness: - % of people who feel lonely often, always or some of the time

Year	Reading	England	
2019/20	20.39	22.26	No updated data (as at July 2023)

Source Public Health Outcomes Framework - OHID (phe.org.uk)

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READING HEALTH AND WELLBEING BOARD

Date of Meeting	14 July 2023
Title	Autism Strategy: Year 1 Action Plan update
Purpose of the report	To note the report for information
Report author	Sunny Mehmi
Job title	Assistant Director: Adult Social Care
Organisation	Reading Borough Council
Recommendations	1. That the Health and Wellbeing Board note the report

1. Executive Summary

1.1. The purpose of this report is to inform the Health and Well-Being Board of the progress of the Year 1 (2022/23) All Age Autism Strategy Action Plan across Reading.

2. Policy Context

2.1. The Autism Act 2009 set out the requirements for local authorities and NHS bodies to work with local partners to improve services and support autistic people. The Act put a duty on Government to produce and regularly review an 'Autism Strategy' to meet the needs of children, young people and adults with autism in England. The latest Autism Strategy was published in July 2021: 'The national strategy for autistic children, young people and adults: 2021 to 2026. Reading's strategy and action plan enables us to align the national priorities with local demands and needs of residents in Reading with autism.

2.2. The Reading All Age Autism Strategy was agreed at the Health and Wellbeing Board on the 20th January 2023. It was agreed at that Board that regular updates on the progress of the action plan would be presented back to the Board.

2.3. Public and partner engagement was a core element of developing Reading's Autism All Age Strategy (2022-2026), including autistic people and their families and carers, third sector and voluntary organisations and professionals from across Reading. Engagement and coproduction took place via interviews, workshops, surveys, forums, existing local groups, targeted outreach to groups and feedback sessions. This insight was used to inform and shape the strategy and its action plan, and to test emerging findings, recommendations, priorities, and vision development.

2.4. As a result of the engagement and feedback **Seven** priorities were developed:

1. Improving awareness, understanding and acceptance of autism
2. Improving support and access to early years, education and supporting positive transitions and preparing for adulthood
3. Increasing employment, vocational and training opportunities autistic people
4. Better lives for autistic people – tackling health and care inequalities and building the right support in the community and supporting people in inpatient care
5. Housing and supporting independent living
6. Keeping safe and the criminal justice system
7. Supporting families and carers of autistic people

3. The Proposal

3.1. Appendix 2 outlines the progress Partner agencies have made in delivering Year 1 of the All Age Autism Strategy. Some of the key developments include:

Autism Training

- Oliver McGowen training, provided by a Skills for Care (as an endorsed provider) is now mandatory for care staff.
- Autism Awareness is also available to all RBC care providers
- Autism Berkshire completed a ½ day training to Primary Care Social Prescribers.
- Autism Berkshire were able to obtain a popup shop in the Oracle Shopping centre and raise awareness and signpost to local services.

Early Years Support

- Where appropriate the Early Years SEND Advisors/Portage Workers will facilitate and support transition planning, joining multi professional meetings, empowering parents/carers to liaise with the SEND team regarding transition concerns.
- There has been two new SCD early years resource bases created to support early intervention for children with Social Communication needs who are able to access a mainstream curriculum; with the ambition for children to make good steady progress and transition into a mainstream school.
- Transitions has become a focus in Early Years newsletters and networks with a reminder that transitions is not a one off event but a process across the year that settings can work with their local schools together to improve support in transitions.

Employment Support

- Elevate continue in delivering careers information, advice, and guidance from the Youth Hub at the Curious Lounge. The hub was established in partnership with the DWP, for young people 16-25 with complex needs, including SEND young people.
- Elevate are currently building the links with employers and advocating for young people who need additional support in the work place.
- Elevate are currently working with the SEND Team at BFfC to set up Reading's first SEND employment forum with the aim to increase the number of local employers who are able to provide work placements to SEND young people including work placements and supported internships.
- Elevate is currently working with the Apprenticeships Team at RBC and Team Reading (HR at RBC) to start developing the offer to SEND young people that also include supported internships.

Healthcare Support

- BOB ICB Berkshire West, have co-produced letters with Children and Young People and the Parent Carer Forum to send to GP's requesting an Annual Health Check. GP training has taken place to raise awareness of the Annual Health Check with the LD champions.
- BOB ICB are currently undertaking a Quality Improvement piece of work reviewing the wait times for autism.
- BOB ICB Berkshire West Place continue to work with the Royal Berkshire Hospital Foundation Trust to improve experience of care for CYP and families. RBHFT have mapped out the 10 transition pathways and the parent carer forums are involved with the transitions steering group
- The Positive Behaviour Service is in place to offer training to education, social care, the voluntary sector, health and parent and carers.

Supported Living Accommodation

- Commissioning have identified that there are potentially some gaps in current services which they will be begin work to address. These gaps include short-term supported living accommodation for:
    - Assessment on hospital discharge

- Step down options to support independence and demonstrate ability to manage a tenancy
- Locked door accommodation

Criminal Justice Support

- Autism Alert cards are now distributed to all Reading Police Stations
- Autism Berkshire has a rolling programme of training with the Thames Valley Police.
- There are proactive links with the National Police Autism Association and the Force Autism Support lead.
- Autism Berkshire are now supporting the Thames Valley Police Neurodiversity Support Network.

Carers and Family Support

- Family Workers are aware of the Autism Advisor support and regularly 'refer' families. They are also aware of other local autism support services and will signpost families to these as appropriate.
- The Autism Advisor Service offers consultations to family workers in order to support their work with families of autistic young people.
- Autism Advisor continues to be copied into all CAMHS reports and offers all families a home visit or virtual meeting.
- New Carers Partnership has now been commissioned to provide a more timely service for carers assessment and support.

3.2. The Autism Board will continue to give annual report to the Health and Wellbeing Board.

4. Contribution to Reading's Health and Wellbeing Strategic Aims

4.1 The formation of the Autism Partnership Board, the Strategy and Action Plan alongside key partners across the Health, Educational and Voluntary sector ensure that Strategic Aims set out in the Berkshire West Health and Wellbeing Strategy are met:

1. Reduce the differences in health between different groups of people
2. Support individuals at high risk of bad health outcomes to live healthy lives
3. Help children and families in early years
4. Promote good mental health and wellbeing for all children and young people
5. Promote good mental health and wellbeing for all adults

4.1 Furthermore the following ambitions are realised through the work plan of the Board, All age Autism Strategy and its Action Plan.

- To promote equality, social inclusion and a safe and healthy environment for all
- Contributions to Community Safety, Health and Wellbeing of children, young people and adults with autism.

5. Environmental and Climate Implications

5.1. There is no environmental or climate implications arising from this report.

6. Community Engagement

6.1. Since the developed on the Autism Strategy and Action Plan throughout 2022, no further consultation has taken place. However ongoing partnership work to deliver the strategy and its action plan continues.

7. Equality Implications

7.1. Under the Equality Act 2010, Section 149, a public authority must, in the exercise of its functions, have due regard to the need to—

- eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;
- advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

7.2. An Equality Impact Assessment (EIA) was completed as part of the development of the Autism Strategy and Action Plan for the January 2023, this has been reviewed and no amendments required.

8. Other Relevant Considerations

8.1. Not applicable.

9. Legal Implications

9.1 There are no duties for the Local Authority regarding the Autism Board however there is a requirement to carry out / implement the Autism Strategy which was published in July 2021: 'The national strategy for autistic children, young people and adults: 2021 to 2026 on a local level. The Local Authority also need to consider the needs of children, young people and adults as part of our legal duties under the Care and Families Act 2014 and Care Act 2014.

9.2 Under the Section 1 and 4 of the Care Act the Local Authority has a duty to 'Promote individual well-being' and 'Provide Information and Advice. We have a responsibility under Section 9 to 'Assess an adult care and support needs' and under section 18 a 'Duty to meet the care and support needs'.

10. Financial Implications

10.1. There are currently no significant budget implications regarding the implementation for the Strategy and Action Plan. The delivery of the Action Plan would be within existing resources and reviewing existing pathways to meet the needs of residents. The care and support needs of children and young people and adults who require social care are met as per our legal duties.

11. Timetable for Implementation

11.1. Not applicable.

12. Background Papers

12.1. There are none.

Appendices

1. All Age Autism Strategy for Reading 2022 to 2026

2. All Age Autism Strategy Action Plan 2022/23

3. The Equality Impact Assessment

Reading's **All Age Autism** Strategy 2022-2026

Brighter Futures for Children

NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

Reading Borough Council
Working better with you

Our Vision

For all of Reading's autistic people and their families and carers to feel supported, included and be enabled to live their best and healthiest lives through awareness and support across the life course

The evidence base for this strategy sits within the All-Age Autism Needs Assessment and the two documents are intended to complement each other.

Contents

Throughout this document, we have tried to use Identity-First language (i.e., 'autistic people' rather than 'people with autism') as an umbrella term for all autistic spectrum conditions and disorders, including Asperger Syndrome as it is acknowledged that for some, this is the preference of some autistic people. Where there is use of alternative language, this is because it is used in the national guidance, or the terminology is being cited from data provided in that format. It is acknowledged that these are not necessarily the terms everyone would choose. However, this strategy is intended to be inclusive to all those identifying with any of these terms, or related terms.

1.0 Introduction

Autism is a national priority. This Strategy has been brought together by a Steering group made up of autistic people, carers, professionals working with autistic people, members of the Autism Board and multidisciplinary professionals from across Reading's system to highlight our joint ambitions.

Those engaged throughout the development of this strategy:

- Autistic people, parents, carers
- Brighter Futures for Children
- Berkshire West Hub
- Reading Borough Council, Public Health Officers
- Reading Borough Council, Public Health Analyst
- Berkshire West Public Health
- Autism Berkshire / Parenting Special Children
- Reading Mencap
- Thames Valley Police
- Berkshire Health Foundation Trust (BHFT)
- Healthwatch Reading
- Reading Families Forum
- Talkback CAMEO
- Liaison and Diversion Service
- Probation Service
- Youth Offending Service
- The Department for Work and Pensions (DWP)
- Job Centre
- New Directions
- Other Employments related organisations
- Special United group
- Reading Autistic Families Together (RAFT)
- Compass Recovery College - Autistic adults
- Reading Families Forum - Attendees
- Autism Berkshire - Parents/Carers
- Engine Shed Session - Children/ Young people
- Parenting Special Children (Auticulate)

Our ambition is to have a whole systems approach to ensure Reading is a more inclusive place to live and that autistic people can get the right support they need when they need it. This strategy and associated plans are for all autistic people in Reading, including those who support them.

Produced by: **Amanda Nyeke**: Public Health & Wellbeing Manager (amanda.nyeke@reading.gov.uk)
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2.0 What is Autism?

Autism is a lifelong difference in brain functioning that affects how people perceive, communicate, and interact with and experience the world around them and others.[1] It is recognised as a difference, not a medical condition requiring a "cure".[2] Autism is not a learning disability, although various reports indicate that approximately 4 in 10 autistic people have a learning disability[3] [4]. Within this strategy, we also talk about neurodiversity.

Neurodiversity

Neurodiversity is the fact that all human beings vary in the way our brains work.

- Take in information in different ways
- Process it in different ways
- Thus, behave in different ways

The Neurodiversity Paradigm

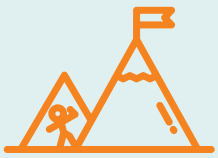
1. Neurodiversity is naturally occurring
2. No one way of being is better than another
3. Neurodiversity operates like other equality diversity dimensions
4. Strength in diversity itself – collective not individual value

Professor Sue Watson

There is growing support for the Neurodiversity Paradigm, which frames all neurodivergence (such as autism, attention deficit hyperactivity disorder [ADHD] and dyslexia) as a positive and creative concept to be embraced rather than regarded as a psychological issue.[5]

Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives.

[1] National Autistic Society (2020). What is Autism? [online] Autism.org.uk. Available at: https://www.autism.org.uk/advice-and-guidance/what-is-autism.
[2] NHS (2019). What Is autism? [online] NHS. Available at: https://www.nhs.uk/conditions/autism/what-is-autism/ [Accessed Dec. 2021].
[3] NICE (2018). Context | Learning disabilities and behaviour that challenges: service design and delivery | Guidance |[online] Available at: https://www.nice.org.uk/guidance/ng93/chapter/Context.
[4] Public Health England (2016). Learning Disabilities Observatory. People with learning disabilities in England 2015: Main report.
[5] Autism UK (2020). Neurodiversity. [online] Available at: https://autisticuk.org/neurodiversity/ [Accessed Dec. 2021].



Some common challenges experienced by autistic people include:

- Social communication and social interaction (including verbal and non- verbal communications; navigating the social world)
- Repetitive and restrictive behaviour (coping with unpredictability and change)
- Over or under-sensitivity to sensory stimuli (reaction to sound, touch, taste, etc.)
- Highly focussed interests or hobbies (may lead to neglect of other aspects of the person's life)
- Extreme anxiety (particularly in social situations or when facing change)
- Meltdowns and shutdowns (can be very intense and exhausting for the person)[1]

Some unique talents and skills that autistic people have include (but not limited to);

- Having logical and methodical approaches
- Good problem-solving skills
- Punctuality and reliability
- Exceptional attention to detail
- Creative thinking
- Strong technical skills (e.g., in IT) with some exceptionally talented and gifted

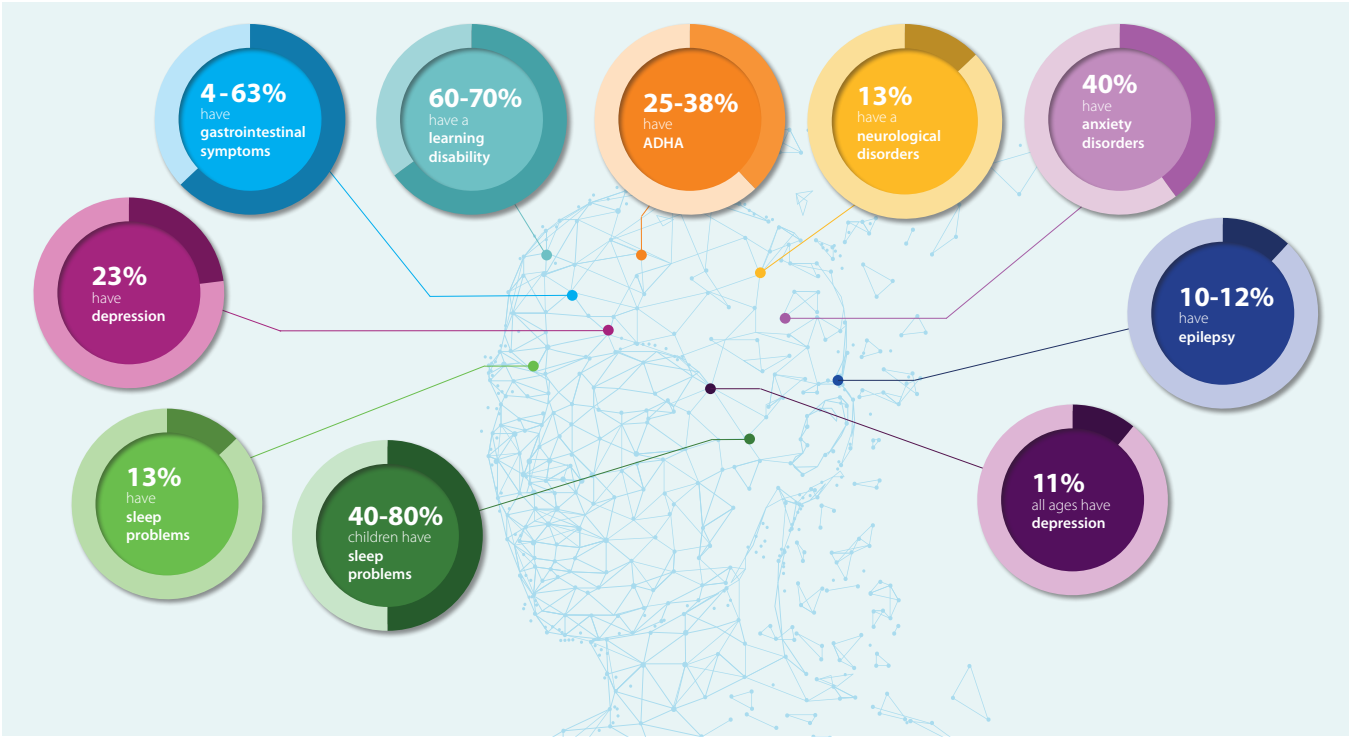
The causes of autism are unknown. It is common for signs of autism to present themselves from a young age. Needs led rather than diagnosis dependent support, with a recognition of neurodiversity is vital. Reading strongly advocates for the importance of neurodiversity, describing autism **as a difference and not a deficit**, seeking to maximise the opportunities for neurodivergent children and young people.[6 7]

[6] Brighter Futures for Children (2021). A growth approach to autism. [online] Brighter Futures for Children. Available at: https://brighterfuturesforchildren.org/professionals/ school-standards-services/school-standards-service-a-growth-approach-to-autism

2.1 Co-occurring conditions

Autistic people often have co-occurring conditions, including dyslexia, dyspraxia, epilepsy, depression, anxiety, ADHD and behaviours such as difficulty sleeping and self-harm. The frequency of co-occurring conditions, means autism is less likely to be diagnosed, leading to inequalities in access to health services and care.[8] Recent studies have shown that approximately 70% of autistic people also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that has an impact on daily life. A learning disability occurs in approximately 50% of young autistic people.[8]

Figure 1: Co-occurring conditions



Caring and supporting an autistic person can be demanding but also rewarding. Demands on families providing ongoing care and support without breaks can be significant. Societal attitudes to autism and the level of support provided by local and national authorities are important factors determining the quality of life of autistic people.

Support needs

Some autistic people can live independent lives, but others may face additional challenges and require extra care and support. Amongst those that do, the type and level of support needed will vary considerably. Some autistic people need full time care, others will benefit from a small amount of support to help with certain activities or situations. Support aims to enable autistic people to live their lives in the way they choose.[9] Although a diagnosis of autism is not always necessary to access groups and some services, for many people, being diagnosed with autism helps to ensure they are able to receive the right support, including adjustments at work or school, and helps them to make sense of their experiences and some of the challenges they face.[10] This strategy aims to ensure actions are implemented that will benefit all autistic people in Reading whether they have a diagnosis or not.

[7] NICE (2011). Context | Autism spectrum disorder in under 19s: recognition, referral and diagnosis | Guidance | NICE. [online] www.nice.org.uk. Available at: https://www.nice.org.uk/guidance/cg128/chapter/Context.
[8] WHO (2017). Autism Spectrum Disorders. Available at: https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.
[9] National Autistic Society. Available at: Varying support needs (autism.org.uk)
[10] National Autistic Society. Available at: Adults (autism.org.uk)

3.0 Why a Reading Autism Strategy is needed

The National Strategy for autistic children, young people and adults, 2021[11] places a statutory duty on local authorities working in partnership with the NHS, the voluntary sector, and autistic people to implement actions in relation to the provision of services for autistic people.

Our strategy will align with the commitments in relevant best practice guidance and other national policies, including the NHS Long Term Plan 2019 which pledges to:

> "do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives."[12]

The Autism Act (2009) highlights the need for the development and regular review of an autism strategy to make provision to meet the needs of autistic adults. Autistic people, their families, carers and professionals that support them, have told us they experience many barriers in meeting their needs. This strategy is a plan that clearly states the goals, priorities and actions to be taken. A better understanding, acceptance and culture shift in Reading will help address many of these barriers. This strategy will be for 4 years from 2022 – 2026. The strategy actions will need to be embedded in organisations including the wider community to ensure its sustainability, and ability to develop as needs change.

Autism inequalities and barriers to support

Despite autism being a national priority, autistic people are disproportionally affected in various areas. Compared to non-autistic people, common inequalities experienced by autistic people include reduced access to public services and spaces, a gap in employment opportunities[13 14], poorer health outcomes, increased likelihood to report a lower quality of life[15] and social isolation, which also impacts health[16 17]. Action to prevent further widening these gaps is vital.

Autistic people are more likely to die early from factors like suicide, cardiovascular disease and mental health problems. Suicide is a leading cause of early death for autistic people with autistic adults with no additional learning disability being over 9 times more likely to commit suicide than the general population and autistic children experiencing suicidal thoughts 28 times more compared to children in the general population [17b 17c]. It is more likely for autistic people to require hospital care or use emergency services than non-autistic people. Many children are diagnosed late; especially girls, resulting in a gender gap, with higher prevalence reported in males than females (ratio of 3:1). Racial, ethnic, and socioeconomic disparities associated with autism also exist.

The Covid-19 pandemic and its effects

Existing challenges experienced by autistic people have been exacerbated by the COVID pandemic such as worsening of mental health conditions, avoidable inpatient admissions, loneliness and barriers to accessing public spaces. The employment and training market was also disrupted. There continues to be insufficient knowledge of how to make reasonable adjustments to existing services, poor access to mainstream services, alongside limited day opportunities, challenges experienced by families

[11] Department of Health and Social Care and Department for Education (2021). The national strategy for autistic children, young people and adults: 2021 to 2026. [online] GOV. UK. Available at: https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.
[12] NHS (2019a). NHS Long Term Plan. [online] Available at: https://www.longtermplan.nhs.uk/online-version/.
[13] Office for National Statistics (2021). Outcomes for disabled people in the UK - Office for National Statistics. [online] www.ons.gov.uk. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020.
[14] Allen M & Coney K (2018). What Happens Next? 2018: A report on the first destinations of 2016 disabled graduates. The Association of Graduate Careers Advisory Services.
[15] Mason D, et al. (2018) Predictors of Quality of Life for Autistic Adults. Autism Res 11(8), 1138-1147.
[16] Rydzewska, E, et al. (2019) General health of adults with autism spectrum disorders – A whole country population cross-sectional study. Research in Autism Spectrum Disorders 60, 59-66.
[17] Westminster Commission on Autism (2016). A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people.
[17b] Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5)
[17v] Mayes, S.D. et al. (2013). Suicide ideation and attempts in children with autism. Research in Autism Spectrum Disorders.

and carers particularly seldom heard groups and challenges within education settings. However, the pandemic also led to increased awareness and understanding of challenges experienced in people's lives, in particular, autistic people and their families, evidenced by the Left Stranded report[18] and other research findings. Knowledge and awareness of autism, the needs of the local population, and insights by autistic people and their families, need to be the basis of commissioning decisions.

Although autism diagnosis rates for adults have improved, waiting times for assessment continue to be very long for many, worse than previous years and exceeding the 13-week NICE recommended timescale. Factors that exacerbate long waiting times, include growing waiting lists linked to increasing autism public awareness leading to increased referrals, so, increasing demand on services. This has been heightened by the pandemic, stopping or slowing down some local assessment processes. Longer waits can also be a result of delays in diagnostic pathways resulting from workforce pressures. Despite many challenges in Reading, service development accelerated in terms of digital solutions (provided by Berkshire Healthcare and external providers). The service adapted well, and staff quickly embraced new ways of working and became skilled in online delivery and making greater use of technology. A costed proposal to reduce waiting times to a sustainable 12 months was taken through CCG and BHFT governance and an additional investment of £800K in 21/22 was provided to reduce waiting times and this was increased to £1.6M FYE for 22/23. The new investment is enabling a significant service expansion across the Autism Assessment Team (AAT) and the ADHD Team. The investment is being used both to increase the workforce and to use partnership working with external providers to increase the service capacity which will significantly increase the number of appointments the service is able to offer.

In Reading, we sought insights and feedback from people with lived experience including autistic people, families, carers, voluntary sector organisations and professionals supporting autistic people. They were engaged in relation to topics that covered diagnosis, health, family/carer support, social experience, transport, local services, education, work, training and housing. This supported us to identify needs and better understand where change is required and has shaped our understanding of the issues autistic people and their families face across their lives. These insights have help shaped Reading's Autism Strategy.
This strategy and its implementation plans will aim to join up all relevant Reading partners to work collaboratively to break down barriers, tackle inequalities autistic people face and implement the changes we want and need to ensure better outcomes for autistic people.

[18] National Autistic Society (2020a). Left stranded: The impact of coronavirus on autistic people and their families in the UK. [online] Available at: https://pearsfoundation.org.uk/wp-content/uploads/Left-Stranded-Report-Autism-Covid-2020.pdf [Accessed Jan. 2021].

3.1 Our Local Plans and Strategies

There are three key strategies for Reading which already include the needs of autistic children, young people and adults and they people who care for them. These are explained below:

The Berkshire West Health and Wellbeing Strategy 2021-2030 has been adopted which sets out how local authorities, the Clinical Commissioning Group and partners will work together to support local people to live healthier and happier lives. The jointly agreed five priorities are:

1. Reduce the differences in health between different groups of people.
2. Support individuals at high risk of bad health outcomes to live healthy lives.
3. Help children and families in early years.
4. Promote good mental health and wellbeing for all children and young people.
5. Promote good mental health and wellbeing for all adults.

Autistic people are recognised in this strategy as being one of the groups at risk of having poorer health, including poorer mental health.

Reading Borough Council's 2021 Corporate Plan is built around three themes:

- Healthy environment
- Thriving communities
- Inclusive economy

Autistic people and their families will benefit from local commitments to make Reading a town which supports health and healthy choices, made up of communities which celebrate diversity and are aware of, understand and accept everyone, and plans to improve access to education, training and work which enhances wellbeing.

[18] National Autistic Society (2020a). Left stranded: The impact of coronavirus on autistic people and their families in the UK. [online] Available at: https://pearsfoundation.org.uk/wp-content/uploads/Left-Stranded-Report-Autism-Covid-2020.pdf [Accessed Jan. 2021].

Brighter Futures for Children (BFfC)19 leads on Reading's Special Educational Needs and Disabilities (SEND) Strategy 2022-27, delivered through seven strands:

- Strand 1: Improving communication
- Strand 2: Early intervention through to specialist provision
- Strand 3: Consistent approaches to emotional wellbeing
- Strand 4: Preparing for adulthood
- Strand 5: Support for families / short breaks
- Strand 6: Capital and School Places
- Strand 7: Funding and finance

The strategy aims to make SEND, including autism, everybody's business by embedding it in the practice of those that work with children, young people and families. The aspiration is to improve outcomes for children and young people by focusing on working together to deliver support in the right place at the right time, foster independence, and ensure their emotional, social and physical health needs are met. Additionally, to have access to universal and specialist services "to lead rich and fulfilling lives and flourish in a healthy, thriving and inclusive borough"

The Growth Approach to Autism in Reading [6]

Reading is adopting a growth approach to autism because the number of autistic children and young people is growing and both children and their families tell us that their experiences in education, and with other public services, still need to be improved. As in the Growth Approach to Autism in Reading, the shared view of autism is that:

Autism should be a difference not a deficit. We advocate for the importance of neurodiversity in our society because diversity gives strength to an organisation, to our communities, and the world we live in. Diversity results in better performance, quality of working environment, and life. Neurodiversity is important to understand and support because children and young people who are not neuro-typical have a lot to contribute and it is our job to make sure they get the opportunity to do so. This is not only because it makes their world better but because it makes our world better.

[19] BFfC are a company limited by guarantee, wholly owned by Reading Borough Council, but run by an independent Board of Directors.

4.0 National Prevalence

Autism prevalence in the UK population aged 5 years+ is 1.1% [20] [21], equating to about 700,000 children and adults. If families and carers are included, autism is part of daily life for 3.7 million people1. Autism was once considered to be an uncommon developmental disorder but recent studies have reported increased prevalence.7 Autism prevalence was found to be higher in men (2%) than women (0.3%)[likely lower than it should be due to females masking and underdiagnosis].

Several recent studies, along with anecdotal evidence, have come up with varying male/female ratios. Whatever the true ratio, clinical referrals to a specialist diagnostic centre have been reported to see a steady increase in the number of females referred. Due to the male gender bias, females are less likely to be identified as autistic. Many females are never referred for diagnosis and may be missed from the statistics. There is a growing consensus amongst practitioners and academics that the real figures for male/female ratios are broadly equal and as we learn more about how autism presents in females and clinical understanding is updated, we will see increased and earlier diagnoses. Having a diagnosis can be the starting point in providing appropriate support for autistic girls and women, including accessing a community of peers. Prevalence estimates are summarised by gender below.

Table 1: Summary of estimated National Autism prevalence

Population Group	Estimated Autism Prevalence
Adult males	2%
Adult females	0.3%
Adult males - no learning disability	1.8%
Adult females - no learning disability	0.2%
Adult males - with a learning disability	36.3%
Adult females - with a learning disability	29.9%
Boys	1.9%
Girls	0.4%
Children with special educational needs	13.9%
Children with n o special educational needs	0.1%

Estimating the Prevalence of Autism Spectrum Conditions in Adults/Mental Health of Children and Young People, 2017 [20]

[20] NHS Digital (2018). Mental Health of Children and Young People in England, 2017 [PAS]. Autism spectrum, eating and other less common disorders. - NHS Digital [online]. Available at: MHCYP 2017 Less Common Disorders.pdf (digital.nhs.uk)

[21] NHS Digital (2012). Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey.

5.0 Local Context

5.1 How the strategy was shaped

Development has been supported by a range of key stakeholders, including autistic people and their families and carers, third sector and voluntary organisations and professionals from across the Reading system (see Introduction, page 4). Engagement and coproduction (though limited in its scope by resources) took place via a mixture of interviews, workshops, surveys, forums, existing local groups, and feedback sessions. This insight was used to inform and shape the strategy, and to test emerging findings, recommendations, priorities, and vision development. We are extremely thankful to all contributors and partners, expressly to autistic people, families and carers who helped shape this strategy, welcomed us to their groups, responded to our surveys and attended workshops. This strategy was developed through two phases from November 2021 to May 2022.

Phase 1: defining the current state and needs

- Reviewing strategic documents, current level of provision and support
- Determining population health need
- Stakeholder engagement and consultation
- Development of an Autism Needs Assessment

The main aim for this phase was to understand the existing challenges and identify potential future opportunities for improvement to inform the development of the strategy.

Phase 2: Prioritisation, vision and strategy development

- Co-development of a local vision and key aspirations and production of a long list of priorities and action areas. Prioritisation process: criteria to review the priorities against to produce a shorter list e.g., for focus in the first year/few years of strategy.
- Strategy development and testing with autistic people, their families, and those who support them to ensure the strategy and focus reflected identified needs, was fit for purpose and adequately ambitious.

Phase 3: Delivery

Upon deciding how the strategy will be taken forward to ensure the best approach for best outcomes for Reading's population, the next phase of delivery will begin.

Figure 2: The Autism Strategy Development Process

Review of current strategies and need of autistic people

November - March 2022
We spoke to professionals in councils, the NHS, the voluntary sector and community organisations across Reading and autistic people, families and carers to find out what they think the needs of the population are from their experiences. We also looked at data to understand what areas we need to improve on and identify any gaps.

Long list of priorities and key actions

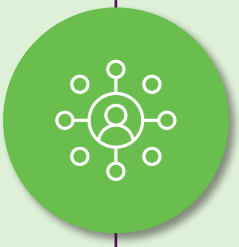
April - May 2022
The data we looked at and the conversations we had with autistic people, families, carers and professionals gave us several ideas we could consider focusing on during the next 5 years. We called this our Long List of Priorites.

Virtual and in person workshops

April - May 2022
Various groups of professionals, autistic people working together to review the long list and prioritising through asking key questions.

After a number of workshops, a short list of priorities areas are drafted.

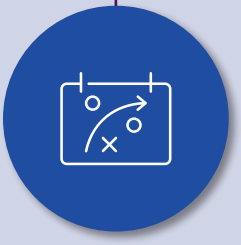
Involving the public



April - May 2022
The public have their say to help decide on which priorities and actions should be included in the final strategy.

Various ways to have a say - online survey, attending focus groups, via email, Facebook or Twitter.

The final strategy



May/June 2022
We will use everything we have heard from the public to create the final strategy.

The All Age Autism Strategy for Reading will be published.

5.2 Our Ambitions

To continue working across the system to achieve a culture shift moving towards needs-led rather than diagnosis dependent support and with a recognition of neurodiversity:

- Accessing help based on need, as early as possible, promoting acceptance of neurodiversity, strength-based approaches, and shared language.

Doing WITH rather than doing TO and enabling and celebrating strengths while fostering independence.

Strengthening understanding, recognition, and support to make life better for autistic people.

For autistic people to be proud, independent and be able to give back to society

6.0 Priorities

This All-Age Autism Strategy for Reading and identified priority areas have been informed by the All-Age Autism Needs Assessment and what autistic people and their families, carers and those working with autistic people have told us.

1. Improving awareness, understanding and acceptance of autism within society

2. Improving support and access to early years, education and supporting positive transitions and preparing for adulthood

3. Supporting more autistic people into vocational training and employment

4. Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

5. Housing and independent living

6. Keeping safe and improving support within the criminal and youth justice system

7. Improving support for families and carers

Priority 1

Improving awareness, understanding and acceptance of autism within society

Aligns with Reading's SEND Strategy :
Strand 1: Improving communication

Our Ambition

An understanding and supportive society to empower autistic children, young people and adults to live fulfilling lives while fostering culture change towards acceptance of difference which reduces barriers.

What we know nationally

The national autism strategy puts emphasis on working towards meaningfully improving public understanding and acceptance of autism, and ensuring autistic people feel less isolated/lonely and feel more included in their communities. The long-term goal is for more public sector services, businesses, and organisations to be more autism inclusive.

What we know in Reading

Ensuring that autistic people can enjoy fulfilling lives in Reading depends on improving awareness, understanding and acceptance across a wide range of services and within the local area as a whole. Children's centres, schools, youth services, GPs and other health services, and voluntary and community organisations and activities – all play their part in helping families to identify the signs of autism and access diagnosis, and with developing strategies to support autistic people and ensuring that they can access support and opportunities. Universal services also play a key role for autistic adults. Emergency services, transport providers, health services such as hospitals, leisure services and other statutory services like the Job Centre must make reasonable adjustments to ensure that autistic people can access and benefit from their services.

Within Reading's Brighter Futures for Children's Autism Advisory Service, families that receive a diagnosis of Autism for their child are supported. The Autism Advisor works with various staff and organisations to raise awareness, understanding and support autistic people and their families.

Training uptake is monitored and recorded. Specific training is provided to staff who carry out statutory assessments on how to make adjustments in their approach and communication for autistic people.

This training is available to staff in Adult Social Care, Children and Young People's Social Care, the Child and Adolescent Mental Health Service (CAMHS), and the NHS Neurodisability Team. Training and awareness delivery can take place through Family Involvements, Seminars, Staff Consultations, Home Visits, Virtual Visits and Parent Training through the Living with Autism 6-week course.

Autism training in schools varies depending on each individual school. The Reading Autism Education Trust (AET) training hub has been recently established which all schools can now access. This will ensure all schools have access to the same training to ensure consistency across Reading. Schools will be asked to embed the AET standards & competencies to help ensure a cultural of change is encourage.

Royal Berkshire Hospital has been accepted by National Autistic Society as a pilot site for Oliver McGowan Mandatory training. A training programme of Positive Behavioural Support for people with learning disability and or autism and behaviour that

Priority 1
Improving awareness, understanding and acceptance of autism within society

challenges is being rolled out to key staff in health, social care, education, support providers, the voluntary sector and family carers during 21/22.

Although various training has been developed and delivered, there is a need to address gaps and for a comprehensive multi-agency autism training plan, raising awareness and facilitating access especially for seldom heard autistic groups.

What is important to Reading people

Through our engagement with autistic people, parent carers and supporting services and professionals across Reading, key areas highlighted included:

Education

- Behaviour within schools can be misunderstood resulting in inappropriate disciplinary action.
- Training is needed for both teachers and other children on autism.
- Build upon existing training resources such as Autism Education Trust (AET)
- Differing interpretations of meeting need, understanding of autism, is still low

Social Experience

- Bullying and exclusion from social events is a common significant problem for autistic children.
- There needs to be more inclusion and training for sports clubs
- Better awareness of what autism is and environmental/sensory impact on autistic people

Employment

- Better understanding, awareness, and acceptance of autism by employers and guidelines around autism would be beneficial
- Reasonable adjustments for autistic employees need to be improved
- There can be a lack of support or employment assistance those over 25 years
- There needs to be self-esteem building to get into the workplace

Pre and Post Diagnosis Support

- Need for ongoing improved understanding and awareness of autism within the Education sector (building on the AET training available to schools)
- Some parents find it easier to advocate for their children than others.
- There needs to be more general awareness, to help break social isolation
- Some people felt that post diagnosis support is not clear and there is limited information between referral and assessment for autism.

Transport

- Training for transport staff, and better awareness of autism is key to improving services
- Autism awareness has gone up significantly, but resources have gone down significantly.
- Support to navigate information, advice and guidance on a wide range of topics
- Many autistic people are not aware of the services available to them.
- Positive feedback received for local services provided by the VCS

Priority 1
Improving awareness, understanding and acceptance of autism within society

Training

- Autism awareness raising sessions to support autistic people for: healthcare and education professionals, businesses, employers, statutory professions
- Training for social care teams about parent carer needs assessments, disability legislation and clear pathways to support parents experiencing aggression or destructive behaviour from their autistic child. Families want their concerns and the impact it has on them acknowledged, honesty, and a clear system in place to support them, drawing on best practice.
- All professionals to ensure families have the SEND guide and know about the Local Offer and parent carer needs assessments
- Criteria for Community Team for People with Learning Disabilities (CTPLD) and children's social care are updated and publicised with parents and professionals.

More training/awareness raising/refresher courses would be welcomed, with an acknowledgement that hands on experience and learning to see autistic people as "individuals and not a series of conditions" are key. Training is often much more effective when delivered/co-delivered by experts by experience.

Priority 1
Improving awareness, understanding and acceptance of autism within society

What we aim to do as a partnership

We will:

- Expand the Autism Board to improve representation (autistic adults, with lived experience of being diagnosed with autism and from diverse backgrounds, work and training providers, criminal justice diversion services, and more voluntary sector partners).
- Create opportunities for more regular and informal engagement (coffee mornings, autism forums)
- Review pathways to ensure these recognise specific needs of older autistic adults, women with autism, autistic people from ethnically diverse backgrounds.

Awareness and Training

We will:

- Develop a comprehensive multiagency training plan to ensure more public sector services, businesses, and organisations, including the private sector, become more autism inclusive within Reading and for all to be aware of safeguarding, a trauma informed approach and have a person-centred approach and understanding of need (including for staff in courts and probation services involving registered intermediaries where relevant).
- Address Employment by improving understanding and guidelines for employers, including reasonable adjustments (applying anticipatory reasonable adjustments duty - Equality Act 2010)
- Improve public understanding of autism and inclusion across Reading Borough Council and Brighter Futures for Children.
- Develop and test autism public understanding and acceptance initiative, working with autistic people, their families and the voluntary sector.
- Use multiple methods of raising awareness of existing pre and post diagnostic support provision and making it clear and easy to find, including addressing language and cultural barriers for underrepresented groups, to aid proactive identification of people awaiting assessment, crisis prevention and prevention of avoidable admissions into inpatient mental health settings, making it easier to find and engage with the appropriate support, offered throughout the life course.

Priority 2

Improving support and access to early years, education and supporting positive transitions and preparing for adulthood

Aligns with Reading's SEND Strategy
Strand 4: Preparing for adulthood &
Strand 6: Capital and School Places

Our Ambition

Schools, staff, students to have a good understanding, awareness and respect of autism and for all autistic people to have equal access to life chances.

What we know nationally

- 6 in 10 young people, and 7 in 10 parents, say that the main thing that would make school better for them is having a teacher who understands autism.
- Fewer than 5 in 10 teachers said they are confident about supporting an autistic child.
- Autistic children are twice as likely to be excluded from school.

What we know in Reading

- Many autistic young people have reported being bullied and/or isolated from their peers and struggling for schools and colleges to take this seriously. Many have reported anxiety preventing them from attending school or attending full-time.
- A joint inspection of Reading by Ofsted and the Care Quality Commission judged Reading's SEND local offer to be amongst the strengths of the partnership, identifying that families had widespread awareness of the online resource and that the local offer team were effective in following up contacts to ensure needs were met. The Local Offer team have also won a national award.
- About 2% of children in mainstream primary and secondary schools in Reading have had autism identified as a primary need, compared to a national rate of 1.44%. The average number of autistic children attending non-selective secondary schools in Reading is 19, with up to 30 attending the largest schools, and 7 autistic children attending each primary school in Reading, including up to 14 children in the largest primary schools. This proportion has increased over the last five years. Some local experts believe that schools with a good reputation for supporting autistic children may be more attractive to families, so a higher number of autistic pupils than average may attend those schools.
- Most autistic children are educated in mainstream schools. Numbers of autistic children in mainstream schools has increased over the last five years and are expected to continue to increase. Although this in part reflects that the total number of pupils in schools has also increased, autism prevalence in the under 25 population in Reading also increased from around 7 per 1,000 in 2017 to 9 per 1,000 in 2020
- Numbers of Reading EHCPs where autism is recorded as the primary need have increased and have consistently represented around 35% of all EHCPs each year; slightly higher than nationally (27% of children with EHCPs in 2017).
- 2,725 EHCPs were funded between 2017 and 2022. Reading has a higher rate of EHCPs than the national average and its statistical neighbours.
- Percentage of all children in Reading who received a permanent exclusion fell from 0.153% in 2016/17 to 0.06% in 2019/20 (15 exclusions in a school year), now in line with national averages and Reading's statistical neighbours (higher than the South-east average).

Priority 2

Improving support and access to early years, education and supporting positive transitions and preparing for adulthood

- There are currently 402 places at Reading schools with special provision. These include 301 places in dedicated special schools. Some schools support autistic children well, but this is not consistent across schools.

What is important to Reading people

Education and School life

- Ongoing improved understanding and awareness of autism within the education (building on the AET training available to schools) including applying a trauma informed approach to support.
- Some schools support autistic children well, but this is not consistent across schools.
- Insufficient support and signposting after completing school or to enter into employment
- Bullying within schools is common and can result in autistic children missing school

> 'I'm of the generation where ADHD/ASD wasn't a thing – It was just naughty children, so I never got any help', and 'depressing - I didn't enjoy it, I was always being bullied'.

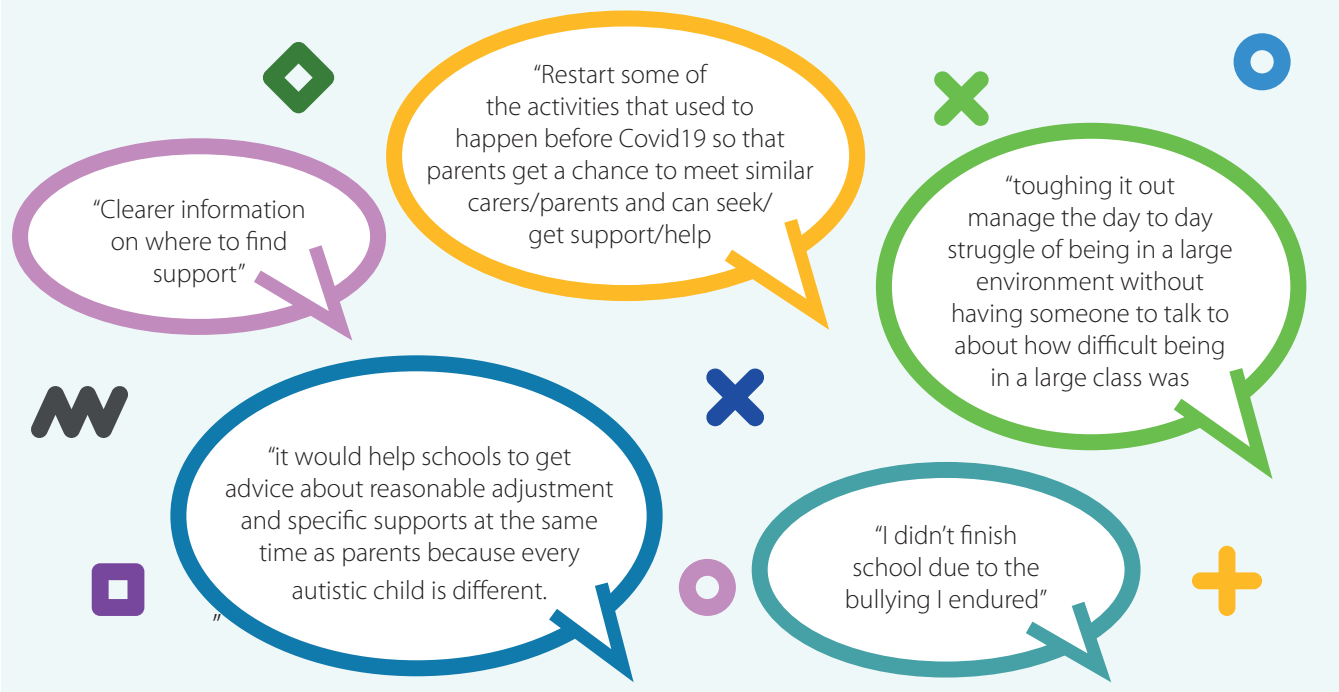
> 'My school never recognised my issues and dismissed me when I was struggling. I was told to 'stop being anxious' constantly.'

> 'My experiences at school will always have an impact on me throughout my life.'

Several autistic people shared similar experiences of "bullying" and being "pulled out of school" due to mental health, "pressure of school as well as how they were treated by some of their teachers". Instead of being offered to "tell what you can do", they were "always told instead what they cannot do", 'making finding a job harder".

Professionals expressed that "early identification and support of Education and Health Care Plan (EHCP) in place before entry to school would support children to thrive".

- Statutory services such as "teachers, social services, medics, counsellors, the police" and Employers… "all need to learn about autism without intellectual disability"
- "Mental health support needs urgent attention" for autistic people.
- "More financial support for disabled autistic people"
- Parent carers reported 'access to special needs school can be improved' and 'need universally accessible public services (starting with a suitable education for my child), and professionals who discharge their statutory duties according to the law.



Priority 2B
Supporting Transition and Preparation for Adulthood

Aligns with Reading's SEND Strategy -
Strand 4: Preparing for adulthood &
Strand 6: Capital and School Places

What we know nationally

Guidance and best practice

NICE guidance on transition from children's to adult services covers the period before, during and after a young person moves from children's to adults' health or social care services, and how this transition should be managed and services work together to support a good transition. The guidance recommends that transitions should take place not by a rigid age threshold, but at a time of relative stability for the young person. This is also supported by the NHS Long Term Plan that commits to offering person centred and age-appropriate care for health needs, rather than basing transitions solely upon age.

Supporting smooth transition to adult services for young people going through the diagnostic pathway and ensuring data collection and audit of the pathway takes place (CG128)7 is a key guideline.

Transition to adult services (dependent on individual need)

- Provide information about adult services to the young person and their parents/carers, including their right to a social care assessment at 18 years of age
- Involve the young person in discussing and planning
- Train staff in autism awareness and skills in managing autism including the importance of key transition points, such as changing schools or health or social care services
- For those who are 16 years and older with complex and severe needs, a care programme approach (CPA) is recommended as an aid to transfer between services

Priority 2B
Supporting Transition and Preparation for Adulthood

What we know in Reading

Moving on to further education, training or work is an important time for autistic young people. While there are several options available in Reading, person-centred support is important to help autistic young people to find the right opportunity. More internships, apprenticeships and meaningful work experience for young people would enhance prospects for autistic people. Within Reading, Children's Transitions to Adult Social Care services is outlined in the Preparing for Adulthood Policy (2019) which aims to ensure that young people and adults have appropriate support as they move into adulthood, and there are no gaps in the delivery of services. The strategy complements the Preparing for Adult Pathway. The Preparing for Adulthood Panel has responsibility for co-ordinating identification and monitoring of the children and young people who may or will require services as they transition into adulthood. Reading Mencap provide the Preparing for Adulthood service funded by Reading Borough Council that support young people and adults (16-25) and their families in preparing for adulthood. A Transitions Family Adviser offers an independent, outreach, information, advice and support service to guide young people and their families through the complexities of becoming an adult, to manage the changes in social care, benefits, housing, health, education, employment and financial management.

As of February 2022:

37%

of young people open to Preparing for Adulthood (PFA) have a **primary or secondary diagnosis of Autism**

33%

of young people open to Preparing for Adulthood (PFA) have **a diagnosis of a learning disability and Autism**

Youth Offending Service (YOS)

Young people transitioning from YOS will involve Adult Probation Services from age 17. Dependent on needs, the transfer may occur at age 18 but could be later.

Healthcare transitions

Within Berkshire Healthcare Children, Young People and Family Services, for young people with long term health conditions, transitions should begin at the age of 14, with the transition usually occurring between the ages of 16 and 19. The child or young person and their families should receive the following to support with their transition to adult care services[23]:

- A named transition co-ordinator
- Received information on the adult service(s) they're transitioning to
- Completed a transition health care plan and received a discharge summary.

[23] Berkshire Healthcare NHS Foundation Trust (2022). Transition to Adult Services | Children Young People and Families Online Resource. Children Young People and Families Online Resource. Available at: https://www.berkshirehealthcare.nhs.uk/5940.

Priority 2B
Supporting Transition and Preparation for Adulthood

What we aim to do as a partnership

Culture change

We will:

- Tackle bullying within schools, and inappropriate exclusions.
- As well as awareness raising in schools, we will implement additional measures to including zero tolerance policies for bullying, autistic champions in schools, and regular whole school and class discussions.
- Increase Autism support in schools including access to support from Occupational Therapist/Speech and language therapists
- Ensure schools are reminded of the support available that they share with parents (resources shared to use inclusive language)
- Ensure person-centred support is in place to help autistic young people to find the right opportunity.

Transitions & Diagnosis

We will:

- Strongly encourage schools to share information they receive about local support and activities – need to ensure this information is shared with all children/families with additional needs.
- Ensure school transport is appropriate for autistic children through training for drivers and escorts to know the needs of the autistic children and how best to communicate with them, to provide better assistance. We will liaise with relevant Transport teams to achieve this.
- Support autistic children and young people to ensure better outcomes throughout their education by schools making reasonable adjustments and a commitment to address bullying towards autistic children.
- Increase support and signposting after completing school e.g., to enter employment (more choice, employment opportunities, work experience etc).
- Put in place effective planning for adulthood including social care after turning 18 and when finishing school/college if later.
- Improve transitions planning for all (education/social care/health) children and adult services – more work needs to be done so Young People and family are provided with robust information to support.
- Support people into adulthood through volunteering opportunities
- Create additional internships, apprenticeships and meaningful work experience for young people which enhance prospects for autistic people.
- Support smooth transition to adult services for young people
- Ensure data collection and audit of the diagnosis pathway takes place

Priority 3
Supporting more autistic people into vocational training and employment

Aligns with the Joint Health & Wellbeing Strategy:
Priority 1: Reduce the differences in health between different groups of people

Our Ambition

Through understanding, awareness and acceptance of autism, autistic people can become integrated as part of society and gain employment and confidence. Including maximising life chances and opportunities and empowering autistic people to meet their potential.

What we know nationally

Training and Employment

- The National Autism Strategy, Equality Act 2010, Care Act 2014, Care and Families Act 2014 and the NHS Long Term Plan 2019 emphasise the importance of facilitating access to education, training and employment opportunities and sustained support, including skills development to empower people to independence wherever possible.
- Approximately 10-15% of autistic adults nationally are in full-time employment and overall, 22% of autistic adults (16-64 years) are in employment (any form).
- Disabled people with autism (21.7%) were among those disabled people with the lowest employment rate and compared to 81% of non-disabled people, showing a significant employment gap for autistic people.

What we know in Reading

- Barriers for autistic adults wanting to be in employment include absence of effective transition from education; absence of reasonable adjustments at interview and in workplaces; unsuitable HR practices and recruitment methods; lack of employer awareness and difficulties accessing support to get into work or when in work.
- Positive changes are recognised in improved access to services, but further work is required.
- There are limited employment support options available for people over 25 years
- The gap between training and employment support needs bridging
- Remove the current cliff edge when young people enter employment after 18+
- Support provision for late diagnosis for people already in employment is needed
- Employers need organisations to go to for support and training

What is important to Reading people

Training and Employment

- Many autistic people want to work, are able to and would value support and awareness of pathways and available opportunities for employment.
- Improved understanding, acceptance, and guidelines for employers around autism, including reasonable adjustments and support for autistic young people to enter the workplace
- Improved support and employment assistance for those over 25.

[23] Berkshire Healthcare NHS Foundation Trust (2022). Transition to Adult Services | Children Young People and Families Online Resource. Children Young People and Families Online Resource. Available at: https://www.berkshirehealthcare.nhs.uk/5940.

Priority 3
Supporting more autistic people into vocational training and employment

What we aim to do as a partnership

Work, volunteering and training

We will:

- Increase volunteering opportunities
- Identify the strengths and needs of neurodivergent children and young people and adults and support them to make good progress and have good outcomes
- Improve options for young people to increase current opportunities
- Develop a clear pathway through school, from school, in further and higher education and into vocational training and work opportunities
- Further develop and promote Elevate Project for autistic young adults
- We will enable and address specific needs of autistic adults through Reading's Economic Covid Recovery Plan
- Establish peer mentorship/championship training
- Increase understanding of barriers faced with the benefits system and support to overcome these
- Support autistic people to get into employment and offer support during employment
- Work with partners and local employers to increase employment opportunities and job support for all autistic adults of working age
- Improve understanding and guidelines for employers, including reasonable adjustments both during recruitment and in employment.
- Improve support and employment assistance for those over 25
- Support autistic young people to enter the workplace
- Organisational members of the Autism Board will seek and promote their recognition as employers of people with disabilities, leading by example when approaching commercial/ industry partners

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Aligns with the Joint Health & Wellbeing Strategy:
Priority 1: Reduce the differences in health between different groups of people
Priority 2: Support individuals at high risk of bad health outcomes to live healthy lives.
Priority 3: Help children and families in early years.
Priority 4: Promote good mental health and wellbeing for all children and young people.
Priority 5: Promote good mental health and wellbeing for all adults.

Aligns with Reading's SEND Strategy:
Strand 2: Early intervention through to specialist provision
Strand 3: Consistent approaches to emotional wellbeing

Our Ambition

Strengthening understanding, recognition, and support to tackle health inequalities experienced by autistic people and to make life and health outcomes better for them. We will continue working across the system to achieve a culture shift moving towards needs-led rather than diagnosis dependent support and with a recognition of neurodiversity. We will have demonstrated improvements in reducing assessment and diagnosis times and support to ensure help is accessed based on need, as early as possible, promoting acceptance of neurodiversity, strength-based approaches, and shared language.

What we know nationally

Autism inequalities and barriers to support

- Inequalities experienced by autistic people include reduced access to public services and spaces, the gap in employment opportunities, poorer health outcomes, increased likelihood to report lower quality of life and social isolation.
- Contributory factors to inequalities in health include challenging communication in inaccessible environments, reduced likelihood to understand signs of poor-health, barriers to NHS service access when needed, uncertainty which brings on anxiety, sensory variances, different responses to pain and difficulty identifying own emotions.
- Early identification, improvements in diagnostic pathways for all ages and reductions in assessment waiting times are key to timely diagnosis and appropriate access to support. This enables autistic people and those supporting them to better understand their needs.
- Many children are diagnosed late; girls are particularly affected as signs of autism are frequently not recognised, resulting in delays in diagnosis until adolescence or adulthood.
- While the diagnosis of adult autism has improved over the years, in Reading adults have to wait years for a diagnosis rather than the National Institute for Health and Care Excellence (NICE) recommended 13 weeks between referral and first assessment.
- There is a gender gap in the prevalence of autism, with higher prevalence reported in males than females which may result from underdiagnosis of autism in females.
- Autistic people have a lower life expectancy (16-year gap) and are more likely to require hospital care or use emergency services than non-autistic people.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- Improving health and care staff's understanding of autism is crucial in enabling progress on reducing health inequalities for autistic people.
- It is suspected that 'detection bias' relating to socioeconomic status means diagnosis may be less likely in children from lower socioeconomic status households and with parents with lower educational attainment levels.
- Racial, ethnic, and socioeconomic disparities associated with autism exist throughout many service areas including access to early assessment, diagnosis, and therapeutic interventions.
- To tackle the health and care inequalities autistic people face, the government passed the Health and Care Act 2022, which included the Oliver McGowan Mandatory Training in Learning Disability and Autism, which will educate and train health and social care staff, at the right level for their role, to provide better health and social care outcomes for people with a learning disability and autistic people.

What we know in Reading

Diagnosis

- In Reading we have implemented a Needs-led, rather than Diagnosis Led approach so that support in schools can be put in place before diagnosis.
- The Berkshire Healthcare NHS Foundation Trust (BHFT) Autism Assessment team based at University of Reading are responsible for diagnosis of children and young people under 17 and a half years. Unfortunately, due to strong demand, the waiting times are over 2 years, well in excess of the 13 weeks NICE guidelines
- Nationally £13 million is being invested in reducing waiting times for all, and Berkshire West CCG has received extra funding to recruit more staff to be able to offer more assessment to children and young people to reduce waiting times for assessment.
- The Neuropsychology ASD Team from BHFT based in Erleigh Road, are responsible for adult diagnosis. Unfortunately, due to strong demand, the waiting times for an adult diagnosis are approximately 4 years, well in excess of the 13 weeks NICE guidelines.
- In Berkshire autism assessment referrals for children and young people, increased from 1209 in 2016/17 to 2045 in 2021/22, a 69% increase. More resources have been commissioned, including a private online provider to reduce waiting times but these have remained stubbornly high.
- For the adults diagnostic pathway, there has been an increase in the number of people referred for a diagnosis but, there has been no increase in resources resulting in increasing waiting times.
- Due to the long waits, Berkshire West CCG commissioned the Pre and Post Autism and ADHD Service for 0 to 25 in 2019. The service was co-produced with partners from health, education and social care plus Reading Families Forum and the voluntary sector. Autism Berkshire, with Parenting Special Children won the tender and started delivery in 2020.
- The new Berkshire West CCG NHS Autism and ADHD Support service has been very successful. In 2021 Autism Berkshire supported over 500 families, with evidenced based graduated support from Helpline calls, one to one consultations, short courses and long courses. The Teen Life course for parents of young people from year 6 to 11 has proved to be particularly popular with parents as previously there was little support aimed at parents of teenagers.
- Half of the families supported by Autism Berkshire are on the waiting list and 40% of the children and young people supported are girls.
- For families of children who receive a diagnosis, support is available from Reading's Brighter Futures for Children Autism Advisor. The service is not available to families on the waiting list.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- The BHFT Autism Assessment Team (AAT) send referral packs providing information on all sources of family support to parents, once a child is added to the waiting list for assessment, to ensure families access this as soon as possible including provision of a letter for school to emphasise need for needs–led support. This includes information about the Berkshire West Autism and ADHD Support Service provided by Autism Berkshire. There are Comprehensive online resource provision with help and advice on a wide range of developmental, emotional/mental health concerns.[24]
- BHFT AAT also run the SHARoN online support network (Support, Hope and Resources online Network) for parents of children and young people waiting for an assessment, or with a diagnosis. The service is moderated by professionals, including the voluntary sector and available online 24 hours a day to parents.
- BHFT deliver co-produced training courses such as the Psychological Perspectives in Education and Primary care (PPEPcare) which is commissioned by the CCG for delivery to health, education, social care and other agencies which equips settings to provide needs-led support.
- Many parents and adults are frustrated by the long waits and seek a private diagnosis.
- Through the engagement process for this strategy, we found that some parents who were waiting for an assessment or who had received an autism diagnosis for their child, were not aware of the Berkshire West CCG NHS Autism and ADHD Support Service, nor the Local Offer and Family Information Service.

Post Diagnostic support

- The BHFT Autism Assessment Team offer a diagnosis only service.
- Post diagnosis support is available from the Berkshire West CCG NHS Autism and ADHD Support Service provided by Autism Berkshire, a local charity set up in 1990 by families of autistic children and those with challenging behaviour. All staff have lived experience and professional training and qualifications in family support and autism. Research has shown that the most effective support for families is peer led support such as the Autism Berkshire service.
- Currently there is no Positive Behaviour Team to support parents whose autistic children have violent and challenging behaviour. It has been agreed this is a gap in services, and the local NHS commissioners, Berkshire West CCG had run a commissioning process in Spring 2022, but not awarded a contract.
- For adults the Neuropsychology ASD Team from Berkshire Health NHS Foundation Trust runs a post-diagnosis course 'Being Me' to help newly diagnosed adults understand autism and how it impacts their life.
- Reading Mencap run an Information and Advice Service which includes support around health and how to access the Annual Health Check for people aged 14 and older with a Learning Disability and those with Autism and a Learning Disability.
- BHFT run the Community Team for Learning Disability (CTPLD), many adults referred to them have autism as well as a learning disability. The team includes nurses, OTs, Physio, Psychiatrists, Psychologists Dieticians, Speech and language therapists. They work in partnership with social workers to make sure people with a Learning Disability and Autism get the best support possible.

Physical and mental healthcare

- The Royal Berkshire Hospital employs two Learning Disability nurses who are highly trained in autism and are available to anyone who has a Learning Disability or Autism and is visiting the hospital as an outpatient or staying as an inpatient.
- Following feedback from people with a Learning Disability and Autism, and their parents and carers, the Royal Berkshire Hospital implemented a Bleep system to reduce the stress of waiting for outpatient appointments.[25]

[25] Your information and what we use it for (royalberkshire.nhs.uk) this should say Use the Bleep

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- The Royal Berkshire Hospital also has a series of Easy Read leaflet for patients with Learning Disability and Autism available on their website.[26]
- Many of Reading's GP have included details of the Berkshire West Autism and ADHD Support Service on their website under the Wellbeing section.[27]
- Berkshire West has a Learning Disability Mortality Review, LeDeR Steering Group, which carries out a number of projects, including collating and sharing anonymised information about the deaths of people with learning disabilities, including those with LD and autism so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements, to try to reduce the early mortality of people with a Learning Disability and those with Autism with Learning disability .
- A training programme of Positive Behavioural Support for people with learning disability and or autism and behaviour that challenges is being rolled out to key staff in health, social care, education, support providers, the voluntary sector and family carers during 21/22.
- BHFT is implementing a Neurodiversity strategy to make all BHFT services, everything from health visiting and school nursing to Integrated Pain and Spinal Management and continence service, accessible for people with a learning disability and/ or autism.[28]

What is important to Reading people

- Better awareness of what autism is and the environmental/sensory impact on autistic people within healthcare settings.
- Waiting times for assessment for children, young people and adults are too long and need to be reduced.
- Waiting times for children and young people who have anxiety and are out of school are too long and need to be reduced.
- Access to appropriate mental health services that understand autism and can make reasonable adjustments need to be improved and a priority.
- Specialist support and pathways needed to address complex health concerns
- Training for hospital staff and GPs about autism, mental health and in responding to autistic adults and children including what other support services are available in the community.
- Having continuity of care from their GP.
- Implementing reasonable adjustments for health appointments including vaccinations is important.

What we will to do as a partnership

- Continue to work to reduce waiting times for assessment for children and young people. The project will continue to be monitored by the BHFT board.
- In order to tackle morbidity and preventable death in individuals with autism it is of utmost importance to provide regular physical health checks and to maintain high level of clinical suspicion towards physical health problems in autism.[29]
- Raise the long waiting times for adult assessments in order to increase resources to bring the waiting times down.
- Raise the lack of a Positive Behaviour Service in order to get the service commissioned.

[26] Disabled Patients | Royal Berkshire NHS Foundation Trust contains a list of Easy Read leaflets for LDA patients
[27] Autism | Balmore Park Surgery
[28] Our Neurodiversity Strategy | Berkshire Healthcare NHS Foundation Trust
[29] Sala et al (2020)

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- All organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West CCG NHS Autism and ADHD support service, as some parents, although sent a referral pack by the AAT, report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- All health and care organisations shall comply with their statutory duty under the Health and Care Act 2022 to ensure that all staff complete their Oliver McGowan Mandatory training in Learning Disability and Autism, so staff feel confident in supporting the individual needs of children, young people and adults with a learning disability and/ or autism.
- We will focus on ensuring there are no barriers to accessing health services for people with a learning disability and/or autism, including access to age 14+ Annual Health Checks for those with autism and Learning Disability. The care they receive will be provided in a suitable environment, by people who understand their needs, with suitable adjustments made when needed for them to receive excellent care.
- Through RBC commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation to prevent help prevent mental ill health in people with learning disability and/or autism

Building the Right Support in the Community and Supporting People in Inpatient Care

Our Ambition

For community support and services to reflect what autistic people and their families say they need.

What we know nationally

Play-based strategies to increase joint attention, engagement and communication including and group based social learning programmes focused on improving social interaction, or individual delivered for people who find groups difficult are encouraged[30] Interventions focused on life skills/activities of daily living e.g., leisure activity programme are also recommended.

Transport

- The National Autism Strategy highlights transport as a key enabler in helping autistic people become active members of society, through access to employment, leisure, and community activities.
- Many autistic people favour driving, walking and cycling as alternatives to using public transport which can sometimes be noisy, crowded and an uncomfortable experience.

Inpatient health settings

- Autism prevalence within adult inpatient mental health settings autism prevalence is estimated to be 2.4-9.9% [31] while autistic people account for 1 in 100 people.

[30] https://www.nice.org.uk/guidance/cg170
[31] Tromans S, Chester V, Kiani R, Alexander R, Brugha T. (2018) The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review. Clin Pract Epidemiol Ment Health. 14:177-187.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

What we know in Reading

Support groups

There are groups that support autistic children, young people and adults through social and leisure activities, or by helping autistic people to access education and employment. Some services providing support to autistic people in Reading expressed their experience of some services relying on a crisis response for people of all ages. However, CAMHS, Anxiety and depression as well as the MHSTs, offer counselling and other support for autistic people. Quality support around education, health (mental health) and social care have an important role. They emphasise the need for timely, accessible support.

Transport

- The Reading Transport Strategy 2036 outlines some actions that can be applied to an 'autism-inclusive' approach for this autism strategy.
- Reading Buses have worked closely with local charities such as Autism Berkshire, to implement a driver training course for staff learn about the needs of autistic people.
- BFfC offer School Transport contracts to companies that have applied to go on the framework and trained escorts are provided as required.
- Readibus is the specialist service used for School Transport, mostly for wheelchair users but provide 6 buses for the Avenue School – and an ambulance for the most complex needs pupils.
- There are 23 companies in Reading operating routes on the School Transport scheme.
- Around 540 pupils are on the School Transport scheme. Those who are autistic is unknown.

What is important to Reading people

Local (community) services

- Need a range of activities covering the full spectrum including those without significant support needs who live more independently.

Transport

- School transport is not always appropriate for autistic children
- Suggestions on what needs to be done to improve on the experience of using transport services, included:
  - "better cycling integration"
  - "temporary blue badge scheme"
  - "joined up national transport strategy"
  - "additional support of getting driving licence for people with anxiety and sensory difficulties"

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Social Experience

- There is a limited range of activities for autistic children, young people and adults.
- Many of the activities that are for young people are very good but limited and often they reach capacity very quickly e.g., Make Sense Theatre, Chance to dance.
- Young people have expressed they're not interested in competitive activities that require performing - saying they want to spend time with other autistic children.
- Activities like Holiday Clubs are difficult to access due to "not enough support personnel available". Families where both parents are working find the situation "hard".

A gap in provision was identified for autistic adults who have received a late diagnosis "and who have different support needs to those who have grown up knowing why they are different" or who are "without learning disabilities". Local services for autistic adults who have "worked" or "lived independently" are reported "non-existent".

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

What we will to do as a partnership

Tackling health and care inequalities for autistic people

We will:

- Continue to work to reduce waiting times for assessment for children and young people. The project will continue to be monitored by the Berkshire Health Foundation Trust Board.
- In order to tackle morbidity and preventable death in individuals with autism, we will provide regular physical health checks and to maintain high level of clinical suspicion towards physical health problems in autism.
- Work at addressing issues related to adult assessments in order to bring the waiting times down.
- Work towards addressing the lack of a Positive Behaviour Service in order to get the service commissioned
- All organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West Clinical Commissioning Group NHS Autism and ADHD support service, as some parents, although sent a referral pack by the Autism Assessment Team (AAT), report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- All health and care organisations shall comply with their statutory duty under the Health and Care Act 2022 to ensure that all staff complete their Oliver McGowan Mandatory training in Learning Disability and Autism, so staff feel confident in supporting the individual needs of children, young people and adults with a learning disability and/ or autism.
- Focus on ensuring there are no barriers to accessing health services for people with a learning disability and/or autism, including access to age 14+ Annual Health Checks for those with autism and Learning Disability. The care they receive will be provided in a suitable environment, by people who understand their needs with suitable adjustments made when needed for them to receive excellent care.
- Through RBC commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation to prevent help prevent mental ill health in people with learning disability and/or autism

Building the right support in the community and supporting people in inpatient care

Support groups, services & Training

We will:

- Make available activities (across all ages), increasing social opportunities and social enterprise projects run by local people with lived experience.
- Provide training to adapt holiday clubs to be more inclusive and suit the needs of the autistic person
- Look at funding streams for the Autism Advisory Service to employ additional Autism Advisors.
- Encourage cafes/shops to clearly indicate to their customers that they can support people who are neurodivergent and how they should let their staff know that adjustments are required.
- Implement a Zero tolerance for bullying and prevent inappropriate exclusion from social events
- Create groups for adults especially social clubs for diverse interests in spaces appropriate for autistic people due to noise and sensory stimulation (i.e. light, noise, volume of music)
- Make provision for autistic adults who received a late diagnosis and have different support needs to those who have Ωhad earlier diagnosis or who are without learning disabilities – an identified gap.
- Support local services for autistic adults who have "worked" or "lived independently."

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Local Services

We will:

- Provide a range of activities covering the full spectrum including for autistic people with less complex needs, as most autistic people need contact with peers, access to one-to-one support and/or local clubs.
- Make needed adjustments for everyday services to increase accessibility to autistic people.
- Invest into activities and services adapted/adjusted to meet the needs of autistic people and to minimise sensory impact.

Transport

We will:

- Provide training for bus drivers, taxi drivers and escorts to know the needs of the autistic person and are trained in how to best to meet these needs and communicate with them.
- Provide additional support of getting driving licence for people with anxiety and sensory difficulties

Health

We will:

- Take action to tackle the over representation of autistic young people in mental health beds.
- Use Root Cause Analysis as part of the CTR/CETR process to address the expected high prevalence of autistic adults in inpatient mental health settings.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

What we will to do as a partnership

Tackling health and care inequalities for autistic people

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Building the right support in the community and supporting people in inpatient care

Support groups, services & Training

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- Support local services for autistic adults who have "worked" or "lived independently."

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

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- Activities like Holiday Clubs are difficult to access due to "not enough support personnel available". Families where both parents are working find the situation "hard".

A gap in provision was identified for autistic adults who have received a late diagnosis "and who have different support needs to those who have grown up knowing why they are different" or who are "without learning disabilities". Local services for autistic adults who have "worked" or "lived independently" are reported "non-existent".

Priority 5
Housing and independent living

Our Ambition

A culture that promotes neurodiversity and creates environments that meet the needs of autistic people and empowers everyone to reach their potential. Environmental respect, integrating rather than segregating and improving autistic lives in Reading.

What we know nationally

The National Strategy for Autistic Adults, Young People and Children: 2021-2026 prioritises housing as an area for improvement, to be achieved through activities including:

- Support for keyworkers for children and young people with complex needs in inpatient mental health settings, and those at risk of being admitted to these settings.
- Increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose.
- 10% of the homes built via the new Affordable Homes Programme will be supported housing by 2026.
- Work with the National Body for Home Improvement Agencies to offer support to local authority DFG teams and work with autism charities to raise autistic people's awareness of how the DFG can support autistic people.

There is no one size fits all solution for housing for autistic people. This should be based on individual needs[32]. In an absence of a needs-led approach and appropriate support, autistic people may be faced with specific difficulties, and a higher risk of homelessness. Lessening barriers within the housing sector is of utmost importance to improve independence, wellbeing and quality of life.

NHS England's 'Building the right home' emphasises that alongside physical adaptations within homes, geographical considerations should be made, particularly where there are sensory needs, e.g., housing away from noisy streets, bright lights and considering triggers which could exist in the surrounding area[32]. Needs of the autistic person that may be linked to the proximity of established sources of support.

What we know in Reading

Locally, the number of autistic people that live within social housing is unknown, as it is not routinely monitored within the housing allocation and sign-up process. There is no specific pathway for autistic people within the housing system, rather, individual needs are considered throughout the process and support referrals made or adaptations may be made to homes. Considerations such as whether it is suitable for children to share bedrooms and space allocated accordingly, may be one such consideration. The Disabled Facilities Grant (DFG) is available for Homeowners, Private Tenants or Housing Association Tenants for adaptations to the home with the aim of making adaptations to live more independently. Within Reading, the DFG has been utilised to make adaptations for autistic people.

The homelessness service reports low numbers of autistic people presenting in need to the service, however, some individuals are placed in emergency accommodation such as bed and breakfasts due to lack of alternative temporary accommodation. This accommodation is often unsuitable for autistic people's needs and can result in disruptive behaviour and exacerbate vulnerabilities.

[32] NHS England, LGA and ADASS (2016). Building the right home: Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display behaviour that challenges. Available at: NHS England report template cobranded-supporting partners

Priority 5
Housing and independent living

- Housing services within RBC do not have access to support in relation to autistic people that approach for homelessness assistance that don't meet the criteria for adult social care.
- Lack of emergency housing options within adult social care and not meeting social care thresholds, may result in autistic people being placed in inappropriate accommodation unsuitable for needs.
- General needs accommodation is not always suitable for all autistic people due to the responsibilities that come with managing a tenancy, there are risks that the pressure of living independently can lead to chaotic lifestyles potentially resulting in rent arrears, eviction and homelessness.
- Training for front-line housing staff is needed to better understand autistic people's needs.
- Clarity is needed on where autism sits within the adult social care and housing pathways
- Adult social care delivering safe accommodation options that are available for those with specific needs through a safe, easily accessible emergency account would be highly beneficial.

What is important to Reading people

Families and young people tell us that it is difficult to find information about what options are available and to obtain reliable support for a young person and adult in accommodation away from their family carers. Many parent carers provide an enormous amount of support to keep their autistic adult healthy and safe, sometimes at a cost to their physical and emotional health.

We asked autistic people and their families what is important to them about housing and what good housing should look like. Some of the responses are detailed below:

- The importance of feeling safe within their home - 'I don't want to move out of my parent's house, I like being there. I feel comfortable'.
- Maintaining their environment - 'I like everything to stay the same and I don't want to move.'
- An ideal home was described as being "tidy", with a "garden, lots of rooms and no noise from neighbours", in a "quiet and safe area" with "easy access to shops (with small wheelchair access) and green spaces" or "basic necessities". The home would be in easy reach of support such as 'housing officer', 'parents.' "On a main bus route" for regular bus schedules.
- For someone who needs "help with household chores", "supported living would be ideal" or "moving to a retirement place early".

Priority 5
Housing and independent living

What we will to do as a partnership

Accommodation

We will:

- Improve data to help inform future commissioning of adapted / specialist housing.
- Support autistic adults to access suitable accommodation
- Include housing-related staff and providers in autism training plans
- Address the specific needs of autistic adults in future housing and homelessness strategies
- Make better use of existing specialist housing
- Ensure there is clearer identification by Brighter Futures for Children of the requirements for children within their current homes so that adaptations may be considered.

Independent Living

We will:

- Improve transitions planning to support independent living
- Implement needs led housing provision for autistic people
- Develop a clear shared strategy for provision of supported accommodation for autistic adults
- Plan to increase investment in aids, adaptations and new technologies which support independent living.
- Develop innovative models of accommodation with agile care and support options including reablement.

Training

We will:

- Increase the number of trained support workers to run activities in the community

Priority 6
Keeping safe and improving support within the criminal and youth justice system

Our Ambition

Greater awareness of the impact of autism on risk and need for autistic people involved with the Criminal Justice System (CJS).

What we know nationally

There is evidence that autistic people often have challenging, poor experiences when they encounter the CJS. Reasons cited include a lack of awareness, confidence and understanding amongst CJS staff and challenges surrounding adjustments required for autistic people to engage in processes.[33] It is the responsibility of local authorities under the Care Act, to assess all resident's needs, inclusive of those in prisons and ensuring that adequate support systems are in place for them. The National Autistic Society states that autistic people are more likely to be witnesses and victims of crime than offenders.

Certain features of autism may predispose young people to offend or be victims of crime, including social naivety, misinterpretation of social cues and poor empathy. Most evidence indicates overrepresentation of autistic people within the CJS, in particular the publication Nobody made the connection: The prevalence of neurodisability in young people who offend by the Children's Commissioner, identified a study which reported the prevalence of autism within youth custody, and suggested an incidence rate of 15% compared to the estimated 0.6 to 1.2% of autism diagnosis in the general population.

What we know in Reading

- Reading has a Police Station, but the custody suite is located at Loddon Valley Police Station. Reading has a Magistrates and Crown Courts and a Probation office, but no prisons or Young Offenders Institutes.
- The CJS is not required to record autism as a condition. Where data was available, a limited analysis of the prevalence of autistic people in Reading was possible.
- Where a person has an autism diagnosis, there are challenges within the different information systems used by Police, Courts, Prison and Probation to transfer the information appropriately.
- In Reading we have the Liaison & Diversion (L&D) service based at Reading courts and at custody at Loddon Valley, that aims to identify people when they first encounter the CJS if arrested or charge, who may need additional support due to mental health, disability, substance misuse or other vulnerability. The service can assess needs, inform criminal justice decision-making and aid in people accessing the appropriate health and social care support as they move through the CJS, and enable people to be diverted away from the CJS into a more appropriate setting, if required.
- Health partners highlighted a lack of appropriate provision within the community post secure system, although the Ministry of Justice is undertaking a tender process in Spring 2022 for an autism support service.
- Families are advised by both Children's Social Care and CAMHS to contact the Police if their autistic child or young person are aggressive to them and they do not feel safe. However, parents have not wanted to call the Police, and when they have done some parents have reported it has not been helpful.
- Currently there is no Positive Behaviour Team to support parents whose autistic children have violent and challenging behaviour. It has been agreed this is a gap in services, and the local NHS commissioners, Berkshire West CCG had run a commissioning process in Spring 2022, but not awarded a contract.
- Reading has a multi-agency partnership to improve outcomes for children, the One Reading partnership includes

[33] S.B. Helverschou, K. Steindal, J.A. Nøttestad, P. Howlin. Personal experiences of the Criminal Justice System by individuals with autism spectrum disorders.Autism, 22 (4) (2018), pp. 460-468, 10.1177/1362361316685554

Thames Valley Police, Reading Borough Council, Brighter Futures for Children, Royal Berkshire NHS Foundation Trust, and Reading Voluntary Action. They have produced the One Reading Young People and Extra Familial Harm Strategy 2021/22 to 23/24 which sets out how the partnership will work together across agencies and with young people and communities to prevent and respond to extra familial harm and keep young people safe in their communities.

- Autism Berkshire launched the Berkshire Autism Alert card in 2010 as a quick and easy way for someone to identify that they were autistic, and over 2000 cards were issued. In 2020, the scheme was updated to include a new online application process and the ability to share information with Thames Valley Police if the individual wished to. In 2021, the card was updated to the Thames Valley Autism Alert card to cover Buckinghamshire, Oxfordshire and Milton Keynes as well as Berkshire, and there are now more than 700 of the new cards in circulation including 200 issued to Reading residents during the 2021-22 financial year. Autism Berkshire has a data sharing agreement with Thames Valley Police and is supported by the Thames Valley Police and Crime Commissioner.

What is important to Reading people

- To prevent offending and support rehabilitation and inappropriate involvement with the CJS, early identification and support to prevent entry into the CJS is vital.
- Ongoing use of and awareness raising of the Thames Valley Autism Alert Cards to appropriate services is encouraged.
- It is acknowledged that within the CJS the system is improving surrounding autism, as there is greater recognition, less stigma and better access to care, compared to some years ago.

Case Study 1:

Youth Criminal Justice Liaison and Diversion Service, Assistant Psychologist

Reason for Referral

Jay was referred to the Berkshire Healthcare NHS Foundation Trust's Youth Criminal Justice Liaison and Diversion Service (YCJL&D) by a Forensic Paramedic who saw him in custody when he was arrested for being concerned in the supply of Class A drugs. He was 'Released Under Investigation' for this matter.

The YCJL&D service completed an assessment with Jay and his mother at the family home. The assessment indicated that Jay experienced difficulties with low mood and substance misuse. He was not engaged in Education or Training (NEET) and was not participating in any regular enjoyable activities. In addition, his mother was very open about experiencing low mood herself, chronic pain and the family were experiencing financial strain. Jay's Mother was not in receipt of Personal Independence Payments (PIP) or Employment Support Allowance (ESA). Jay was not in receipt of Carers Allowance, despite providing a significant caring role for his mother. Due to a mistake made by the Housing Association, the family were left with limited means to purchase food. Jay enjoyed football and was motivated to engage in education or training. Jay and his mother benefit from a close relationship and she demonstrated a sensitive understanding of his needs.

The YCJL&D service supported Jay's mother to complete a self-referral for Talking Therapies. Over coming weeks, the YCJL&D Assistant Psychologist (AP) completed referrals to the Specialist Mental Health Team and 'Source', which is the youth Drug and Alcohol Service provide by the local Council. Also, a referral was made for Jay to attend an Education Provision within a local sports club. Support was additionally given to assist Jay's Mother to apply for PIP and ESA. Whilst Jay's Mother was awaiting an appointment for a PIP face-to-face interview, we referred the family to the local food bank who delivered weekly parcels of food and toiletries.

Outcomes

When the mental health referral was triaged, it was recommended that Jay was supported by a clinician from Source as it was felt that his mental health needs were secondary to his issues with substance misuse. In the weeks leading up to his first appointment, our Assistant Psychologist provided weekly individual sessions to Jay to provide short-term psychological support focussed on psychoeducation about mood and stress, sleep hygiene and scheduling enjoyable activities. Jay engaged well with the clinician from Source and they completed the appropriate work to support him in reducing his drug use.

The referral for Jay to attend an Education Provision within a local sports club was accepted. He attended the 12 week course and completed it, receiving his qualifications and inviting the YCJL&D service along to his graduation. Jay's mother's PIP application was accepted and she was back paid for 3 months. We then supported Jay in applying for Young Carer's benefits, which were also accepted and he too was back paid for 3 months..

Jay's Mother attended Talking Therapies and found the support offered by them very useful.

YCJL&D had contact with Jay 10 months after the case was closed to the service, and Jay tells us that he is working night shifts at a local fast food restaurant and completing a plumbing apprenticeship with the local college. He reports that he and his mother are doing really well and he has had no contact with the police since.

We asked Jay and his mother a few questions on their experience with YCJL&D:
1) What have you found most useful about the Youth Criminal Justice Liaison and Diversion Service "Everything!" Jay and his mother report that the YCJL&D service have been the only "people that have listened" to them properly. Jay's mother reported "the amount of pressure that you've taken off me is immense". Jay reported that he is pleased to be engaged with an education sports programme. Jay was glad that we could help his mother with the more practical help, such as letters, benefits and phone calls as he feels he doesn't understand it all.

2) What do you think would be different if the YCJL&D did not have an input? Jay's mother said that they'd be 'homeless' due to the fact that they would have kept on struggling with their relationship, they felt that Jay would have carried on getting arrested as well. Jay's mother reported "We're off the merry-go-round and it's stopped", she reports that the merry go round is negative and they finally have some positives in their lives.

Jay and his mother took part in the making of a short film that tells their journey with the Youth Criminal Justice Liaison

Priority 6
Keeping safe and improving support within the criminal and youth justice system

and Diversion Service. With reassurance that only proportionate information from his clinical assessment would be shared together with his progress in the form of a report, consent was given by Jay and his mother to share information with criminal justice decision makers. Jay was invited in for a voluntary interview with the police for the offence. In recognition of the work that he completed, and the progress made, he was given a caution for possession of Class A drugs.

What we aim to do as a partnership

We will

- Support Autism Berkshire in the continued roll out of the Thames Valley Autism Alert card.
- By supporting this collaboration work with Thames Valley Police and Autism Berkshire, officers will be better equipped, so that any interactions should be more positive for all concerned.
- Work with partners so there is a much wider understanding of "county lines ", "mate crime" and "cuckooing" within all sectors and the wider community and provide a multi-agency response to the victim. The One Reading Young People and Extra Familial Harm Strategy 2021/22 to 23/24 covers these types of crime.
- The crime type itself will be better understood by partners and the community and the support package provided will be tailored to the needs of the victim to prevent and protect going forward.
- Work with partners to better understand the representation and needs of Autistic people within the Criminal Justine System. And ensure they are aware of and using the registered intermediary where appropriate.
- By effectively understanding the demand we will be better placed to provide support where appropriate.
- Make universal use of a consistent screening tool within the Criminal Justice System is needed along with an information sharing protocol for information sharing between services.

In order for autistic young people and adult to keep safe:
We will:

- Through our commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation.
- Support people who are vulnerable, including teaching anti-victimisation and personal safety skills.
- Support autistic people with paid employment and fixed activity routines, that they feel safe and confident doing, thus minimising the risk of vulnerabilities being exploited by others
- Mainstream services/local organisations will work in partnership with Prevent/Channel to identify those at risk of being drawn into extremism, assess and offer appropriate support plans to suit individual's need

Priority 7
Improving support for families and carers

Aligns with Reading's SEND Strategy:
Strand 5: Support for families / short breaks

Our Ambition

Understanding and tailored support and communication so that autistic people, and their families and carers are enabled to live their healthiest lives to the fullest, throughout their life span.

What we know nationally

Families and carers of autistic people are often key to people being able to live independently in community settings. However, supporting another person, often for many years, can place a great deal of strain on the carer, especially if the person with autism does not want outside support, or struggle to engage with services or new people.

National picture

There are an estimated 3 million family members and carers of autistic people in the UK[34]

Some autistic people will need very little or no support in their everyday lives while others need high levels of care, such as 24-hour support in residential care. The National Strategy for autistic children, young people and adults aims at putting in place effective measures to 'make a difference to autistic people and their families' lives' and for their life to be 'fundamentally better.'

The Government has also pledged to provide support to facilitate engagement, including supporting Parent Carer Forums, to strengthen the engagement of parents and young people in the Special Educational Needs and Disability (SEND) system, the Transforming Care for Children and Young People accelerator programme, and a review of advocacy for families and carers to be able to speak up about the experiences of their loved ones.

The Care Act 2014 has given carers of adults the same rights as those they care for – the right to a carer's assessment and support plan if they have eligible needs and a personal budget, as well as information, advice and guidance on support available or that they are entitled to (e.g., carer's breaks) and how to access this. In Reading this can be provided through social care or the Reading Carers Hub. Under the Children and Families Act 2014, the Council has a duty to assess parent carers on the appearance of need or where an assessment is requested by the parent. The assessment covers the health and wellbeing of the parent carer and the need to safeguard and promote the welfare of the child cared for. The Council must be satisfied that the child and their family come within the scope of the Children's Act 1989.[35]

What we know in Reading

- Parents and carers need to be supported and feel supported at the outset even whilst a child, young person or adult is waiting for an assessment as the waiting lists in Reading are significantly

[34] Local Government Association (LGA) (2022). Support for autistic people | Local Government Association. [online] www.local.gov.uk. Available at: https://www.local.gov.uk/our-support/sector-support-offer/care-and-health-improvement/autistic-and-learning-disabilities/autistic#:~:text=It%20is%20estimated%20that%20there.

[35] National Autistic Society (2020b). Carers assessments in England. [online] www.autism.org.uk. Available at: https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/carers-assessments.

longer than the 13-week NICE guideline.

- Reading has a wide range of voluntary groups/organisations that offer support for autistic people with or without a learning disability, and their families. Details are on the Reading Services Guide and the Local Offer.
- The Berkshire West Autism and ADHD Support Service has been commissioned by Berkshire West CCG and co-produced by stakeholders in health, education, social care and the voluntary sector. It is run by Autism Berkshire and delivers autism support for families and carers whilst they wait for their child or young person to be assessed or after diagnosis (see Priority 4)
- The Autism Berkshire service encompasses advice, support and workshops for families, of children and young people aged 5 to 25 who may or may not have Autism or ADHD or are waiting for assessment. Advice & strategies cover topics including child development, speech, play, food issues, toileting, sleep, supporting behaviour, sensory issues, puberty and supporting anxiety. Autism Berkshire also support parents in navigating the school and social care system.

The service includes a Helpline, one to one consultations and workshops:

- Home Visits – an in-depth one-to-one discussion online or face-to-face (where possible) with parents and carers
- Autism advice workshops: online workshops lasting 2 hours Understanding More About Autism; Sensory Differences plus Plan and Q and A session; and Supporting Behaviour plus Plan and Q and A session, parents can attend one or all three
- Teen Life, a National Autistic Society 6 week course for parents and carers of autistic children aged 10 to 16. Includes a workbook which parents can refer back to after the course.
- Additional workshops/webinars for parents and carers cover: Autism and Girls, with autism advocate Carly Jones MBE, Emotional Regulation, Food Refusal, Sleep Difficulties, Transitions to Adulthood

Support for children and young people includes:

- Tailored interventions, based on individual need, for children aged 5 to 7
- Social interaction skills groups for children/young people 8-16, to develop confidence and emotional wellbeing (run by Parenting Special Children)
- SocialEyes, a NAS course for autistic 17 to 25-year-olds, looking at further social interaction skills and strategies to boost wellbeing and independence.
- Parents can self-refer to the Autism Berkshire service using an online form Berkshire West Autism & ADHD Support Service referral form for parents, carers and autistic young people - Autism Berkshire this includes consent to store their data and to receive the newsletter.
- Professions can refer families Berkshire West Autism & ADHD Support Service referral form for professionals - Autism Berkshire Both referral forms are secure and comply with the NHS Data Protection and Security Toolkit.
- Short breaks are opportunities for children and young people with disabilities to spend time away from their families and carers, socialise with peers and have fun as well as provide opportunities for families and carers to have a break from caring responsibilities.
- Brighter Futures for Children commission a range of Short Breaks. These are advertised via the Local Offer[36] and are either free or subsidised. Currently we have a performing arts, dance, football, Lego and independence Short Breaks running.

[36] Special Educational Needs & Disabilities - Reading's Local Offer | Reading Services Guide

- The Local Offer also listed other activities for children with SEND including autism. Parents can use the Local Offer website or phone to speak to one of the very knowledgeable staff.
- The Local Offer staff can help families with individual queries, for example finding a SEND childminder or a Short Break for a child with a special interest.
- For children who have been assessed by a qualified social worker in line with Section 17 Children Act 1989 as being eligible for services as Child in Need may be eligible for an overnight residential Short Break service at Cressingham. This is for no more than 75 nights per year away from their families. The referral route to this service is via Brighter Futures for Children Single Point of Access (available online).
- For children who have been assessed by qualified social workers to need more than 75 nights per year of care away from their parents may be eligible for shared care at Pinecroft residential accommodation. The children are resident without their parents and have weekly and regular nights at Pinecroft to enable parents and siblings to have a break. Cressingham and Pinecroft are regulated childcare provisions and are managed by Brighter Futures for Children and regularly inspected by OFSTED with Cressingham rated Outstanding and Pinecroft Good at the last inspections in 2021.
- Pinecroft has been remodelled with a new sensory room and outside space. An Open Day was held in Spring 2022 and well attended by families and professionals.
- RBC's Adult Social Care team run a Preparing for Adulthood Team to support families when their child moves from children's to adult services. See section 2.
- Reading Mencap runs a highly regarded Family Adviser service providing information, advice and guidance, to support adults with Learning Disability and Autism, and their families, including advice about daily living, helping maintain a tenancy, health appointments and access to statutory services, including benefits. RM employ a specialist Transition Family Adviser.
- Reading Mencap runs day services and clubs for people with a Learning Disability, or a Learning Disability and Autism to reduce loneliness and isolation and improve mental wellbeing, and provide respite for carers:

  2 day services of 7 hours a day with 60 places each service
  1 weekly x Self Advocacy day-time club
  1 x monthly evening disco
  2 x Gateway evening Clubs
  1 x evening Performing Arts Group
  1 x 5 hour Saturday Daytime Transitions club 18-25 (awaiting a start date)
  Quarterly carers coffee mornings

- The Whitley Wood respite service is available to learning disability and autistic adults and is run by Reading Borough Council. It was rated Good at its last inspection by the CQC in 2017.
- Tuvida Carers Hub is commissioned by Reading Borough Council and BFfC to provide support to adult carers, including information, advice and guidance, respite breaks or crisis support with the Carers Break service.
- Parents and family carers can access the Reading Carers Card, allowing carers to be identified at various local outlets for easier access and targeted support.
- Carers can request a carer's assessment of their needs to identify areas where they need additional support or explore opportunities to improve their health and wellbeing. This could be through allocation of a personal budget specifically for the carer to use for an activity of their choice.
- Reading Families Forum (RFF) is funded by government grant and is an independent charity run by and for families of disabled children and young adults aged 0 – 25 years. RFF are part of the National Network of Parent Carer Forums. They

work to ensure that local parent carers and young people with all additional needs co-produce local services that they use. Co-production means that families are at the heart of discussions, giving their views and experiences about what is needed and setting priorities.

- COVID-19 measures taken to reduce the spread of the virus have limited access to many services, including respite care. These services are now re-opening, but many carers have gone without a break for many months and are in great need of time off to recuperate.

What is important to Reading people

We spoke to Reading parents and carers and found that less than 10% of respondents felt supported by statutory health, care services and voluntary community sector services in their caring role.

Some needs identified included the below:

- o Facilitate access to breaks for families and carers
- o Better child-care provision and activities during half-term and school holidays or weekend clubs needed for primary school age children
- o Improve communication to keep parents informed of progress or additional services available

What we aim to do as a partnership

We will

- Through our commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice, guidance, and activities to reduce loneliness and isolation.
- Through commissioning of the new carers service later in 2022, we will support carers and families to access carers assessments, information, advice and guidance, respite and crisis support and more easily.
- In order to support carers better, all organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West CCG NHS Autism and Attention Deficit Hyperactivity Disorder (ADHD) support service, as some parents, although sent a referral pack by the Autism Assessment Team (AAT), report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- To support carers better, all organisations will refer all parents to the Local Offer, so they can access information and signposting, as some parents are reporting that they are unaware of the service.
- Brighter Futures for Children, Adult Social Care, the Local Offer, Reading Services Guide, and Autism Berkshire and Reading Mencap will promote the ordinarily available, and specialist autism and learning disability services to families and carers.
- Brighter Futures for Children will review the provision of Short Breaks to ensure it meets the needs of families

7.0 Delivering our future priorities

Reading's multi-agency Autism Board must be supported to ensure that key work and insights contribute to timely, appropriate provision of services and resource for Reading's population of autistic people and those that support them.

Local Governance and Monitoring Arrangements

Progress made against the priorities, associated actions and any commissioning intentions set out in this strategy will be formally reported to and monitored by:

- Autism Board
- Health and Wellbeing Board

Using existing networks and partnerships the work included in this strategy's implementation plans will be communicated and updates provided to:

- Autism Board
- SEND Standards Board
- Health and Wellbeing Board
- Community Safety Partnership Transitional Care Partnership
- Learning Disability Partnership Board
- Mental Health Forum
- MH/LDA ICP Board and CYP ICP Board

The Autism Partnership Board - will lead on co-ordinating the implementation of the strategy through developing implementation plans and measures of success to support priorities across partners to achieve the planned outcomes, provide answerable leadership in partnership with all partners with the duty, knowledge and desire to improve the lives of autistic people and their families and carers. This board will consist of key stakeholders from across the system including autistic people and family representatives. The board will further define monitoring arrangements.

This strategy and implementation plans are live documents which will be used to monitor progress and work with partners to drive positive outcomes for autistic people and their families. A significant joint effort will be needed. As live working documents, the implementation plans will be updated to reflect any changes to need and develop as the strategy progresses.

Reading All-Age Autism Action Plan Year 1 2022/23

Q4 update

Priority 1: Improving awareness, understanding and acceptance of autism		Lead (s): Autism Partnership Board		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Develop a training programme to raise awareness of Autism across public and private agencies	Training programme in place and is accessed by partners	Feb 2023	Autism Partnership Board	Oliver McGowen training, provided by a Skills for Care endorsed provider and now is mandatory for care staff. Autism Awareness is also available to all RBC care providers via greymatter learning hub - Social Care Autism Awareness Training Course | CQC eLearning | GML (greymatterlearning.co.uk) Autism Berkshire completed a ½ day training to Primary Care Social Prescribers.
Develop a programme of awareness events, promotional activities for World Autism Awareness Week (29th Mar – 4 Apr 2023)	All partnership to offer a range of public promotional and awareness events	Mar 2023	Autism Partnership Board	Autism Berkshire were able to obtain a popup shop in the Oracle Shopping centre and raise awareness and signpost to local services. AAW was promoted via the RBC social media.
Develop an Autism Web page/site	Web page developed Promotion of all providers/ activities/ information on Autism	Mar 2023	Chair of Autism Partnership Board	Centre Reading Autism webpage has now been developed. Autism - Reading Borough Council

Priority 2: Improving support and access to early years, education and supporting positive transitions and preparing for adulthood		Lead (s): BFFC & Adult Social Care		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Communication between Early Years and SEND Team to highlight number of expected children with Autism & Complex needs to be coming up into school.	SEND team able to place plan appropriately for children with Autism and Complex needs.	Ongoing	BFFC Early Years & SEND Team	There are still too few places in special schools to meet the identified need coming through from early years.
AET Training; Attention Autism & Intensive Interaction Training available within the Early Years programme	Each programme ran yearly with uptake of 30 people attendance.	Ongoing – Yearly	BFFC Early Years & SEND Team	Attention Autism 2 day course was delivered with 23 delegates Attention Autism Whole Setting Training delivered across 6 Early Years Settings Intensive Interaction delivered with 26 attendees
Early Years to Primary Transition Workstream – see attached	Actions completed from paper – less number of children requiring to offset	Ongoing – Yearly Transition plan	BFFC Early Years & SEND Team & Mainstream Admissions	This year is particularly pressured for early years places in special schools and there are likely to be a higher number of offset children remaining in nursery for another year.
Prioritising school leavers for EY SEND Advisory visit & EYFS Prime Support focussing on 2 year olds.	Increasing number of appropriate EHCPs applied before school start to ensure support in place.	Ongoing	BFFC Early Years Team	We have a Local Authority shared documentation that we encourage our Early Years Sector to use when sharing information about transitions including a family friendly SEND passport to school. Where appropriate the Early Years SEND Advisors/Portage Workers will facilitate and support transition planning, joining multi professional meetings, empowering parents/carers to liaise with the SEND team regarding transition concerns.

				There has been two new SCD early years resource bases created to support early intervention for children with Social Communication needs who are able to access a mainstream curriculum; with the ambition for children to make good steady progress and transition into a mainstream school. Transitions has become a focus in Early Years newsletters and networks with a reminder that transitions is not a one off event but a process across the year that settings can work with their local schools together to improve support in transitions. There is a clear frequently asked questions guide for parent/carers that is available online to support transitions from early years to school with a focus on SEND. This provides supports clear consistent messages to the parent/carers from BFfC.
Priority 3. Increasing employment, vocation and training opportunities autistic people		**Lead (s): BFFC Elevate & New Directions College**		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Deliver a high quality careers service to young people and their families in order to support them to access a range of employment and training opportunities and reduce the number of SEND young people being out of education, training or employment.	Sufficient and appropriate support is provided for families Increased participation of SEND young people in education, training and employment, reduction of young people becoming long term NEET	Ongoing	BFFC Elevate	Elevate continue in delivering careers information, advice, and guidance from the Youth Hub at the Curious Lounge. The hub was established in partnership with the DWP, for young people 16-25 with complex needs, including SEND young people. Between January 2022 and February 2023 over 100 young people were referred by the DWP to Elevate and were supported by the Elevate careers service. 80% of young people we supported had improved their confidence and skills and were more prepared to get closer to employment. 20% of young people we worked with moved into employment. The aim of the youth hub was to reduce barriers for some of the most vulnerable young people towards employment by helping them access the support from Elevate and partner organisations.

				In November 2022 we attended the SEND networking event at the Avenue school, and we provided advice and guidance to parents and students, some of whom were at risk of becoming NEET. Elevate careers coach has delivered personalised one-to-one careers information, advice and guidance to 12 students at the Avenue school who were planning for their transition to adulthood while they were still at school. Between February 2022 and February 2023, 450 1:1 and group sessions were held with Elevate at the youth hub. Over 200 young people accessed the support such as job searching, information events with Prince's Trust, job interview preparation etc. We are proactively tracking our SEND young people who live in Reading and are 16-25 years old. Currently our data shows that we have 39 young people, 16-25 who are NEET- Seeking Employment and Training (8.04%); 17 young people 16-25 with SEND are currently destinated as Illness (3.5%). We have significantly reduced our number of 18-25 who are Not Known, currently we have 5 young people 18-25 whose destination is Not Known (1.03%). The Not Known percentage in December was 20.3%.
Identify and work with local services that provide re-engagement into employment, education or training for neurodivergent young people and identify gaps in provision to improve post 16 outcomes for young people.	Young people to develop independent skills for working and living independently; Supporting more autistic people into vocational training and employment	Ongoing	BFFC Elevate & New Directions	Our plan for 2023/2024 is to increase the number of young people re-engaging into education, employment and training. A significant number of our NEET young people are not ready to look for work or training due to social anxiety, low self esteem and not feeling prepared to start work. In May 2023 we will launch the Hatch employability programme in partnership with UK Youth charity. We have two autistic young people already signed up on the programme. We will secure a paid work placement for 10 participants and provide job coaching during and after the programme is finished. We are currently building the links with employers and advocating for young people who need additional support in work place. We plan to commission The Alt Pro training provider in the summer term, to work with 15 young people who have multiple barriers to accessing employment, education or training, such as difficulties

Page 177				accessing new provision due to high anxiety levels. The Alt Pro are also able to provide work experience and certified courses in various job sectors such as construction. Currently, in Reading we have 6 learners on supported internship programme. We are currently working with SEND Team at BFfC to set up Reading's first SEND employment forum with the aim to increase the number of local employers who are able to provide work placements to SEND young people including work placements and supported internships. Our target is to double the number of participants on supported internships in 23/24. The SEN team at BFfC have commissioned Shaw Trust to deliver the supported internship programme in April and then have a new cohort starting from September. Elevate will be promoting this option to young people, parents and colleagues who work with SEND young people to increase participation. We are planning to hold another careers networking event in July with the aim to invite all SEND young people from year 11. Elevate is currently working with the Apprenticeships Team at RBC and Team Reading (HR at RBC) to start developing the offer to SEND young people that also include supported internships. We will continue to work closely with schools/ Reading College to identify SEND young people at risk of becoming NEET and offer support as early as possible, before they leave education or training.
New Directions College to offer bespoke provision for adults with LD/Autism with a focus on developing pathways to supported employment, volunteering or apprenticeships.	Volume of adults with LD/Autism accessing bespoke programmes and progressing to supported employment.	Ongoing	New Directions College	No update received

Priority 4. Better lives for autistic people – tackling health and care inequalities and building the right support in the community and supporting people in inpatient care		**Lead (s): BOB Integrated Care Board**		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Reduce risk of admission and readmission Y3 of CETRs / DSR development: - Deliver agreed trajectory for children and young people (15/1M target) and CETR policy - Positive Behavioural support in place	Key worker model will be Business as Usual There will be evidence of service improvements Reduction in issues and admissions through promotion of PBS	April 2023	BOB ICS Place leads	BOB ICB Berkshire West Place have developed an agreed trajectory which they are working to. The Keyworker Programme is fully staffed and is Business as Usual. The PBS service is in place to offer training to education, social care, the voluntary sector, health and parent and carers.
Better start in life for CYP: - Plan in place to monitor & support increase in AHCs	75% CYP >14 years receive AHCs	April 2023	BOB ICS Place Leads	BOB ICB Berkshire West Place, have co-produced letters with Children and Young People and the Parent Carer Forum to send to GP's requesting an AHC. GP training has taken place to raise awareness of the AHC with the LD champions. Monthly reporting of the AHC's
Reduce wait times for autism diagnosis & pre / post diagnostic support	Autism diagnosis within 1 year Agreed model fully implemented across BOB	April 2024	BOB ICS Place leads and providers	BOB ICB are currently undertaking a Quality Improvement piece of work reviewing the wait times for autism.
Transition to adult services - 0-25 services designed and integrated with SEND & MH LTP	Improved experience of care for CYP & families	April 2023	BOB ICS Place Leads	BOB ICB Berkshire West Place continue to work with Royal Berkshire Hospital Foundation Trust to improve experience of care for CYP and families. RBHFT have mapped out the 10 transition pathways and the parent carer forums are involved with the transitions steering group/

Priority 5. Housing and supporting independent living		**Lead (s): Adult Social Care Commissioning**		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Undertaken a needs assessment on the number of autistic people living within social housing and the type of support they require	Needs assessment which helps to inform commissioning intentions	April 2023	Adult Social Care Commissioning	Commissioning have identified that there are potentially some gaps in our current services, including: • Short-term supported living accommodation for: o Assessment on hospital discharge o Step down to show Housing that they can manage a tenancy o Locked door accommodation • Specialist accommodation-based support for: o YP with neurodiversity requirements o Adults with complex MH issues o YP with dementia o People with Korsakoff Syndrome o People with Huntingdon's Disease o OP with complex dementia We are reviewing the boundaries of working with people who present a risk to staff through their behaviour (which is not necessarily caused by their condition). Commissioning are working on a behaviour agreement with providers.
Identify and map the different types of supported housing accommodation available in Reading and is it meeting the required need	Reconfiguration of specifications where needs provision is not meeting need	April 2023	Adult Social Care Commissioning	
Ensure guidance has considered on designing for neurodiversity (PAS 6463:2022), and ensure these policies included in the Local Plan Review and Public Realm Strategy	There is increasing understanding of how neurodivergent people experience the built environment in different ways, and how choices made within streets and spaces may affect people differently, for instance in terms of colours, materials,	Ongoing	RBC Planning Policy	The Local Plan Review, which reported in March 2023, identified the need for neurodivergence to be incorporated into an update to policy CC& on design and the public realm. This policy will be updated as part of a wider Local Plan Partial Update, due to be submitted to the Secretary of State by November 2024

	patterns and levels of visual clutter.			
Priority 6 Keeping safe and improving support within the criminal and youth justice system		**Lead (s): Autism Berkshire**		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Support Autism Berkshire in the continued roll out of the Thames Valley Autism Alert card.	Increased use of the card across all areas	Mar 2023	Autism Berkshire	Autism Alert cards are now distributed to all Reading Police Stations
Support collaboration work with Thames Valley Police and Autism Berkshire, and the continued roll out of the Autism awareness training to front line officers	Autism awareness training of all front line officers completed.	Mar 2023	Autism Berkshire	Autism Berkshire has a rolling programme of training with the Thames Valley Police. There is proactive links with the National Police Autism Association and the Force Autism Support lead. Autism Berkshire are now supporting the TVP Neurodiversity Support Network.
Priority 7: Supporting families and carers of autistic people		**Lead (s): Autism Partnership Board**		
Action	**Measure of Success / Outcome**	**By When**	**By Whom**	**Quarter 4 update**
Early Help Service's at BFfC to ensure that all families/carers of autistic children are linked with the Autism Advisor and local autism support services.	Family Workers will refer families to autism advisor as part of their work and this will be captured in the EH plan and/or case notes.	Ongoing – Yearly	BFfC Early Help	Family Workers are aware of the Autism Advisor support and regularly 'refer' families to her. They are also aware of other local autism support services and will signpost families to these as appropriate. Autism Advisor Service offers consultations to family workers in order to support their work with families of autistic young people.

All parent/carers in Reading following a child's autism diagnosis have access to BFfC's Autism Advisor. The autism advisor can offer advice & guidance to parent/carers. Ensure families are linked with relevant services and will run the Living with Autism course for parents 5 times per year.	Living with Autism post course questionnaires. Autism Advisors yearly summery of support offered and number of parent meetings.	Ongoing – Yearly	BFfC's Autism Advisor	Autism Advisor continues to be copied into all CAMHS reports and offers all families a home visit or virtual meeting. April 2022 – April 2023: Autism Advisor Service received 221 referrals. April 2022 – April 2023: Autism Advisor Service 103 parent meetings completed
BFfC reviewing short breaks to meet the needs of families and consider the strategic interplay with SENDS. Overall offer of short breaks to family in communications with all SENDS organisations and via BFfC local offer.	Parents/Carers have a clear understanding of short break services. This is captured via BFfC parent feedbacks.	Ongoing – Yearly	BFfC Early Help	Family Workers are able to support families to these services as appropriate. BFFC have a robust feedback process.
Commissioned ASC/BFfC carers assessments to the Partnership Board.	Sampling of carers assessments and services available and afterwards from BFfC and RBC.	Ongoing – Yearly	ASC / BFfC	New carers partnership has now been commissioned to provide a more timely service for carers assessment and support For Carers - Reading Mencap

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Appendix 3 - Equality Impact Assessment (EIA)

For advice on this document please contact Clare Muir on 72119 or email Claire.Muir@reading.gov.uk.

Please contact the Project Management Office at pmo@reading.gov.uk for advice and/or support to complete this form from a project perspective.

Name of proposal/activity/policy to be assessed:

Reading's All Age Autism Strategy 2022 - 2026

Directorate:

Directorates of Adult Care and Health Services and Council wide services

Service: **Adult Social Care and Public Health and Wellbeing Team**

Name: **Sunny Mehmi**

Job Title: **Assistant Director: Adult Social Care**

Date of assessment:**01/06/2023**

Version History

Version	Reason	Author	Date	Approved By
1.0	Creation	Amanda Nyeke	07/06/2022	
2.0	Reviewed	Sunny Mehmi	09/06/2022	
3.0	Reviewed	Sunny Mehmi	01/06/2023	

Scope your proposal

- **What is the aim of your policy or new service/what changes are you proposing?**

The proposal is to adopt a Reading All Age Autism Strategy for the period 2022-2026 in accordance with The Autism Act 2009 which sets out the requirements for local authorities and NHS bodies to work with local partners to improve services and support autistic people. The Act put a duty on Government to produce and regularly review an 'Autism Strategy' to meet the needs of adults with autism in England. Following the publication of the latest "**The national strategy for autistic children, young people and adults: 2021 to 2026",** Reading has started the development of a local autism strategy. This aligns the national priorities in conjunction with local demands and needs of those autistic residents in Reading.

Reading's All Age Autism Strategy 2022-2026 sets out key priorities across Reading and the services which serve the Reading autistic population, their families and carers.

The Strategy identifies 7 priorities. These are:

1. Improving awareness, understanding and acceptance of autism
2. Improving support and access to early years, education and supporting positive transitions and preparing for adulthood
3. Increasing employment, vocation and training opportunities autistic people
4. Better lives for autistic people – tackling health and care inequalities and building the right support in the community and supporting people in inpatient care
5. Housing and supporting independent living
6. Keeping safe and the criminal justice system
7. Supporting families and carers of autistic people

- **Who will benefit from this proposal and how?**

It is intended to be an important strategy in improving the health, wellbeing and wider outcomes of Reading autistic people, their families and carers;

- **What outcomes does the change aim to achieve and for whom?**

Adopting the 2022-2026 Reading All Age Autism Strategy will give the Autism Partnership Board a focus on the 7 identified priorities (see above), and set a framework for ensuring that plans to address these are monitored effectively and help to:

- Promoting the partnership working and integration of services.
- To promote equality, social inclusion and a safe and healthy environment for all
- Contributions to Community Safety, Health and Wellbeing of residents with autism.

In turn, the commissioning plans over the next four years should also be driven by and reflect Reading's All Age Autism Strategy 2022-2026 priorities.

The Strategy is aimed at the entire autistic population in Reading including their families and carers and adopting it should co-ordinate efforts to outcomes for any resident potentially affected by the priority issues.

The Autism Partnership Board will drive performance forward in the chosen priority areas as set out in the Strategy. In addition, the Autism Board will continue to work collaboratively and receive reports and monitor strategy action from other local strategic partnerships involved in supporting autistic people and improving health and wellbeing.

Reading's All Age Autism Strategy 2022 - 2026 acknowledges the risks related to climate change but is not designed to address those risks at this point in time. However, the implementation plans will endeavour to include detailed actions wherever relevant to address those risks and the health implications of climate risks.

- **Who are the main stakeholders and what do they want?**

- Current autistic children, young people and adults

- Carers and family of autistic people

- Staff and volunteers across care and support providers in the statutory, private and voluntary sectors that support autistic people.

Assess whether an EqIA is Relevant

How does your proposal relate to eliminating discrimination; advancing equality of opportunity; promoting good community relations?

- **Do you have evidence or reason to believe that some (racial, disability, sex, gender, sexuality, age and religious belief) groups may be affected differently than others?**
- **Make reference to the known demographic profile of the service user group, your monitoring information, research, national data/reports etc.**

Priority 1 and 4 of the strategy, address raising awareness, acceptance, understanding and reducing the health differences between groups based on the data analysis and consultation we have undergone to ensure all in the population benefit from the strategic aims.

- **Is there already public concern about potentially discriminatory practices/impact or could there be? Make reference to your complaints, consultation, feedback, media reports locally/nationally.**

No

If the answer is **Yes** to any of the above, you need to do an Equality Impact Assessment.

If **No** you **MUST** complete this statement.

An Equality Impact Assessment is not relevant because:

Lead Officer

Sunny Mehmi

Assistant Director: Adult Social Care

Assess the Impact of the Proposal

Your assessment must include:

- **Consultation**
- **Collection and Assessment of Data**
- **Judgement about whether the impact is negative or positive**

Think about who does and doesn't use the service? Is the take up representative of the community? What do different minority groups think? (You might think your policy, project or service is accessible and addressing the needs of these groups, but asking them might give you a totally different view). Does it really meet their varied needs? Are some groups less likely to get a good service?

How do your proposals relate to other services - will your proposals have knock on effects on other services elsewhere? Are there proposals being made for other services that relate to yours and could lead to a cumulative impact?

Example: A local authority takes separate decisions to limit the eligibility criteria for community care services; increase charges for respite services; scale back its accessible housing programme; and cut concessionary travel.

Each separate decision may have a significant effect on the lives of disabled residents, and the cumulative impact of these decisions may be considerable.

This combined impact would not be apparent if decisions are considered in isolation.

Consultation

How have you consulted with or do you plan to consult with relevant groups and experts. If you haven't already completed a Consultation form do it now. The checklist helps you make sure you follow good consultation practice. Consultation manager form - Reading Borough Council Dash		
Relevant groups/experts	**How were/will the views of these groups be obtained**	**Date when contacted**
Autistic Reading residents, their families, carers and professionals and organisations working with autistic people. Including completion of an All Age Autism Needs Assessment	Engagement and coproduction (though limited in its scope by resources) took place via a mixture of interviews, workshops, surveys, forums, existing local groups, and feedback sessions. This insight was used to inform and shape the strategy, and to test emerging findings, recommendations, priorities, and vision development. We received contributions from 227 people.	15 November 2021 – 31 May 2022
Autistic Reading residents, their families and carers. Organisations across all sectors involved in support for autistic people and promoting or protecting health and wellbeing	A second consultation on the strategy will be carried out to ascertain if the aims and priorities set out in the strategy met people's expectations.	15th July 2022-15th September 2022

Collect and Assess your Data

Using information from Census, residents survey data, service monitoring data, satisfaction or complaints, feedback, consultation, research, your knowledge and the knowledge of people in your team, staff groups etc. describe how the proposal could impact on each group. Include both positive and negative impacts.

(Please delete relevant ticks)

- **Describe how this proposal could impact on racial groups**
- **Is there a negative impact?** No

No negative impact in terms of different racial groups has been identified.

Where take up of other services is disproportionately low for some racial groups which may face particular barriers to access, there will be a focusing of resources on those communities as part of the drive to reduce inequalities.

There is an ongoing need to recognise that cultural norms and barriers such as language may impact on access to support, and the All Age Autism Strategy should be a tool to address this.

Responses to the initial engagement raised the importance of ensuring that information and advice about health and wellbeing and other key information is accessible to all groups.

- **Describe how this proposal could impact on Sex and Gender identity (include pregnancy and maternity, marriage, gender re-assignment)**
- **Is there a negative impact?** No

No negative impact in terms of gender has been identified.

- **Describe how this proposal could impact on Disability**
- **Is there a negative impact?** No

No negative impact in terms of disability has been identified.

- **Describe how this proposal could impact on Sexual orientation (cover civil partnership)**
- **Is there a negative impact?** No

No negative impacts on the grounds of sexual orientation have been identified.

- **Describe how this proposal could impact on age**
- **Is there a negative impact?** No

No negative impacts on the grounds of age have been identified

- **Describe how this proposal could impact on Religious belief**
- **Is there a negative impact?** No

No negative impact in terms of religion or belief has been identified.

Make a Decision

If the impact is negative then you must consider whether you can legally justify it. If not you must set out how you will reduce or eliminate the impact. If you are not sure what the impact will be you MUST assume that there could be a negative impact. You may have to do further consultation or test out your proposal and monitor the impact before full implementation.

No negative impact identified – Go to sign off

- **How will you monitor for adverse impact in the future?**

The long-term impact of adopting Reading's All Age Autism Strategy 2022 - 2026 should be a reduction in health inequalities and improvement in outcomes for autistic people, their families and carers. In order to track progress towards this goal, Action Plans will be developed with progress reports made to the Autism Partnership Board and fed into the Health and Well Being Board.

Lead Officer

Sunny Mehmi

Assistant Director: Adult Social Care

READING HEALTH AND WELLBEING BOARD

Date of Meeting	14 July 2023
Title	Place Based Partnership briefing
Purpose of the report	To note the report for information
Report author	Sarah Webster
Job title	Executive Place Director – Berkshire West
Organisation	BOB - ICB
Recommendations	1. That the Health & Wellbeing Board note the revised Place Based Partnership governance arrangements and partnership commitments 2. That the Health & Wellbeing Board note the refreshed Place Based Partnership overarching programme plan 3. That the Health & Wellbeing Board (HWBB) note consideration of the important role of the HWBB in ensuring our joint work at Place is delivering on behalf of the specific needs of the residents that the HWBB represents and; contributes towards the delivery of our Joint Health and Wellbeing Strategy.

1. Executive Summary

1.1. This report seeks to update the Health and Wellbeing Board on the revised Unified Executive arrangements as a Place Based Partnership including the governance, programme of priority areas as well as seeking to strengthen accountability of the United Executive into the Health and Wellbeing Board and its delivery against the Health and Wellbeing Board Strategy

2. Policy Context

2.1. Since January 2023 **Unified Executive members, seeking to develop our Berkshire West Place Based Partnership have:**

2.1.1. Met twice as an extended Unified Executive Group for facilitated workshops on 12 January and 9 March 2023; and

2.1.2. Met as a weekly 'Task and Finish Group' with senior representatives from all our organisations to progress the outputs from the workshops.

2.2. The discussions were extremely productive following which some specific outputs were agreed covering the following areas:

2.3. **Place Priority Programmes:** A proposed list of eight priority areas of high impact joint work, which in turn have been scheduled into a work plan based on current maturity (see section 3 below).

2.4. **Revised joint governance arrangements for our Place Partnership**: We proposed improvements to the existing governance structure, rather than completely reshaping the current arrangements, to avoid destabilising our system. The improvements aim to ensure that we get an appropriate balance of focus at Local Authority level and at Place based on the needs of any given programme of work, and that all partners are appropriately engaged without it becoming burdensome (see section 4 below).

2.5. **Partnership Commitments:** To set the tone and expectations for our partnership we agreed in principle some commitments that we are working towards (see Section 5 below).

2.6. **Unified Executive workplan:** The Unified Executive will ensure that our joint programme of work is delivering improvements for our residents. We are proposing a workplan that ensures good oversight and assurance over our core priority programme alongside other important partnership subjects (see Section 6 below).

2.7. It is important for the Health & Wellbeing Board to note that whilst consensus was reached by the Task & Finish Group in many areas, due to the complexity of our Place there will always be a range of potential ways forward that have merit. A crucial relevant partnership commitment is that of continual review and improvement: if something that we agree on now does not work in practice then we are all open minded to amending and improving as we go.

3. Place Based Partnership

3.1. <u>Place Priority Programmes</u>

3.2. The Task & Finish Group, with wider support from within each organisation, has worked to refine the long list of priorities generated at the 12 January workshop.

3.3. The table below summarises the current position of the original long list:

PBP Programmes – June 2023

UE Project	UE Sponsor	SRO	Housed within Governance Structure	Status	Target Start Date for Intervention (23/24)	Status
Same Day Urgent Access	Andy Statham	Adrian Chamberlain	BW UEC Joint Programme Board	UE Sponsor is linking with BOB -wide work being commissioned on Primary Care Strategy to align. Further local work will be commissioned if necessary as agreed at UE in May 23.	Q3	
Intermediate Care Review	Matt Pope	Lisa Shoubridge	BW UEC Joint Programme Board	3 active workstreams to deliver quick wins identified from the Phase 1 diagnostic exercise are underway. The Sponsor and SRO are meeting imminently to confirm the programme mandate for phase 2. with the programme plan and plans for spend to be presented to the next UEC PB July 23.	Q1	
Reducing preventable premature deaths	TBC (Sarah Webster in interim)	Belinda Seston	BW Prevention & Inequalities Working Group / Locality Integration Boards	Spending plan for ICB £1.3m fund agreed 2023/25 agreed with LIBs to develop local service offer in July 2023	Q2	
CHC & Joint Funding	Sarah Webster	Liz Hodgkinson	BW CHC & Joint Commissioning Place Engagement Group	Centralised BOB CHC assessment model agreed at ICB EMC in May. Current focus on bringing Oxford and Bucks service in house and will then ensure consistent processes across BOB. JF pilot continuing.	Q1	
Special Educational Needs and Disability	Susan Parsonage	Paul Coe	LA CYP Partnerships / BW CYP Programme Board (TBC)	Work ongoing at present directly with LA partners. Further scoping required during Q2 to determine if BW -wide programme is required.	tbc	
CYP Mental Health	Nigel Lynn	Tehmeena Ajmal	LA CYP Partnerships / BW CYP Programme Board (TBC)	Further scoping required during Q2	tbc	
High Complexity High Cost Placements	Julian Emms	Tehmeena Ajmal	BW MH & LD Place Engagement Group	Further scoping required during Q2	tbc	
Place Delegation Development	Sarah Webster	Belinda Seston	BW Place Development and Enablers Programme Board	Scoping underway for ST/MT & LT deliverables	Q2 24/25	

3.4 A detailed programme plan will be presented to a future HWBB.

3.5 Two of the front-runner programmes (Same Day Urgent Access and Intermediate Care) were noted as benefiting from securing additional expert capacity to ensure they can progress at pace and capitalise on the existing momentum in the system in these areas. The Unified Executive Flagship Fund which held £112k of joint funding rolled forward from previous years has been equally allocated to these two programmes to accelerate success.

3.6 It is acknowledged that these programmes of work are a starting point and that over the next twelve months we will consider and develop a longer-term strategic joint programme of work with clear links into the H&WB Strategy and the ICP Strategy. This is included in the UE Workplan discussed in Section 5 below.

4. Place Partnership Governance Arrangements

4.1. To deliver against our Priority Programmes, we needed to be clear on our joint governance arrangements including responsibilities and accountabilities.

4.2. It is important to acknowledge that we are different as a 'Place' and our given geography isn't coterminous to our individual partner footprints. Our Place boundary covers approximately half of the core catchment area for BHFT, the majority but not all of the population base for RBFT, it encompasses three separate Local Authority areas, and contains multiple PCNs and VCSE organisations within each LA area.

4.3. This complexity creates a spectrum of risk ranging from arrangements which are overly homogenised and duplicative from an LA perspective to structures that feel fragmented and triplicated from an NHS perspective.

4.4. The Task & Finish Group has considered several different theoretical governance models ranging from a 'quasi-three-Place' model to a more 'single-Place-centric' model. These open and wide-ranging discussions have highlighted that there is broad agreement with the following principles:

4.5. There are definite benefits to be derived from coming together across the Berkshire West footprint to tackle issues in common, and there are many examples where shared functions/services are already operating successfully across this geography. It would be a lost opportunity to move away completely from a collective of this nature.

4.6. Equally, there is a wealth of knowledge, expertise, and momentum at a Local Authority footprint level through existing integrated forums, most notably (for this paper) the Health & Wellbeing Boards, Locality Integration Boards, and Local Children Young People Boards. We should capitalise on this and avoid any assumption that 'Place' should always be the focal point for joint priorities and for delegated funds.

4.7. With this in mind, we proposed improvements to the existing joint governance structure across Berkshire West rather than completely reshaping the current arrangements. This was preferred as a starting point to enable us to test the above principles without risking destabilising our system.

4.8. The improvements aim to ensure that we get an appropriate balance of focus at Local Authority level and at Place (and wider BOB-system) based on the needs of any given programme of work – the 'centre of gravity' question - and that all partners are appropriately engaged without the governance becoming burdensome.

4.9. The revised governance arrangements for Berkshire West are included below. Key points to highlight include:

4.10. There is an important role for the three Health and Wellbeing Boards within our Place Based Partnership arrangements in ensuring our joint work at Place is delivering on behalf of the specific needs of the residents that each Board represents and contributing towards the delivery of our Joint Health and Wellbeing Strategy. These Boards also include VCSE and Healthwatch colleagues and therefore provide a vital role in ensuring their engagement in the

Partnership work. We seek therefore to strengthen the accountability link between the work of the Unified Executive and the H&WB Boards.

4.11. The Unified Executive will continue largely as it currently does, with a commitment from all partners to prioritise this meeting so that CEO (or equivalent) attendance is the norm.

The UE sub-groups (Place-wide) will fall into one of two categories:

a formal *Programme Board* where 'Place' is agreed as the focal point for the programme of work; and

a less formal *Place Professional Groups* A single category of informal Place-level groups has been identified noting generally the 'centre of gravity' for decision making in these subject areas are not at Place, but a need may arise for these groups to come together to discuss opportunities in common, make recommendations to formal Boards or committees, and/or take decisions within the remits of individual authority.

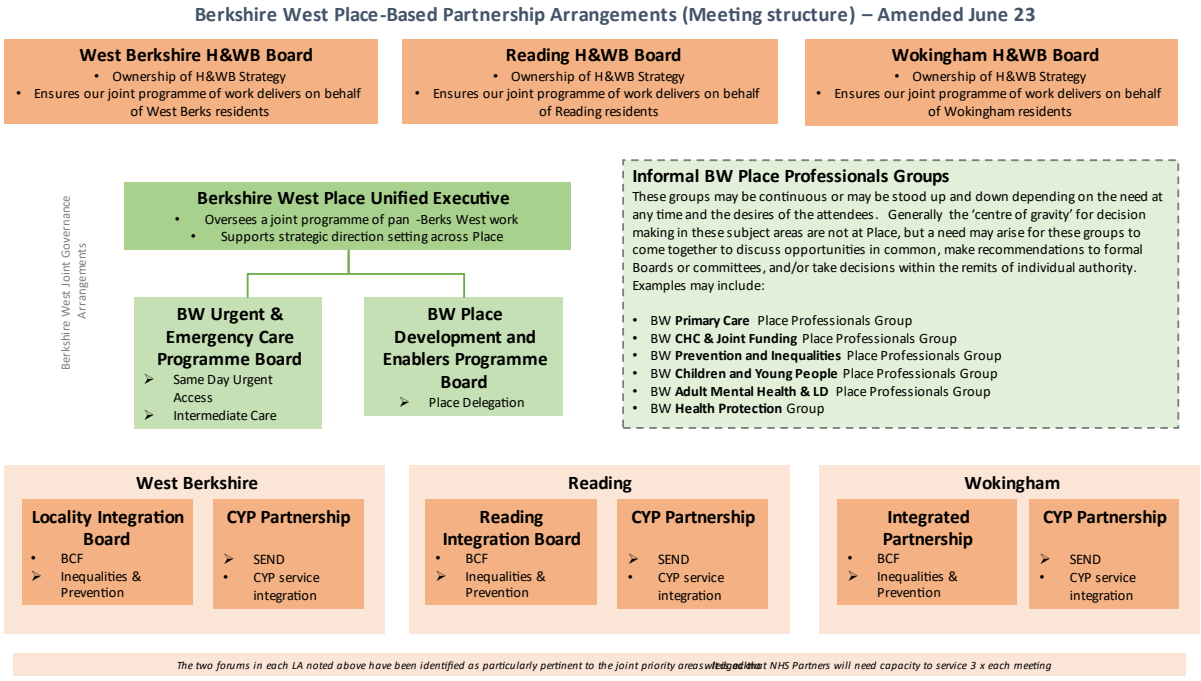
4.12. The 'Locality Integration Boards' and the 'Children and Young People's Partnership Boards' are key integrated forums within each Local Authority. All partners are currently reviewing attendance at these Boards to ensure an appropriate level of seniority to contribute towards decision making.

4.13. It is proposed that each Place Priority Programme will be housed within the appropriate UE sub-group noting the existing subject matter experts in attendance. The previous Delivery Group and Flagship Groups are now disbanded.

4.14. The Partnership Enablers Programme Board will work with the Chair's of each forum to support a review of their Terms of Reference[1], confirm appropriate representatives from each organisation, and confirm the reporting arrangements to and from Unified Executive. It will also undertake further engagement with Elected Members, Healthwatch and the VCSE regarding the proposed model.

4.15. Our previous joint governance structures were branded as the Berkshire West Integrated Care Partnership. This terminology now relates to the BOB-wide ICP and is creating some confusion locally, however the need for a clear shared identity as a Place Partnership is still acknowledged and the Partnership Place Enablers Programme Board will lead development of a new brand identity for the Berkshire West Place**.**

[1] Noting the need to follow formal governance arrangements via the H&WB Boards for the LA level Boards.



5. Place Partnership Commitments

5.1. Alongside governance structures, it is important that we are all committed to a common understanding of what working in partnership means in practice.

5.2. To set the tone and expectations for our partnership we are working towards the following principles:

5.3. We are a partnership of equals.

5.4. We will trust each other, be open and transparent and share common purpose.

5.5. We will assume the best of each other and support one another to better understand the drivers behind individual organisational perspectives.

5.6. We will lead beyond organisational boundaries and always act in the best interests of the residents we serve.

5.7. We will look at information and outputs at a Local Authority level (and beyond) by default where possible to better understand specific local needs.

5.8. We will move away from a legacy transactional, contracting, commissioner-provider model to a transformational, collaborative, outcomes-focussed way of working.

5.9. We will actively work to remove barriers that prevent effective team-working.

5.10. We will continually review our partnership ways of working and make improvements as we go.

5.11. We will hold each other to account.

5.12. We will make decisions and stick to them.

5.13. We will protect the time to meet as a Unified Executive.

6. Unified Executive Work Plan

6.1. The Unified Executive will ensure that our joint programme of work is delivering improvements for our residents, in line with the commitments noted in Section 4 above.

6.2. The workplan ensures good oversight and assurance over our core priority programmes alongside other important partnership subjects.

7. Contribution to Reading's Health and Wellbeing Strategic Aims

7.1.

1. Reduce the differences in health between different groups of people
2. Support individuals at high risk of bad health outcomes to live healthy lives
3. Help children and families in early years
4. Promote good mental health and wellbeing for all children and young people
5. Promote good mental health and wellbeing for all adults

7.2. The PBP structure and priorities for integrated working contained within this report will support the above Health and Wellbeing Strategy priorities by strengthening our combined attention and oversight across Berkshire West on key areas of delivery to ultimately improve resident outcomes. It therefore links either directly or indirectly to the Reading Health and Wellbeing Board strategic aims.

8. Environmental and Climate Implications

8.1. There are no Environmental and Climate Impacts arising from this report.

9. Equality Implications

9.1. Not applicable.

10. Other Relevant Considerations

10.1. Not applicable.

11. Legal Implications

11.1. Not applicable.

12. Financial Implications

12.1. Not applicable.

13. Timetable for Implementation

13.1. Not applicable.

14. Background Papers

14.1. There are none.

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READING HEALTH AND WELLBEING BOARD

Date of Meeting	14 July 2023
Title	BOB ICB Joint Capital Resource Use Plan 2023/24
Purpose of the report	To note the report for information
Report author	Sarah Webster
Job title	Executive Place Director – Berkshire West
Organisation	BOB - ICB
Recommendations	1. That the Health & Wellbeing Board note the BOB ICB Capital Resource Use Plan for information

1. Executive Summary

1.1. This briefing seeks to update the Reading Health and Wellbeing Board on the 2023/24 Capital Resource Plan published by the Buckinghamshire, Oxfordshire, Berkshire West ICB which sets out plans for ICS Estate / infrastructure capital spend for the year.

2. Policy Context

2.1. The National Health Service Act 2006, as amended by the Health and Care Act 2022 (the amended 2006 Act) sets out that an ICB and its partner NHS trusts and foundation trusts:

• must before the start of each financial year, prepare a plan setting out their planned capital resource use

• must publish that plan and give a copy to their integrated care partnership, Health & Well-being Boards and NHS England

• may revise the published plan - but if they consider the changes significant, they must re-publish the whole plan; if the changes are not significant, they must publish a document setting out the changes.

2.2. In line with the amended 2006 Act, ICBs are required to publish these plans before or soon after the start of the financial year and report against them within their annual report.

3. Joint Capital Resource Use Plan

3.1. The document sets out that the Vision for the Estates workstream across BOB ICB is to work collaboratively to provide an estate that facilitates the delivery of the BOB ICS long term plan, responding to, and supporting the delivery of the aims of each of the service workstreams;

▪ Ensuring the ICS Estate can support the delivery of the Long-Term Plan service aims and objectives

▪ Driving efficiency and reducing variation wherever feasible by using information related to utilisation, cost, and efficiency in relation to the healthcare estate in BOB ICS

▪ Working across partners to maximise the use of good quality healthcare buildings, where required, and rationalising poor-quality premises.

- Improving the quality and provision of assets across the ICS
- Ensuring a collaborative approach to use of assets across the full extent of the public estate to support the changing models and locations for delivery of care.

4. Contribution to Reading's Health and Wellbeing Strategic Aims

4.1.

1. Reduce the differences in health between different groups of people
2. Support individuals at high risk of bad health outcomes to live healthy lives
3. Help children and families in early years
4. Promote good mental health and wellbeing for all children and young people
5. Promote good mental health and wellbeing for all adults

4.2. This document both directly and indirectly supports the broad strategic Health and Wellbeing strategic aims through its vision and ambition to improve healthcare estate and rationalising use of poor quality premises accessed by the wider workforce and residents.

5. Environmental and Climate Implications

5.1. There are no immediate Environmental and Climate Impacts arising from this report although the reduction in use of poor quality and inefficient estate will have a positive impact .

6. Equality Implications

6.1. Not applicable.

7. Other Relevant Considerations

7.1. Not applicable.

8. Legal Implications

8.1. Not applicable.

9. Financial Implications

9.1. Direct implications on use of capital spend to the BOB ICB with indirect implications to Reading HWBB.

10. Timetable for Implementation

10.1. Not applicable.

11. Background Papers

11.1. There are none.

12. Appendices

12.1. Please see link to the Joint Capital Resource Plan - a copy is also attached

23-24-joint-capital-resource-use-plan-bob-system.pdf (icb.nhs.uk)

Joint capital resource use plan – 2023/24

Overview

The National Health Service Act 2006, as amended by the Health and Care Act 2022 (the amended 2006 Act) sets out that an ICB and its partner NHS trusts and foundation trusts:

- must before the start of each financial year, prepare a plan setting out their planned capital resource use
- must publish that plan and give a copy to their integrated care partnership, Health & Well-being Boards and NHS England
- may revise the published plan - but if they consider the changes significant, they must re-publish the whole plan; if the changes are not significant, they must publish a document setting out the changes.

In line with the amended 2006 Act, ICBs are required to publish these plans before or soon after the start of the financial year and report against them within their annual report.

The relevant section of the Health and Care Act 2022 can be found via the following Health and Care Act 2022 (legislation.gov.uk) and reference should be made to sections **14Z56 and 14Z57.**

REGION	**South East**
ICB / SYSTEM	**Buckinghamshire Oxfordshire and Berkshire West**

Introduction

Guidance:
Please provide some high level commentary about the joint capital plan which should be developed between the ICB and partner NHS Trust and foundation trusts – key strategic priorities, key schemes throughout the year, background to what happened last year, overview funding sources etc.

Our Vision

Our vision for the Estates workstream across BOB is to work collaboratively to provide an estate that facilitates the delivery of the BOB ICS long term plan, responding to, and supporting the delivery of, the aims of each of the service workstreams;

- Ensuring the ICS Estate can support the delivery of the LTP service aims and objectives
- Driving efficiency and reducing variation wherever feasible by using information related to utilisation, cost and efficiency in relation to the healthcare estate in BOB ICS
- Working across partners to maximise the use of good quality healthcare buildings , where required, and rationalising poor quality premises.
- Improving the quality and provision of assets across the ICS
- Ensuring a collaborative approach to use of assets across the full extent of the public estate to support the changing models and locations for delivery of care.

Key Aims of the BOB ICS Estates workstream.

- To develop an estate and capital plan which supports the delivery of the clinical service delivery with the maximum possible flexibility whilst ensuring that estates are safe and as efficient as possible - Continuing to agree priorities and programmes for asset investment and disposal.
- Identifying, prioritising and supporting resourcing options for capital projects, including appropriate involvement and decision making associated with business case development and formal approval.
- Ensuring that the ICS makes the best possible use of assets and that any capital investment is used to maximise service transformation.
- A commitment to sustainable development and environmental targets and ICS wide sustainable development plans
- Ensuring safe, warm and effective services and environments, recognising the needs of our patients, visitors and staff, working together with our partners in health and public services
- Ensure the Estate responds to the changes and efficiencies driven out by digital transformation.

Current and forthcoming BOB ICS capital & estates activity

Over 2022/23 BOB worked together to support the improvement of the NHS estate and the delivery of the BOB Clinical Strategy by providing suitable accommodation in the required locations (via the BOB Estates work stream). This work continues to progress through collaborative working across places and organisations to deliver:

- Production of priorities for BOB ICS Estates activity, and plans by organisation for the development of place Estates work.
- Development of a prioritisation framework to inform strategic estates and capital investment across the three places within BOB – to be carried forward into capital investment processes.
- Prioritisation and consolidation of the three place strategies into BOB estates and capital investment priorities. Capital investment priorities and plans were rated 'good' by NHSE.
- Reduction of backlog maintenance within the estate. This is recognised as critical to supporting the delivery of the BOB clinical Strategies. It is recognised that funds are limited and we will work together to ensure that the strategic clinical need for the properties within our estate is understood, ensuring that funds are allocated appropriately.
- Removing Unwarranted Variations. The estates work stream is utilising the model hospital data to identify unwarranted cost variations relating to estates and facilities, and investigating opportunities to remove these. Opportunities include shared procurement, and where appropriate the development of shared services.
- Development of BOB wide sustainability plans to deliver the system's required reduction in carbon emissions. The workstream will undertake a self-audit, and identify potential areas for improvement, including co-working and procuring, the use of alternative energy systems.

This work will continue into 2023/24 and beyond to align the estates priorities and vision with the overall priorities and vision of the ICS Long Term Plan. Work will include focusing on development and delivery of robust, affordable local estates strategies that include delivery of agreed surplus land disposal ambitions across places and the ICS as well as maximising opportunities for additional capital into the area.

Primary Care Networks (PCNs) across BOB engaged with the national PCN Toolkit programme during 2022/23 which aims to build on the initial national Primary Care Estate baseline exercise undertaken in the prior year.
Use of the PCN Toolkit support PCNs in developing their Clinical Strategies and then their emerging Estate Strategy to support this clinical need.
This work will provide both the baseline and strategic direction of travel across Primary Care that can be built into the overall ICS Estates strategy and allow the evidence base for prioritisation should any new capital streams become available.

Royal Berkshire NHS Foundation Trust has recently been awarded seed funding via the New Hospitals Programme. This will support the development of a long term investment programme in the health infrastructure and we are keen to develop these principles further across the ICS and support all our organisations to benefit from future waves to eradicate backlog maintenance, improve safety and transform the way our services are provided to our population.
We are awaiting the formal ministerial announcement relating to associated timeframes for progressing with the project with the ambition likely for delivery in 2028-2030.

Assumed Sources of Funding for 2023/24

Guidance:
Please provide detailed of the overall funding envelopes to which the system will be working to.
Explain any assumptions (and related risks) associated with the assumed sources and quantum's of funding for the ICB and Partner Trusts
Draft table inserted which can be expanded upon.

Source	£k
23/24 Provider Capital Allocation	92,212
Prior Year Revenue Performance (75% assumed)	6,332
	98,544
5% Over programming	2,313
	100,857
23/24 ICB Capital Allocation	**2,996**
Total Source of 23/24 Capital Funds	**103,853**

- The above table gives detail of the assumed capital funding envelope that the BOB system will be working to in 23/24.
- £6.3m of the allocation relates to performance against revenue funding in the prior year and whilst on target to achieve required financial performance the final position for 22/23 is subject to audit confirmation.
- 5% Overprogramming has been assumed to allow for slippage in some of the schemes at the beginning of the financial year.

Overview of Ongoing Scheme Progression

Guidance:
Please provide an overview of scheme progression. Probably should only be schemes above a certain level

The main schemes that will be invested in across BOB during 2023/24 relate to:

- £43m - Routine/Backlog Maintenance
- £23m - Digital & IT Investment
- £11m - Theatre Reprovision
- £15m – Plant & Machinery, Public Sector Decarbonisation Scheme
- £5m - Equipment

Risks and Contingencies

Guidance:
Insert any notable risks and/or contingencies associated with the capital plan. Consider RAG rating risks also.

The estate across BOB is a mix of bespoke buildings built in a range of different eras across multiple sites and includes PFI hospitals and LIFT premises. While several hospitals / buildings are relatively new and in good condition, much of the estate is over 35 years old, no longer fit for purpose, cannot be effectively redesigned and used to provide health services in the 21st century. Key details:

- ICS estate extends to some 317 properties on over 116 Hectares and buildings with a gross internal area of over 800,000m2
- ICS total estate cost of c.£116m (exc. GP properties)
- c.£204.5m backlog maintenance
- c.£68m high-risk backlog maintenance

As such there are significant risks across the system

- that buildings will fail to conform to modern building compliance regulations.
- to building structure and service provision due to backlog maintenance issues.
- the historic piecemeal nature of the estate gives potential risks to modern joint service provision.

As a result of historic funding challenges and siloed ways of working the majority of estate in BOB is unfit for purpose and unable to accommodate population growth and new ways of working including integrated neighbourhood teams as described in the Integrated Care Partnership Strategy. there is the risk of: BOB ICB being unable to transform primary and community care and meet its access objectives as per the Operational and Joint Forward plans Resulting in: inadequate primary and community access to essential services and an increase in inappropriate A&E attendance.

Business Cases in 2023/24

Guidance:
Please insert detail of some of the key business cases in the ICB that are likely to be submitted in 2023/24.

In addition to our core system capital Bob is planning to submit business case against national capital schemes as below:

National forum for Endoscopy Funding

- £5.7m Endoscopy Space Bracknell, Royal Berkshire NHS Foundation Trust

Additional Capacity Funding

- £10.1m General & Acute Beds, Buckinghamshire NHS Trust
- £ 5.9m General & Acute Beds, Oxford University Hospital NHS Foundation Trust

National Upgrades Programme – Wave 2 Capital Funding

- £5.9m Lacehill Primary Care Development North Bucks, BOB ICB
- £1.4m Whitehill Primary Care Development Central Aylesbury Bucks, BOB ICB

Cross System Working

Guidance:
If applicable, can you detail how your system capital plan is coordinated with other systems or providers located in other systems.

There is continual close system working between BOB and other local systems and providers :

- Hampshire and Isle of Wight ICS (SHIP) - co-ordination of capital programme pertaining to South Central Ambulance Service (SCAS)
- Frimley ICS – interlinked working relationships through Berkshire Healthcare Foundation Trust
- Milton Keynes NHS Foundation Trust & Swindon NHS Foundation Trust – interlinked working relationships with Oxford University Hospitals NHS Foundation Trust through Radiotherapy Outreach Services.

Capital Planning & Prioritisation

Guidance:
Please detail how your system is prioritising available resources for investments which contribute *to the wider local strategic priorities of the ICS, and maximise efficiencies within an affordable envelopes as well as how this aligns with and supports the ICS' wider infrastructure strategy - in particular, priorities and plans for future use and development of its estate and assets.*

Significant investment is required within the estate portfolio to address lack of investment over a number of years, clinical compliance, backlog maintenance, capacity and to support new models of care and transformation. As such whilst more efficient use of the estate is envisaged (supported through digital transformation opportunities, care closer to home and through acute, primary care and community transformation) it is unlikely that either overall running costs of the estate or the GIA footprint will reduce significantly with the existing estate.
The estate workstream will be working to ensure that opportunities identified via Carter, ERIC and model hospital metrics are identified and progressed. This will include opportunities for identifying and resolving unoccupied space across all health partners, and increasingly across the wider public estate.
The estate workstream has already identified a pipeline of major estate investment that will be required to meet these ambitions and reduce cost.

Annex A – Buckinghamshire Oxfordshire and Berkshire West ICB 2023/24 CAPITAL PLAN

	CDEL	ICB	Berkshire Healthcare NHS Foundation Trust	Buckinghamshire Healthcare NHS Trust	Oxford Health NHS Foundation Trust	Oxford University Hospitals NHS Foundation Trust	Royal Berkshire Hospitals NHS Foundation Trust	Total Full Year Plan	Narrative on the main categories of expenditure
		£'000	**£'000**	**£'000**	**£'000**	**£'000**	**£'000**	**£'000**	
Provider	Operational Capital		11,470	20,347	10,109	31,538	27,393	**100,857**	Digital/IT; Routine Maintenance; Backlog Maintenance; New build; Equipment
ICB	Operational Capital	2,996						**2,996**	GPIT refresh; Minor improvement Grants
	Total Op Cap	**2,996**	**11,470**	**20,347**	**10,109**	**31,538**	**27,393**	**103,853**	
Provider	Impact of IFRS 16		867	6,580		6,544	30,870	**44,861**	Leases
ICB	Impact of IFRS 16	524						**524**	Leases
Provider	Upgrades & NHP Programmes								
Provider	National Programmes (diagnostics, Front line digitisation, Mental Health, TIF)			6,294	3,732	12,399		**22,425**	Front Line Digitalistation; Diagnostic Digitalisation Capability; Elective Care Recovery/Targeted Investment Fund
Provider	Other (technical accounting)		1,524	3,177		6,893		**11,594**	
	Total system CDEL	**3,520**	**13,861**	**36,398**	**13,841**	**57,374**	**58,263**	**179,737**	Total Providers only

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Team Reading

COVID 19 pandemic update

Reading Health and Wellbeing Board
14th July 2023

Reading Borough Council
Working better with you

Current situation: WHO

End of the public health emergency

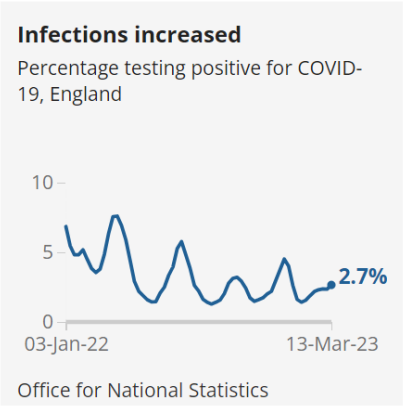
- On 5th May 2023 the Director General of the UN World Health Organization (WHO) declared an end to COVID-19 as a public health emergency.
- For over 12 months, the pandemic had been assessed as on a downward trend with immunity increasing due to the vaccination programmes. Death rates have decreased and the pressure on once overwhelmed health systems, has eased.

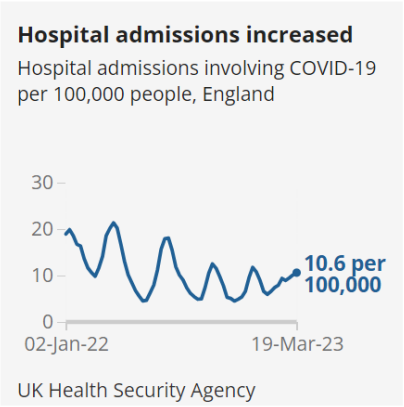
This did not mean that the disease is no longer a global threat.

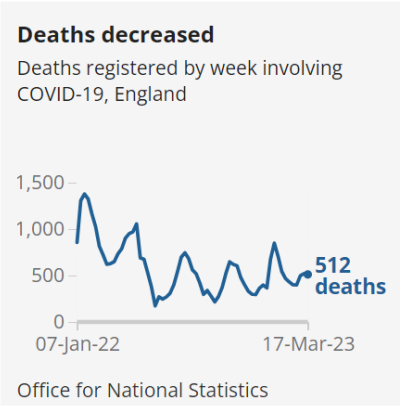
- Cumulative cases worldwide now stand at 765,222,932, with 6,921,614.deaths that are known about
- As of 30 April, a total of more than 13.3 billion vaccine doses have been administered worldwide.
- COVID 19 is still killing and changing. With estimations of three deaths per minute globally. The risk remains of new variants emerging that cause new surges in cases and deaths.
- In The United Kingdom, from 3 January 2020 to 12:23pm CEST, 7 June 2023, there have been 24,618,868 confirmed cases of COVID-19 with 226,645 deaths, reported to WHO. As of 11 September 2022, a total of 151,248,820 vaccine doses have been administered.

https://covid19.who.int/?mapFilter=cases

Current situation England







- Between 28 May 2023 and 3 June 2023, 4,331 people had a confirmed positive test result. This shows a decrease of 27.1% compared to the previous 7 days.
- 3,232,651 people had been given a spring booster by the end of 31 May 2023.
- Between 16 May 2023 and 22 May 2023, 2,268 went into hospital with coronavirus. This shows a decrease of 13.5% compared to the previous 7 days.
- There were 3,116 patients in hospital with coronavirus on 24 May 2023
- There were 81 coronavirus patients in hospital beds with a mechanical ventilator on 24 May 2023.
- Between 6 May 2023 and 12 May 2023, there have been 252 deaths with COVID-19 on the death certificate. This shows a decrease of 7.4% compared to the previous 7 days.

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19/latestinsights
https://coronavirus.data.gov.uk/
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronaviruscovid19infectionsurveypilot/1june2022

Current situation Reading

- On the 29th May the number of people receiving a PCR test and positivity in the previous 7 days was 180 5.6% from 5% on 21st May
- By 31st May the uptake of the spring booster was 65%
- On 22nd May 4 COVID 19 patients were admitted to hospital RBFT
- On 24th May there were 18 COVID 19 patients in hospital
- 19th May was the last day on which there was COVID 19 patient on mechanical ventilation
- There was 1 death on 19th May and none recorded since

Vaccine Booster Programme 2023

- At the start of 2023 the transition continued away from a pandemic emergency response towards pandemic recovery.
- In January 2023 the Joint Committee on Vaccination and Immunisation advised that the 2021 booster offer (third dose) for persons aged 16 to 49 years who are not in a clinical risk group should close in alignment with the close of the autumn 2022 booster vaccination campaign. The autumn 2022 booster campaign and the first booster offer closed on 12 February 2023. Vulnerable people aged 75 years and older, residents in care homes for older people, and those aged 5 years and over with a weakened immune system were offered the spring booster until 30 June 2023
- In January the JCVI advised further booster vaccines for persons at higher risk of serious illness through into an autumn booster programme later in Autumn 2023 yet to be announced.
- Emergency surge vaccine responses may be required should a novel variant of concern emerge with clinically significant biological differences compared to the Omicron variant.

Ongoing Concerns

- On 24th February the government removed the last domestic restrictions and moved to 'Living with Covid' which depends upon everyone getting vaccinated and adopted behaviours that reduce the risk of respiratory infection
- The global pandemic is not yet over and the Government's Scientific Advisory Group for Emergencies (SAGE) is clear there is considerable uncertainty about the path that the pandemic will now take in the UK
- There have been 226,645 deaths in the UK
- It is estimated that there are 2m cases of self reported Long Covid in the UK (3.1% of the population)
- The coronavirus is still a challenge in areas of the world not fully covered by vaccine programmes, it has the ability to mutate into a more virulent form and present a new risk
- The risk of an influenza pandemic remains high so resources for vaccinations and pandemic control measures need to be maintained and embedded within systems
- The structural barriers that restricted uptake by vulnerable population groups remain with the potential to impact on the uptake of other important vaccination and immunisation programmes

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1june2022
https://www.gov.uk/government/publications/covid-19-response-living-with-covid-19/covid-19-response-living-with-covid-19#living-with-covid-19

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