Notice of Meeting

Oxfordshire Joint Health Overview & Scrutiny Committee

Thursday, 21 November 2024 at 10.00 am

Room 2&3 - County Hall, New Road, Oxford OX1 1ND

These proceedings are open to the public

If you wish to view proceedings online, please click on this Live Stream Link. However, that will not allow you to participate in the meeting.

Membership

Chair - Councillor Jane Hanna OBE
Deputy Chair – District Councillor Katherine Keats-Rohan

Councillors:	Nigel Champken-Woods	Nick Leverton	Freddie van Mierlo
	Jenny Hannaby	Michael O'Connor	Mark Lygo
District Councillors:	Paul Barrow	Elizabeth Poskitt	Dorothy Walker
	Susanna Pressel		
Co-optees:	Barbara Shaw		

Date of next meeting: *30 January 2025*

Notes:

For more information about this Committee please contact:		
Scrutiny Officer	-	*Email: scrutiny @oxfordshire.gov.uk*
Committee Officer	-	*Scrutiny Team* *Email: Email: scrutiny@oxfordshire.gov.uk*

Martin Reeves
Chief Executive

November 2024

What does this Committee review or scrutinise?

- Any matter relating to the planning, provision and operation of health services in the area of its local authorities.
- Health issues, systems or economics, not just services provided, commissioned or managed by the NHS.

How can I have my say?

We welcome the views of the community on any issues in relation to the responsibilities of this Committee. Members of the public may ask to speak on any item on the agenda or may suggest matters which they would like the Committee to look at. **Requests to speak must be submitted to the Committee Officer no later than 9 am on the working day before the date of the meeting.**

About the Oxfordshire Joint Health Overview & Scrutiny Committee

The Joint Committee is made up of 15 members. Twelve of them are Councillors, seven from Oxfordshire County Council, and one from each of the District Councils – Cherwell, West Oxfordshire, Oxford City, Vale of White Horse, and South Oxfordshire. Three people can be co-opted to the Joint Committee to bring a community perspective. It is administered by the County Council. Unlike other local authority Scrutiny Committees, the work of the Health Scrutiny Committee involves looking 'outwards' and across agencies. Its focus is on health, and while its main interest is likely to be the NHS, it may also look at services provided by local councils which have an impact on health.

About Health Scrutiny

Health Scrutiny is about:

- Providing a challenge to the NHS and other organisations that provide health care
- Examining how well the NHS and other relevant organisations are performing
- Influencing the Cabinet on decisions that affect local people
- Representing the community in NHS decision making, including responding to formal consultations on NHS service changes
- Helping the NHS to develop arrangements for providing health care in Oxfordshire
- Promoting joined up working across organisations
- Looking at the bigger picture of health care, including the promotion of good health
- Ensuring that health care is provided to those who need it the most

Health Scrutiny is NOT about:

- Making day to day service decisions
- Investigating individual complaints.

What does this Committee do?

The Committee meets up to 5 times a year or more. It develops a work programme, which lists the issues it plans to investigate. These investigations can include whole committee investigations undertaken during the meeting, or reviews by a panel of members doing research and talking to lots of people outside of the meeting. Once an investigation is completed the Committee provides its advice to the relevant part of the Oxfordshire (or wider) NHS system and/or to the Cabinet, the full Councils or scrutiny committees of the relevant local authorities. Meetings are open to the public and all reports are available to the public unless exempt or confidential, when the items would be considered in closed session.

If you have any special requirements (such as a large print version of these papers or special access facilities) please contact the officer named on the front page, giving as much notice as possible before the meeting

A hearing loop is available at County Hall.

AGENDA

1. Apologies for Absence and Temporary Appointments

2. Declarations of Interest - see guidance note on the back page

3. Minutes (Pages 1 - 12)

To approve the minutes of the meeting held on 12 September 2024 and to receive information arising from them.

The Committee is recommended to **AGREE** the minutes as an accurate record having raised any necessary amendments.

4. Co-Optee Appointment

The purpose of this item is for the Committee to **AGREE** to the appointment of a Coopted member.

The Committee is **RECOMMENDED** to: -

1. **NOTE** the requirement to fill in two vacant co-opted posts on the Oxfordshire Joint Health Overview Scrutiny Committee (JHOSC) and the work undertaken to fill these posts.

2. **AGREE** to Sylvia Buckingham's appointment as a co-opted member of the JHOSC (subject to her completion of the necessary paperwork).

NB This paper is to follow.

5. Speaking to or Petitioning the Committee

Members of the public who wish to speak at this meeting can attend the meeting in person or 'virtually' through an online connection.

To facilitate 'hybrid' meetings we are asking that requests to speak or present a petition are submitted by no later than 9am four working days before the meeting i.e., 9am on Friday 15 November. Requests to speak should be sent to scrutiny@oxfordshire.gov.uk and omid.nouri@oxfordshire.gov.uk

If you are speaking 'virtually', you may submit a written statement of your presentation to ensure that your views are taken into account. A written copy of your statement can be provided no later than 9am 2 working days before the meeting. Written submissions should be no longer than 1 A4 sheet.

6. Chairs Update (Pages 13 - 94)

Cllr Hanna will provide a verbal update on relevant issues since the last meeting.

There are SIX documents attached this item:

1. A HOSC report containing recommendations from the Committee on Adult and Older Adult Mental Health in Oxfordshire, which was discussed during the 12 September 2024 HOSC meeting.

2. A HOSC report containing recommendations from the Committee on Winter Planning, which was discussed during the 12 September 2024 HOSC meeting.

3. A HOSC report containing recommendations from the Committee on Medicine Shortages, which was discussed during the 12 September 2024 HOSC meeting.

4. A HOSC report containing recommendations from the Committee on Epilepsy Services, which was discussed during the 12 September 2024 HOSC meeting.

5. A letter on behalf of the Committee sent to Karin Smyth MP, urging for greater resource to be allocated to epilepsy services, and for the suspension the MHRA regulatory updates of 2024 pending an independent national review of the UK's Pregnancy Prevention Programme.

6. A letter on behalf of the Committee sent to NHSE Specialist Commissioning, urging for further funding to be allocated to epilepsy services and for NHSE to escalate to ministers to support the suspension of the MHRA regulatory updates of 2024 pending an independent national review of the UK's Pregnancy Prevention Programme.

7. A letter on behalf of the Committee sent to Layla Moran MP, requesting the Health and Social Care Parliamentary Select Committee to embark on thorough and ongoing scrutiny of the Pregnancy Prevention Programme.

The Committee is recommended to **NOTE** the Chair's update having raised any relevant questions.

7. BOB ICB Restructure Situation Update

A verbal update will be provided to the committee on the BOB ICB restructure by Stephen Chandler, OCC Executive Director (People), on current discussions around the BOB ICB restructure. The Committee will also be provided with the letter sent to the Secretary of State and is recommended to **CONFIRM** its support for the submission.

NB This report is to follow.

8. Oxfordshire Healthy Weight (Pages 95 - 124)

Derys Pragnell (Consultant in Public Health, Oxfordshire County Council) has been invited to present a report providing an update on the work undertaken by Oxfordshire County Council and its partners to promote healthy weight amongst Oxfordshire residents.

Please note: The report submitted for this item includes input from the BOB Integrated Care Board so as to take account of the NHS's work around healthy weight in Oxfordshire.

There are FOUR documents attached to this item:

1. The main report.

2. Appendix 1: Recommendations from Healthy Weight Health Needs Assessment

3. Appendix 2: Whole systems approach to healthy weight action plan 23/24

4. Appendix 3: Oxfordshire WSA To excess weight: Work undertaken or in progress update 2024

The Committee is invited to consider the report, raise any questions and **AGREE** any recommendations arising it may wish to make.

9. Healthwatch Oxfordshire Update - Project on People's Experiences of Leaving Hospital in Oxfordshire (Pages 125 - 224)

Veronica Barry (Executive Director, Healthwatch Oxfordshire) and Katharine Howell (Senor Research and projects officer, Healthwatch Oxfordshire) have been invited to present a report on a Healthwatch Oxfordshire project on 'People's Experiences of Leaving Hospital in Oxfordshire'.

There are TWO key reports attached to this item:

1. A general Healthwatch Oxfordshire Update Report.

2. The report produced by Healthwatch Oxfordshire on peoples' experiences of leaving hospital.

The Committee is invited to consider the Healthwatch Oxfordshire reports and **NOTE** them having raised any questions arising Barry (Executive Direc Veronica Barry (Executive Director, Healthwatch Oxfordshire) and Katharine Howell (Senor Research and projects officer, Healthwatch Oxfordshire) have been invited to present a report on a Healthwatch Oxfordshire project on 'People's Experiences of Leaving Hospital in Oxfordshire'.

10. Maternity Services in Oxfordshire (Pages 225 - 238)

Oxford University Hospitals NHS Foundation Trust has been invited to present a report on the current state of Maternity Services in Oxfordshire.

The Committee is invited to consider the report, raise any questions and **AGREE** any recommendations arising it may wish to make.

11. Forward Work Plan (Pages 239 - 242)

To **AGREE** the Committee's proposed work programme for its upcoming meetings.

12. Actions and Recommendations Tracker (Pages 243 - 278)

The Committee is recommended to **NOTE** the progress made against agreed actions and recommendations having raised any questions.

Councillors declaring interests

General duty

You must declare any disclosable pecuniary interests when the meeting reaches the item on the agenda headed 'Declarations of Interest' or as soon as it becomes apparent to you.

What is a disclosable pecuniary interest?

Disclosable pecuniary interests relate to your employment; sponsorship (i.e. payment for expenses incurred by you in carrying out your duties as a councillor or towards your election expenses); contracts; land in the Council's area; licenses for land in the Council's area; corporate tenancies; and securities. These declarations must be recorded in each councillor's Register of Interests which is publicly available on the Council's website.

Disclosable pecuniary interests that must be declared are not only those of the member her or himself but also those member's spouse, civil partner or person they are living with as husband or wife or as if they were civil partners.

Declaring an interest

Where any matter disclosed in your Register of Interests is being considered at a meeting, you must declare that you have an interest. You should also disclose the nature as well as the existence of the interest. If you have a disclosable pecuniary interest, after having declared it at the meeting you must not participate in discussion or voting on the item and must withdraw from the meeting whilst the matter is discussed.

Members' Code of Conduct and public perception

Even if you do not have a disclosable pecuniary interest in a matter, the Members' Code of Conduct says that a member 'must serve only the public interest and must never improperly confer an advantage or disadvantage on any person including yourself' and that 'you must not place yourself in situations where your honesty and integrity may be questioned'.

Members Code – Other registrable interests

Where a matter arises at a meeting which directly relates to the financial interest or wellbeing of one of your other registerable interests then you must declare an interest. You must not participate in discussion or voting on the item and you must withdraw from the meeting whilst the matter is discussed.

Wellbeing can be described as a condition of contentedness, healthiness and happiness; anything that could be said to affect a person's quality of life, either positively or negatively, is likely to affect their wellbeing.

Other registrable interests include:

a) Any unpaid directorships
b) Any body of which you are a member or are in a position of general control or management and to which you are nominated or appointed by your authority.

c) Any body (i) exercising functions of a public nature (ii) directed to charitable purposes or (iii) one of whose principal purposes includes the influence of public opinion or policy (including any political party or trade union) of which you are a member or in a position of general control or management.

Members Code – Non-registrable interests

Where a matter arises at a meeting which directly relates to your financial interest or wellbeing (and does not fall under disclosable pecuniary interests), or the financial interest or wellbeing of a relative or close associate, you must declare the interest.

Where a matter arises at a meeting which affects your own financial interest or wellbeing, a financial interest or wellbeing of a relative or close associate or a financial interest or wellbeing of a body included under other registrable interests, then you must declare the interest.

In order to determine whether you can remain in the meeting after disclosing your interest the following test should be applied:

Where a matter affects the financial interest or well-being:

a) to a greater extent than it affects the financial interests of the majority of inhabitants of the ward affected by the decision and;
b) a reasonable member of the public knowing all the facts would believe that it would affect your view of the wider public interest.

You may speak on the matter only if members of the public are also allowed to speak at the meeting. Otherwise you must not take part in any discussion or vote on the matter and must not remain in the room unless you have been granted a dispensation.

OXFORDSHIRE JOINT HEALTH OVERVIEW & SCRUTINY COMMITTEE

MINUTES of the meeting held on Thursday, 12 September 2024 commencing at 10.00 am and finishing at 4.55 pm

Present:

Voting Members:	Councillor Jane Hanna OBE – in the Chair
	Councillor Nigel Champken-Woods Councillor Jenny Hannaby Councillor Nick Leverton Councillor Michael O'Connor Councillor Roz Smith Councillor Mark Lygo District Councillor Susanna Pressel District Councillor Katharine Keats-Rohan District Cllr Dorothy Walker District Cllr Ron Batstone
Co-opted Members:	Barbara Shaw
Other Members in Attendance:	Councillor Damian Haywood

Officers:

Dan Leveson- BOB ICB Director of Place.
Karen Fuller- Director of Adult Social Care.
Ansaf Azhar- Director of Public Health OCC.
Lily O'Connor- Programme Director Urgent and Emergency Care for Oxfordshire.
Ed Capo-Bianco- Urgent Care, Palliative and End of Life Care, Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB.
Ben Riley-Executive Managing Director for Community, Primary and Dental Care.
Chris Wright- Assistant Director Partnership Development (Oxfordshire).
Lola Martos- Head of Older Adult Services at Oxford Health NHS Foundation Trust.
Manny Jhawar-Gill- Commissioning Manager (Improve Enable), Adult Social Services, OCC.
Pippa Corner- Deputy Director Commissioning, Adult Social Services, OCC.
Nicola Leavesley- CEO of Response and current Chair of the Oxfordshire Mental Health Partnership (OMHP).
Catherine Sage- Oxford Health NHS Foundation Trust.
Julie Dandridge- Head of Primary Care Infrastructure,

Head of Pharmacy, Optometry and Dentistry, Lead for Primary Care across Oxfordshire, BOB ICB.
Claire Critchley- Medicines Optimisation Lead Pharmacist.
David Dean- Chief Executive Officer, Community Pharmacy Thames Valley.
Bhulesh Vadher- Clinical Director of Pharmacy and Medicines Management, Oxford University NHS Hospital Trust.
Professor Arjune Sen- Consultant Neurologist, OUH.
Jackie Roberts- Lead Learning Disability Epilepsy Specialist Nurse, OUH.
Rohini Rattihalli- Consultant Paediatric Medicine, OUH.
Marcus Neale- Epilepsy Specialist Nurse, Oxford University Hospitals NHS Foundation Trust.
Rustam Rea- Consultant, OUH.
Jane Adcock- Consultant Neurologist, OUH.
Janice Craig- Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB.

The Scrutiny Committee considered the matters, reports and recommendations contained or referred to in the agenda for the meeting [, together with a schedule of addenda tabled at the meeting/the following additional documents:] and agreed as set out below. Copies of the agenda and reports [agenda, reports and schedule/additional documents] are attached to the signed Minutes.

60/24 APOLOGIES FOR ABSENCE AND TEMPORARY APPOINTMENTS
(Agenda No. 1)

The following members tendered their apologies:
Cllr Paul Barrow, with District Cllr Ron Batstone substituting.
Cllr Freddie van Mierlo, with Cllr Roz Smith substituting.

61/24 DECLARATIONS OF INTEREST - SEE GUIDANCE NOTE ON THE BACK PAGE
(Agenda No. 2)

Cllr Hanna declared her interest as working for the health charity SUDEP Action.
Cllr Hannaby declared that she was involved with Wantage Community Hospital.
Cllr Haywood declared his interest in working for the NHS.

62/24 MINUTES

(Agenda No. 3)

The minutes of the Committee's meeting on 2 August 2024 were assessed for their accuracy.

The Committee **AGREED** the minutes as an accurate record of proceedings and that the Chair should sign them as such.

63/24 SPEAKING TO OR PETITIONING THE COMMITTEE

(Agenda No. 4)

No statements were made at this point.

64/24 RESPONSE TO HOSC RECOMMENDATIONS

(Agenda No. 7)

The Committee had received Acceptances and Responses to recommendations made as part of the following items:

1. GP provision in Oxfordshire (held during the 18 April 2024 HOSC meeting).

2. Integrated Neighbourhood Teams in Oxfordshire (held during the 06 June 2024 HOSC meeting).

The Committee **NOTED** the responses.

65/24 CHAIR'S UPDATE

(Agenda No. 5)

The Committee Chair outlined the following points to update the Committee on developments since the previous meeting:

1. A HOSC report containing recommendations from the Committee on Palliative/End of Life Care, which was discussed during the 06 June 2024 HOSC meeting, had been published in the agenda papers for this meeting.

2. A brief statement from the BOB Integrated Care Board Director of Urgent and Emergency Care for Oxfordshire, which outlined the redesignation of the Urgent care centres on the Horton General Hospital and John Radcliffe hospital sites, was included in the agenda. Lily O'Connor, Programme Director Urgent and Emergency Care for Oxfordshire, BOB ICB, explained that this redesignation was primarily for governance and reporting purposes and did not affect the centres' operations or names.

3. The HOSC's Oxford Community Health Hubs Working Group met with senior representatives of Oxford Health NHS Foundation Trust as well as the OCC Cabinet Member for transport to discuss the avenues of transportation and access to the newly developing health hubs for both patients and staff.

4. Maternity Update: HOSC had been involved in close and ongoing scrutiny of maternity services. Members would have seen the dossier produced by Keep the Horton General, and the Committee had received a briefing from OUH in July on the state of maternity services and highlighted the issues emerging from the dossier, urging the Trust to have a clear plan and to take adequate measures to address the issues with maternity services. A public meeting on maternity services was scheduled for the next HOSC meeting in November.

5. Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) Proposed Restructuring: The Chair addressed the proposals for restructuring within the ICB, which was the focus of the HOSC meeting in August. The Committee had expressed concerns about the impact of these proposals on partnership working with local authorities, the NHS, and the voluntary sector. The Chair noted that positive negotiations had been ongoing, but the ICB had not provided a written statement to reassure the Committee.

Stephen Chandler, the Director for People and Transformation, provided further details on the negotiations with the ICB. He mentioned that while there had been positive discussions, no written confirmation of this progress had been received. The Director expressed concerns about the ICB's operating model and the potential impact on local services. He also highlighted the importance of prevention and early intervention, which could be undermined by the proposed changes. The ICB had chosen not to give an update on the state of the proposed changes until after their Board Meeting at the end of September, which would be held in private.

The Committee **NOTED** the Chair's Update.

The Committee **AGREED** the following recommendations:

1. For the Committee to **DELEGATE** to the Health Scrutiny Officer, in consultation with the Chair and Director for People and Transformation, to request a call-in (on behalf of the County Council) from the Secretary of State for Health & Social Care in relation to the BOB ICB proposed operating model.
2. For the Committee to **DELEGATE** to the Health Scrutiny Officer and Chair to communicate to the Chair and CEO of the ICB the decision of HOSC, and to write to all Oxfordshire MPs to offer a briefing and to seek their support for a call-in.

66/24 WARNEFORD PARK HOSPITAL REDEVELOPMENT PROJECT

(Agenda No. 6)

The Committee had been closely involved in scrutinising and reviewing the Warneford Park Hospital Redevelopment Project. Oxford Health NHS Foundation Trust had approached the Committee with a view to brief them on the proposals for the redevelopment, as well as to seek endorsement and support for the Trust's bid for government funding to redevelop the hospital.

The Committee **AGREED** the following recommendations:

1. For the Committee to **AGREE** to the HOSC endorsement report. This endorsement report will then be sent to Oxford Health NHS Foundation Trust to support the bid for funding from government to redevelop the hospital.

2. For the Committee to **AGREE** that the Warneford Redevelopment Project does NOT constitute a Substantial Change.

67/24 WINTER PLANNING

(Agenda No. 8)

Lily O'Connor (Programme Director Urgent and Emergency Care for Oxfordshire), Ed Capo-Bianco (Urgent Care, Palliative and End of Life Care, Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB), Ben Riley (Executive Managing Director for Community, Primary and Dental Care), Sally Steele (Service Manager Hospitals, Adult Social Services), Tamsin Cater (Head of Transfer of Care Hub, OUH), Karen Fuller (Director of Adult Social Care), Ansaf Azhar (Director of Public Health OCC), and Dan Leveson (BOB ICB Director of Place) submitted a report on Winter Planning in Oxfordshire.

The first question from the Committee focused on workforce and funding challenges for the upcoming winter. The Committee asked what measures were being taken to address these challenges in the short term. The BOB ICB Director of Place highlighted that the winter plan was essentially an urgent emergency care plan, with workforce being a significant challenge. The Director of Adult Social Care explained that across the Oxfordshire system, efforts were being made to maximise the workforce, ensuring the right people were in the right place at the right time. She mentioned an ambitious recruitment campaign that had yielded positive results, particularly in recruiting qualified social workers and occupational therapists. Additionally, work was being done with care providers to support hospital discharges and ensure a buoyant home care market.

The Committee then raised concerns about A&E and ambulance handover times. The BOB ICB Director of Place indicated that while the four-hour standard in A&E had been challenging, improvements had been made through partnerships and the establishment of urgent care centres. The performance had improved, with the target for the year being 78%. He also touched on the challenges faced by different trusts and the importance of system-wide collaboration to manage discharges and patient flow.

The Committee inquired about the confidence in reducing ambulance handover times. The Head of Transfer of Care Hub reiterated that Oxfordshire was performing well in this area, with excellent relationships with the South Central Ambulance Service. She noted that it was rare for ambulance handover delays to exceed 60 minutes, and efforts were being made to further reduce this time.

The Committee asked about the maturity of community services. The Executive Managing Director for Community, Primary and Dental Care reflected on the challenges faced due to stagnant funding despite increasing demands from a

growing and ageing population. To address these challenges, he discussed efforts to streamline and consolidate services, such as implementing a single point of access for planned, urgent, and emergency care. This approach aimed to free up clinical time and improve efficiency, with some success already seen in the planned care sector.

Additionally, the Director mentioned ongoing staffing changes to make services more sustainable, moving away from short-term staffing solutions to long-term employment plans. This shift was expected to reduce costs associated with agency fees and provide more reliable staffing. He also discussed the development of hubs to bring together services from multiple locations, aiming to deliver more care closer to home.

The Committee raised concerns about primary care capacity during the winter. The Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB acknowledged that GP capacity was stretched, but efforts were being made to manage demand through triage models and the involvement of multidisciplinary teams. Investments in community pharmacies and same-day emergency care units were also supporting primary care capacity.

The Committee asked about the availability of vaccines and the challenges faced in certain areas. The Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB indicated that the vaccine programme had been commissioned to ensure better alignment and availability, with efforts to address any gaps in provision. The Director for Public Health reported no significant issues with vaccine availability this year, though prioritisation remained necessary. Compared to previous years, there was no notable increase in respiratory illnesses, but they would not be complacent.

The Committee inquired about the capacity for reablement services and the balance between patient flow and personalised care. The Service Manager for Hospitals in Adult Social Services explained that the discharge to assess model had been implemented to ensure decisions were made in patients' homes, allowing for better reablement opportunities. She acknowledged the challenges but emphasised the importance of system-wide collaboration to maximise resources and support patients effectively.

The Committee **AGREED** to delegate to the Health Scrutiny Officer and the Chair to finalise the wording of the recommendations.

68/24 ADULT AND OLDER ADULT MENTAL HEALTH IN OXFORDSHIRE

(Agenda No. 9)

Dan Leveson (BOB ICB Place Director for Oxfordshire), Chris Wright (Assistant Director Partnership Development, Oxfordshire), Lola Martos (Head of Older Adult Services at Oxford Health NHS Foundation Trust), Manny Jhawar-Gill (Commissioning Manager, Improve Enable, Adult Social Services, OCC), Pippa Corner (Deputy Director Commissioning, Adult Social Services, OCC), Nicola Leavesley (CEO of Response and current Chair of the Oxfordshire Mental Health Partnership, OMHP), Catherine Sage (Head of Service for Mental Health Urgent Care, Social Care, and Adult Eating Disorder Service, Oxford Health), Jared Fellows

(Health Improvement Practitioner, Public Health, OCC), Karen Fuller (Director of Adult Social Care, OCC), and Ansaf Azhar (Director of Public Health, OCC) presented a report on Adult and Older Adult Mental Health in Oxfordshire.

The Committee first inquired about the adult eating disorder service, specifically the contract between the BOB ICB and other providers covering community eating disorders. They asked about the extent to which these services were dealt with separately or as part of the overall mental health aspect, and the level of specialist provision available. The BOB ICB Place Director for Oxfordshire explained that specialist adult eating disorders services were commissioned on a larger scale through specialist commissioning, with Oxford Health as the lead commissioner. He clarified that the community services were delivered locally and were part of the system they worked on together. The Head of Service for Mental Health Urgent Care added that the regional services primarily included inpatient services and some intensive treatment services to avoid admission or support post-discharge. She mentioned that Oxfordshire had one inpatient service at Cotswold House in the Warneford Hospital and that the community adult eating disorder service covered the entire county.

The Committee then asked about the engagement of older adults, specifically those over 65, in the design and commissioning of older adult mental health services. The Head of Older Adult Services emphasised the importance of engaging service users and carers through active groups and working closely with the voluntary sector. She acknowledged the difficulties faced by older adults to have their voices heard, and this concern was always at the forefront of the service's efforts. The BOB ICB Place Director for Oxfordshire added that Oxford Health had a long history of person-centred, goals-based care, and that patient feedback was integral to service design. The Assistant Director of Partnership Development at Oxford Health highlighted their strategic initiative to increase patient involvement in care, surpassing their 80% target with 88% of service users reporting participation. This approach aimed to enhance patients' experiences and inform service delivery and commissioning decisions. Additionally, they planned to consolidate services for older adults and eating disorders under a single contract to offer a broader range of interventions. Patient surveys and external reviews were conducted to understand current service perceptions and identify gaps and challenges.

The Committee raised the issue of loneliness among older adults and asked about measures being taken to address this. The BOB ICB Place Director for Oxfordshire acknowledged the challenge, citing factors like rurality and transient populations. He highlighted various initiatives, such as the Move Together programme and Integrated Neighbourhood Teams, aimed at bringing people together and fostering community engagement. The Director for Public Health also mentioned the establishment of community hubs funded by Community Capacity Grants. He highlighted the Mental Health Prevention Concordat, a quarterly partnership focusing on enablers like green spaces, voluntary sector resources, and addressing different settings such as residential care and maternity. The approach aimed to systematically bring partners together to enhance mental health services, ensuring no one was overlooked, and to build workforce confidence in providing better mental health support.

The Committee asked about the extent of research collaboration with academic and voluntary sectors to improve mental health services. The CEO of Response and current Chair of Oxfordshire Mental Health Partnership (OMHP) expressed the need for more research and understanding, particularly in providing holistic services and prevention work. She noted the challenges of funding and resources but emphasised the sector's commitment to engaging communities and delivering flexible services.

The Committee inquired about the outcomes-based contract, which was coming to an end in March next year. They asked about its success, future plans, and evaluation methods. The BOB ICB Place Director for Oxfordshire explained that the outcomes-based contract was a pioneering model that linked payments to outcomes, although measuring outcomes had proven challenging. He mentioned that the contract had evolved over time, with a focus on delivering better value care through integrated pathways.

The Committee then turned to specific issues around suicide prevention and workforce support. They asked about the influence of the 2023 National Suicide Prevention Strategy on local efforts, stakeholder input, and training for professionals. The Health Improvement Practitioner explained that the local strategy was being refreshed to align with national priorities, with a focus on high-risk groups and targeted training. He reported that local suicide statistics and risk factors in Oxfordshire were consistent with national trends, with drugs, alcohol, relationship breakdowns, and bereavement being the leading risk factors for men. The male-to-female suicide ratio in Oxfordshire was lower than the national average, with 60% male and 40% female. At the end of the previous year, Oxfordshire Mind was commissioned to deliver a suicide prevention and mental health training programme, which began in January. This programme targeted key groups identified in national strategies, such as middle-aged men, pregnant women and new mothers.

The Committee also asked about the transition between different mental health services and the potential risks involved. The Head of Service for Mental Health Urgent Care acknowledged the challenges but assured that mechanisms were in place to ensure smooth transitions and minimise risks. She highlighted the importance of maintaining patient history and effective communication among professionals.

Finally, the Committee addressed the issue of detentions under Section 136 and the high rate of admissions to adult acute psychiatric beds in Oxfordshire. The Head of Service for Mental Health Urgent Care attributed this to the lack of a countywide crisis resolution home treatment team, which was a known gap in provision. She mentioned ongoing plans to establish such a team and improve crisis care.

The Committee **AGREED** to delegate to the Health Scrutiny Officer and the Chair to finalise the wording of the recommendations.

69/24 MEDICINE SHORTAGES

(Agenda No. 11)

Julie Dandridge (Head of Primary Care Infrastructure and Pharmacy), Claire Critchley (Medicines Optimisation Lead Pharmacist), David Dean (Chief Executive Officer for Community Pharmacy Thames Valley), Bhulesh Vadher (Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust), and Rustam Rea (Consultant at Oxford University NHS Hospital Trust) and Leyla Hannbeck (CEO of the Independent Pharmacies Association) attended to speak on the issue of Medicine Shortages.

The Head of Primary Care Infrastructure and Pharmacy highlighted the multifaceted root causes of medicine shortages and the significant impact on patients and healthcare providers. She noted the anxiety patients face when their usual medications are unavailable and the challenges for pharmacists and clinicians in managing these shortages.

The Committee inquired about the main complexities causing medicine shortages. They asked about the international context of manufacturing capacity and whether the impacts of this had now been addressed. The CEO of the Independent Pharmacies Association responded, explaining that global manufacturing capacity issues, dependency on raw materials from countries like China and India, and geopolitical factors contributed to the problem. She also mentioned the impact of Brexit and the UK's pricing strategies, which make it less attractive for manufacturers to supply medicines to the UK. She highlighted the increased demand for certain medications, such as HRT and ADHD treatments, which exacerbated the shortages.

The Committee then asked how NHS contracts and pricing strategies impacted medicine availability. The Chief Executive Officer for Community Pharmacy Thames Valley explained that the national contract for community pharmacies had remained unchanged for several years, creating financial pressures that had led to pharmacies closing. He noted that the contract drove down prices, discouraging manufacturers from supplying the UK market and causing pharmacies to dispense many items at a loss.

The Committee sought clarification on distribution issues contributing to shortages and whether these issues were national or local in scope and what measures could be taken to address them. The Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust explained that the distribution network itself was not the problem; rather, it was the availability of stock from wholesalers and manufacturers. He described the sophisticated systems in place within hospital pharmacies to manage stock and share resources regionally, contrasting this with the less coordinated systems in community pharmacies.

The Committee asked about the impact of medicine shortages on individual patients, particularly those with conditions requiring specific medications. The Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust provided examples of how shortages forced the use of alternative or unlicensed products, which could lead to further shortages. He emphasised the randomness of these shortages and the various factors that could cause them, such as

manufacturing issues or supply chain disruptions. The CEO of the Independent Pharmacies Association explained that while national protocols, such as the serious shortages protocol, allowed pharmacists to switch medicines during shortages, high demand still led to product shortages, as seen with antibiotics and Hormone Replacement Therapy (HRT) medicines. Despite pharmacists' extensive knowledge, they were unable to make simple prescription changes without prescriber approval, which added to the workload of healthcare professionals and caused delays for patients. The CEO advocated for regulatory changes to allow pharmacists to make minor remedial prescriptions, such as substituting different dosages of the same medicine, to improve efficiency.

The Committee raised concerns about the impact on patients with "cliff edge" conditions, where the absence of medication could be life-threatening. The Medicines Optimisation Lead Pharmacist explained the national and local mitigations in place, including systems to manage shortages and ensure alternative medications are available. She noted that while stockpiling was not done locally, there were national reserves for critical medications. Various systems were implemented locally to address shortages, including providing information on alternative medicines, although this could lead to further shortages. Collaboration between primary and secondary care was essential, with efforts to import supplies locally when necessary.

The Committee asked whether the issue of medicine shortages had impacted the workload of the clinical side of the NHS, and if this was being monitored. They also inquired about the global vulnerability to supply chain issues, and whether production could be brought into the UK to improve resilience. The Clinical Director of Pharmacy and Medicines Management noted that the UK's pharmaceutical industry had been offshored over the years, making it challenging to bring manufacturing back. He suggested that while it would be beneficial to increase local production, it was not entirely within the government's control. The Consultant at OUH highlighted the increased clinical and pharmacy burdens due to drug shortages, which necessitated additional resources and adjustments in patient care, particularly in managing diabetes medication.

The Committee questioned the communication and coordination efforts between Community Pharmacies to mitigate the risks associated with medicine shortages. The Chief Executive Officer for Community Pharmacy Thames Valley explained that pharmacies across BOB frequently shared stock via messaging groups to ensure patients received their medications. However, this practice added to pharmacists' workload, with each spending about a day a week locating stock.
The Medicines Optimisation Lead Pharmacist described the various communication channels used to keep healthcare providers informed, including regular updates on the ICB and OUH websites and newsletters. She acknowledged the challenges of keeping information current due to the rapidly changing situation.

The Committee **AGREED** to delegate to the Health Scrutiny Officer and the Chair to finalise the wording of the recommendations.

70/24 EPILEPSY SERVICES UPDATE

(Agenda No. 12)

Professor Arjune Sen (Consultant Neurologist, OUH), Jackie Roberts (Lead Learning Disability Epilepsy Specialist Nurse, OUH), Rohini Rattihalli (Consultant Paediatric Medicine, OUH), Marcus Neale (Epilepsy Specialist Nurse, OUH), Rustam Rea (Consultant, OUH), Jane Adcock (Consultant Neurologist, OUH), and Janice Craig (Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB), Rachael Corser (Chief Nurse, BOB ICB) and Sarah Fishburn (Senior Clinical Quality Improvement Manager, NHS England) attended to speak on the topic of epilepsy services.

The Chair invited registered speaker Kristi McDonald to address the Committee.

Kristi McDonald shared her personal experience with epilepsy and the impact of the new regulations on her life. She highlighted the severe neglect and ignorance faced by epilepsy patients. She described the complexities of living with epilepsy, the mental health impacts, and the recent tightening of policies on sodium valproate and topiramate. She criticised the policy for stripping away patient involvement and breaching reproductive rights, sharing examples of how the policy had negatively affected other patients.

The Committee then asked the Consultant Neurologist to introduce the epilepsy team and provide an overview of the service. The Consultant Neurologist explained the unpredictability of epilepsy, the associated comorbidities, and the socioeconomic impact. He highlighted the significant demand on the service, the shortage of specialist nurses and neurologists, and the long waiting times for patients. He also discussed the impact of the Medicines and Healthcare products Regulatory Agency (MHRA) regulations on the service, including the need for additional patient appointments and the challenges of implementing the new guidelines.

The Committee asked why the Oxfordshire epilepsy team was significantly under-resourced compared to other areas with similar populations, and what the historical context and funding situation behind this disparity were. The Epilepsy Specialist Nurse reflected on the increasing complexities in neurology since the late 1990s. Despite prioritising patient care, the nurse highlighted the difficulties in sustaining services due to insufficient resources, staffing, and funding, especially when national programmes lacked additional support.

The Committee inquired about the rise in demand for services for patients with learning disabilities and epilepsy. The Lead Learning Disability Epilepsy Specialist Nurse had been working closely with Oxford Health and Oxford University Hospitals to streamline services for patients in Oxfordshire. There were two learning disability teams, each with experienced Band 6 and Band 7 nurses. These teams primarily supported individuals with epilepsy and other health conditions, ensuring medication compliance and addressing potential risks like SUDEP. A significant focus was on the transition from children's to adult services, with efforts to facilitate smooth transitions through transition clinics.

The Committee asked the Consultant Paediatrician about the complexities of managing epilepsy in children, particularly those with learning disabilities. The Consultant Paediatrician discussed the need for personalised risk-benefit assessments and the lack of a national framework to guide these decisions.

The Committee asked the Medicines Optimisation Lead Pharmacist about the regional approach to the MHRA regulations and the evidence of harm caused by the policy. The Senior Clinical Quality Improvement Manager at NHS England discussed the longstanding awareness of risks associated with sodium valproate and the subsequent conversations with the MHRA following the first alert last year. Concerns were raised by clinicians and service users about the impact on medication choices and family planning. The MHRA focused on drug safety, stating that while they regulate medication, it is the NHS's responsibility to implement these regulations.

The Committee then asked about the potential for improving services and NHS performance on epilepsy. The Epilepsy Specialist Nurse discussed the setup of a satellite clinic in Brackley, which reduced travel times for patients significantly.

The Committee **AGREED** to delegate to the Health Scrutiny Officer and the Chair to finalise the wording of the recommendations.

71/24 FORWARD WORK PLAN
(Agenda No. 13)

The Committee **AGREED** the proposed forward work plan.

72/24 ACTIONS AND RECOMMENDATIONS TRACKER
(Agenda No. 14)

The Committee **NOTED** the progress made against agreed actions and recommendations

..... in the Chair

Date of signing .....

OXFORDSHIRE COUNTY COUNCIL

REPORT OF: THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (HOSC):

Adult and Older Adult Mental Health in Oxfordshire:

REPORT BY: HEALTH SCRUTINY OFFICER, OXFORDSHIRE COUNTY COUNCIL, DR OMID NOURI

INTRODUCTION AND OVERVIEW

1. At its meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (HOSC) received a report providing an update on adult & older adult mental health in Oxfordshire.

2. The Committee felt it crucial to receive an update on both the general patterns of adult and older mental health in Oxfordshire, as well as around the development and delivery of mental health services for adults as well as older adults. The Committee also sought to assess the degree to which system partners were working collaboratively to deliver and improve adult mental health services.

3. This item was scrutinised by HOSC given that it has a constitutional remit over all aspects of health as a whole; and this includes the mental health and emotional wellbeing of adults, as well as the availability and effectiveness of services to diagnose as well as to treat ill mental health amongst adults. Prevention is another key area that would also encompass mental health, and is a key commitment within the Oxfordshire Health and Wellbeing Strategy. When commissioning this report on Adult/Older Adult Mental Health, some of the insights that the Committee sought to receive were as follows:

    - The degree to which there is an Adult and Older Adult Mental Health service for Oxfordshire, and how this operates.

    - Current trends and patterns of Adult and Older Adult Mental Health amongst Oxfordshire residents; including any data relating to this.

    - The nature of commissioning for such services, and any examples of such Adult and Older Adult Mental Health Services being commissioned.

    - The degree to which there is overall effective partnership working within the Oxfordshire system for the purposes of Adult/Older Adult Mental Health.

    - The extent to which there is an adequacy of resource, including funding and workforce, for adult/older adult mental health services.

    - The support being provided to tackle suicide.

- Whether there are any high-risk groups that have been identified, and the kind of support that such vulnerable groups can expect to receive.

- Whether any Mental Health Needs Assessments have been conducted.

SUMMARY

4. The Committee would like to express thanks to Dan Leveson (BOB ICB Place Director for Oxfordshire), Chris Wright (Assistant Director Partnership Development, Oxfordshire), Lola Martos (Head of Older Adult Services at Oxford Health NHS Foundation Trust), Manny Jhawar-Gill (Commissioning Manager, Improve Enable, Adult Social Services, OCC), Pippa Corner (Deputy Director Commissioning, Adult Social Services, OCC), Nicola Leavesley (CEO of Response and current Chair of the Oxfordshire Mental Health Partnership, OMHP), Catherine Sage (Head of Service for Mental Health Urgent Care, Social Care, and Adult Eating Disorder Service, Oxford Health), Jared Fellows (Health Improvement Practitioner, Public Health, OCC), Karen Fuller (Director of Adult Social Care, OCC), and Ansaf Azhar (Director of Public Health, OCC) for attending the meeting and answering questions from the Committee in relation to this item.

5. The Committee first inquired about the adult eating disorder service, specifically the contract between the BOB ICB and other providers covering community eating disorders. They asked about the extent to which these services were dealt with separately or as part of overall mental health, and the level of specialist provision available. The BOB ICB Place Director for Oxfordshire explained that specialist adult eating disorders services were commissioned on a larger scale through specialist commissioning, with Oxford Health as the lead commissioner. He clarified that the community services were delivered locally and were part of the system they worked on together. The Head of Service for Mental Health Urgent Care added that the regional services primarily included inpatient services and some intensive treatment services to avoid admission or support post-discharge. She mentioned that Oxfordshire had one inpatient service at Cotswold House in the Warneford Hospital and that the community adult eating disorder service covered the entire county.

6. The Committee then asked about the engagement of older adults, specifically those over 65, in the design and commissioning of older adult mental health services. The Head of Older Adult Services emphasised the importance of engaging service users and carers through active groups and working closely with the voluntary sector. She acknowledged the difficulties faced by older adults to have their voices heard, and this concern was always at the forefront of the service's efforts. The BOB ICB Place Director for Oxfordshire added that Oxford Health had a long history of person-centred, goals-based care, and that patient feedback was integral to service design. The Assistant Director of Partnership Development at Oxford Health highlighted their strategic initiative to increase patient involvement in care, surpassing their 80% target with 88% of service users reporting participation. This approach aimed to enhance

patients' experiences and inform service delivery and commissioning decisions. Additionally, they planned to consolidate services for older adults and eating disorders under a single contract to offer a broader range of interventions. Patient surveys and external reviews were conducted to understand current service perceptions and identify gaps and challenges.

7. The Committee raised the issue of loneliness among older adults and asked about measures being taken to address this. The BOB ICB Place Director for Oxfordshire acknowledged the challenge, citing factors like rurality and transient populations. He highlighted various initiatives, such as the Move Together programme and Integrated Neighbourhood Teams, aimed at bringing people together and fostering community engagement. The Director for Public Health also mentioned the establishment of community hubs funded by Community Capacity Grants. He highlighted the Mental Health Prevention Concordat, a quarterly partnership focusing on enablers like green spaces, voluntary sector resources, and addressing different settings such as residential care and maternity. The approach aimed to systematically bring partners together to enhance mental health services, ensuring no one was overlooked, and to build workforce confidence in providing better mental health support.

8. The Committee inquired about the outcomes-based contract, which was coming to an end in March next year. They asked about its success, future plans, and evaluation methods. The BOB ICB Place Director for Oxfordshire explained that the outcomes-based contract was a pioneering model that linked payments to outcomes, although measuring outcomes had proven challenging. He mentioned that the contract had evolved over time, with a focus on delivering better value care through integrated pathways.

9. The Committee then turned to specific issues around suicide prevention and workforce support. They asked about the influence of the 2023 National Suicide Prevention Strategy on local efforts, stakeholder input, and training for professionals. The Health Improvement Practitioner explained that the local strategy was being refreshed to align with national priorities, with a focus on high-risk groups and targeted training. He reported that local suicide statistics and risk factors in Oxfordshire were consistent with national trends, with drugs, alcohol, relationship breakdowns, and bereavement being the leading risk factors for men. The male-to-female suicide ratio in Oxfordshire was lower than the national average, with 60% male and 40% female. At the end of the previous year, Oxfordshire Mind was commissioned to deliver a suicide prevention and mental health training programme, which began in January. This programme targeted key groups identified in national strategies, such as middle-aged men, pregnant women and new mothers.

10. The Committee also asked about the transition between different mental health services and the potential risks involved. The Head of Service for Mental Health Urgent Care acknowledged the challenges but assured that mechanisms were in place to ensure smooth transitions and minimise risks. She highlighted the importance of maintaining patient history and effective communication among professionals.

KEY POINTS OF OBSERVATION & RECOMMENDATIONS

11. Below are four key points/themes of observation that the Committee has in relation to adult and older adult mental health in Oxfordshire. These four key points of observation relate to some of the themes of discussion during the meeting on 12 September, and have also been used to shape the recommendations made by the Committee. Beneath each observation point is a specific recommendation being made by the Committee.

Personalisation and coproduction of adult eating disorder services: The Committee was keen to understand the extent to which adult eating disorder services constituted a specialist form of provision that was distinct from the general mental health support services available to adults. The importance of having specialist eating disorder services is due to the complex nature of adult eating disorders. According to a study published in the Journal of Biological Psychiatry in 2015, adult eating disorders are indeed complex, and this is partly due to the fact that such disorders can be elicited by a plethora of factors including genetics, biological conditions, psychological factors[1]. Additionally, according to Mind, adult eating disorders are complicated in nature and there are various types of such disorders[2]. Therefore, the Committee urges Oxfordshire system partners to recognise this complexity, and to ensure that adult eating disorder services are as personalised as they could be so as to address this complexity. Individuals with such disorders may themselves feel confused as to why they are experiencing such symptoms, and may not always recognise the type of help and support that they need. It is crucial that eating disorder services are sufficiently resourced and that these services have a reach and capacity that is countywide. Additionally, professionals ought to be adequately trained in being able to provide as much targeted and personalised support to such patients. The process through which patients can be referred to such services should also be as smooth and efficient as possible. Patients with such disorders can often feel reluctant to seek support, and any complications in being referred or being able to access eating disorder services could increase this reluctance.

Related to the above is the importance of coproducing eating disorder services with individuals who have experienced such disorders and symptoms. It is the first-hand experience of these disorders that makes the insights and experiences of such patients valuable in the design of such services. Coproducing the service with service users could also help reassure such patients that the system is there to hear, understand, and support them.

[1] What Causes Eating Disorders, and What Do They Cause? - Biological Psychiatry (biologicalpsychiatryjournal.com)
[2] Types of eating disorders - Mind

Recommendation 1: *To ensure that adult eating disorder services are personalised in a manner that takes the unique needs and experiences of each individual patient. it is recommended that this service is coproduced with adults with eating disorders as much as possible.*

Tackling loneliness amongst older adults: Loneliness is a pervasive and often overlooked issue that affects individuals across all age groups. However, it is particularly prevalent among older adults, leading to significant mental health implications. As society continues to age, understanding and addressing the causes and effects of loneliness in the elderly population becomes increasingly vital. According to recent studies, a substantial proportion of older adults report feeling lonely. Factors contributing to this sense of isolation include the loss of loved ones, retirement, reduced mobility, and the decline of social networks. For many seniors, the transition from an active, social lifestyle to one of relative isolation can be abrupt and challenging. Physical health declines can also contribute to loneliness. Chronic illnesses, mobility issues, and sensory impairments can limit an older person's ability to engage in social activities. Moreover, the stigma associated with certain health conditions may lead individuals to withdraw from social interactions.

According to a study published in the Annual Review of Clinical Psychology, depression is one of the most common mental health issues associated with loneliness in older adults. The persistent feeling of being isolated can lead to a sense of hopelessness and sadness, diminishing one's quality of life[3].

Therefore, the Committee is calling for adequate measures to be taken to tackle loneliness amongst older adults. It is also vital that efforts are made to reach out to older adults, particularly those with lived-experience of poor mental health elicited by loneliness, and to include such adults in the process of designing older adult mental health services. The Committee is pleased that system partners acknowledge the challenges around rurality and transient populations. The Move Together programme and ongoing development of Integrated Neighbourhood Teams should play a key role in bringing people together and fostering further community engagement. The Committee also calls for further collaboration with/within the Oxfordshire Mental Health Partnership to help to explore appropriate and innovative avenues to improve the coproduction and use of I statements for older adult mental health services. The Committee notes that meaningful coproduction and I statements are core to the strategy of over 200 third sector organisations working across health and care who make up National Voices https://www.nationalvoices.org.uk/about-us/our-strategy-2024-2029/

Recommendation 2: *To take adequate measures to tackle loneliness amongst older adults, and to make every effort to reach out to older adults (with lived-experience) and to include them in the designing of older adult mental health services. It is*

[3] Depression in Older Adults | Annual Reviews

recommended that there is liaison with the Oxfordshire Mental Health Partnership to explore avenues to improve coproduction and use of I statements here.

Communication, information-sharing and preventing 'bouncing': Transparency and the ethical sharing of information regarding mental health patient history and records are fundamental to providing quality care. In the realm of mental health, patient records hold sensitive and personal information that must be handled with the utmost care and confidentiality. At the same time, transparency in sharing this information among healthcare providers is essential for ensuring continuity of care, improving treatment outcomes, and fostering trust between patients and healthcare professionals.

Transparency in handling mental health records involves clear, open communication, and the ethical sharing of information. It is crucial for several reasons:

- Trust: Patients are more likely to trust healthcare providers who are transparent about their treatment processes, including how their records are managed and shared. Trust is a cornerstone of effective mental health treatment, as patients need to feel safe and secure in sharing their personal and often distressing experiences.

- Improved coordination of care: Mental health patients often receive care from multiple professionals, including potentially from psychiatrists, psychologists, social workers, or primary care physicians. The sharing of patient history and records ensures that all providers are on the same page, which is critical for coordinated care. This seamless exchange of information helps to avoid redundant tests, conflicting treatments, and potential medication interactions. The Committee is also aware of the need for improved sharing of information and coordination with health and care professionals working outside of mental health because of needs highlighted in annual reports for improving the physical health of adults with serious mental health conditions. The Committee understands that physical health problems significantly increase our risk of developing mental health problems and that people with poor mental health are more likely to have a preventable physical health condition.

- Improved treatment outcomes: If healthcare professionals have good access to comprehensive patient history, this enables them to make better-informed decisions about treatment plans. Understanding a patient's prior diagnoses, treatment responses, medication history, and other contextual factors can significantly enhance the effectiveness of current and future interventions.

Furthermore, the Committee urges that every effort is made by system partners to avoid the prospect of patients being or feeling 'bounced' between various mental health providers or services. Patients need to be

provided with the support that they require in as smooth a manner as possible. Suffering from poor ill health is challenging enough for patients, and such patients should be made to feel and understand that help is available and is accessible. The process of referrals for mental health and person-centred support for physical and mental wellbeing should also be as seamless as possible.

Recommendation 3: *To ensure that patient history is effectively communicated and shared amongst professionals/organisations providing mental health support (including those providing patients with treatment for acute or chronic physical conditions), and to avert the prospects of patients being or feeling bounced between various mental health services or across the NHS.*

Voluntary Sector Organisations and suicide prevention: Third sector or Voluntary sector organisations (VSO) play a crucial role in providing support and services to those in need of mental health support as well as in the realm of suicide prevention. These organisations are often community-led and can fill crucial gaps left by governmental and private sectors. Their contributions are vital in addressing the complex and sensitive issue of suicide, offering hope and lifelines to those that may be in despair. They often operate with limited resources but have a profound impact due to their professionalism, networks, grassroots connections and ability to mobilise volunteers. One of the most significant advantages of VSOs is their accessibility if they are signposted to effectively. These organisations often work within local communities or work with specific communities of need, making them more approachable and trusted by individuals who might be reluctant or unable to seek help from formal institutions. This proximity allows VSOs to identify and support at-risk individuals early, potentially preventing crises before they escalate.

VSOs are often skilful at providing tailored support that meets the unique needs of individuals. Unlike larger institutions, they can offer personalised assistance and maintain flexibility in their approaches. This individualised support is crucial in suicide prevention, as it acknowledges and respects the diverse experiences and needs of those seeking help.

Education and awareness campaigns are fundamental components of VSO efforts. These campaigns aim to reduce the stigma surrounding mental health issues and suicide, encouraging open dialogue and understanding. By equipping communities with knowledge about the warning signs of suicide and available resources, VSOs empower individuals to act fast and to respond to temptations for suicide.

VSOs often can also provide specific services to support those more susceptible to suicide including through counselling, peer support groups, and crisis interventions. Peer support groups create safe spaces for individuals to share their experiences and find solidarity, reducing feelings of isolation and hopelessness. Additionally, VSOs can potentially contribute to provide training for volunteers, community

members, and professionals to recognise and respond to suicide risks. This can enhance a community's overall capacity to address mental health issues, ensuring that more people are equipped to offer support and intervention when needed.

It is for the above reasons, and also from learnings through the pandemic about the value of VSOs, that the Committee is recommending that VSO stakeholder organisations working on suicide prevention should be invited to register so that all available resources across Oxfordshire are recognised and engaged. It is also recommended that the system has sufficient resource to tackle suicide, and that all partner organisations/system partners work in a collaborative manner that makes effective use of collective resource, contribution, and responsibility for tackling suicide.

Recommendation 4: *That voluntary sector stakeholder organisations who work in Oxfordshire on suicide prevention are invited to register with a VSO suicide prevention stakeholder register. It is also recommended that there is adequate resource, engagement, and a collaborative system inclusive of the VSO registered stakeholders to tackle suicide.*

Recommendation 5: *That there is collaborative system work to develop KPIs on serious mental health to maximise the impact of the existing resource available across Oxfordshire, with a view to prevention and to increase the support available to people and families in distress. It is recommended that there is engagement with the local authority and Region on KPIs relating to patients residing in long-term inpatient settings away from their families.*

Legal Implications

12. Health Scrutiny powers set out in the Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide:
    - Power to scrutinise health bodies and authorities in the local area
    - Power to require members or officers of local health bodies to provide information and to attend health scrutiny meetings to answer questions
    - Duty of NHS to consult scrutiny on major service changes and provide feedback on consultations.

13. Under s. 22 (1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 'A local authority may make reports and recommendations to a responsible person on any matter it has reviewed or scrutinised'.

14. The Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

Annex 1 – Scrutiny Response Pro Forma

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October 2024

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OXFORDSHIRE COUNTY COUNCIL

REPORT OF: THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (HOSC):

Winter Planning

REPORT BY: HEALTH SCRUTINY OFFICER, OXFORDSHIRE COUNTY COUNCIL, DR OMID NOURI

INTRODUCTION AND OVERVIEW

1. At its meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (HOSC) received a report providing an update on the plans developed by system partners to manage demand for health and care services during the ensuing winter months.

2. The Committee felt it crucial to examine the preparations for the winter months, particularly given the anticipated increases in pressures and demands on Urgent and Emergency Care services.

3. This item was scrutinised by HOSC given that it has a constitutional remit over all aspects health as a whole; and this includes initiatives by the NHS and the County Council to ensure that adequate measures and preparations are in place to cope with potential increases in demand and pressures during the Winter. When commissioning this report on Winter Planning, some of the insights that the Committee sought to receive were as follows:

   - Emergency department capacity and waiting times.
   - The degree to which there is a sufficient amount of workforce, and how recruitment and retention will be optimised.
   - The extent to which plans are in place to support staff wellbeing, both in terms of the physical and mental wellbeing of staff.
   - Whether there are any vaccination programmes for Flu and Covid-19, and how these will meet demand.
   - The extent to which Primary Care access can be optimised, including through the use of out of hours services.
   - The discharge processes that are in place and whether there is sufficient resource for efficient discharging; including in the context of discharge-to-assess.
   - The extent to which there is effective coordination overall amongst the various actors in the system, and what the channels of coordination between these actors will be.

SUMMARY

4. The Committee would like to express thanks to Lily O'Connor (Programme Director Urgent and Emergency Care for Oxfordshire), Ed Capo-Bianco (Urgent Care, Palliative and End of Life Care, Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB), Ben Riley (Executive Managing Director for Community, Primary and Dental Care, Oxford Health NHS Foundation Trust), Sally Steele (Service Manager Hospitals, Adult Social Services), Tamsin Cater (Head of Transfer of Care Hub, OUH), Karen Fuller (Director of Adult Social Care OCC), Ansaf Azhar (Director of Public Health OCC), and Dan Leveson (BOB ICB Director of Place) for attending this item and answering questions from the Committee in relation to Winter Planning.

5. The Committee noted that whilst there was a helpful discussion about the winter risk assessment at the scrutiny session, information on the acuities in the paper for the Committee could have been elaborated on, and that the fullest transparency on acuities was important for public confidence and scrutiny.

6. The first question from the Committee focused on workforce and funding challenges for the upcoming winter. The Committee asked what measures were being taken to address these challenges in the short term. The BOB Integrated Care Board (ICB) Director of Place highlighted that the winter plan was essentially an urgent emergency care plan, with workforce being a significant challenge. The Director of Adult Social Care explained that across the Oxfordshire system, efforts were being made to maximise the workforce, ensuring the right people were in the right place at the right time. She mentioned an ambitious recruitment campaign that had yielded positive results, particularly in recruiting qualified social workers and occupational therapists. Additionally, work was being done with care providers to support hospital discharges and ensure a buoyant home care market.

7. The Committee raised concerns about A&E and ambulance handover times. The BOB ICB Director of Place indicated that while the four-hour standard in A&E had been challenging, improvements had been made through partnerships and the establishment of urgent care centres. The performance had improved, with the target for the year being 78%. He also touched on the challenges faced by different trusts and the importance of system-wide collaboration to manage discharges and patient flow.

8. The Committee inquired about the confidence in reducing ambulance handover times. The Head of Transfer of Care Hub reiterated that Oxfordshire was performing well in this area, with excellent relationships with the South Central Ambulance Service. She noted that it was rare for ambulance handover delays to exceed 60 minutes, and efforts were being made to further reduce this time.

9. The Committee asked about the maturity of community services. The Executive Managing Director for Community, Primary and Dental Care reflected on the challenges faced due to stagnant funding despite increasing demands from a growing and ageing population. To address these challenges, he discussed efforts to streamline and consolidate services, such as implementing a single

point of access for planned, urgent, and emergency care. This approach aimed to free up clinical time and improve efficiency, with some success already seen in the planned care sector.

10. Additionally, the Director mentioned ongoing staffing changes to make services more sustainable, moving away from short-term staffing solutions to long-term employment plans. This shift was expected to reduce costs associated with agency fees and provide more reliable staffing. He also discussed the development of hubs to bring together services from multiple locations, aiming to deliver more care closer to home.

11. The Committee raised concerns about primary care capacity during the winter. The Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB acknowledged that GP capacity was stretched, but efforts were being made to manage demand through triage models and the involvement of multidisciplinary teams. Investments in community pharmacies and same-day emergency care units were also supporting primary care capacity.

12. The Committee asked about the availability of vaccines and the challenges faced in certain areas. The Cardiovascular Disease Clinical Lead for Oxfordshire Place in BOB ICB indicated that the vaccine programme had been commissioned to ensure better alignment and availability, with efforts to address any gaps in provision. The Director for Public Health reported no significant issues with vaccine availability this year, though prioritisation remained necessary. Compared to previous years, there was no notable increase in respiratory illnesses, but they would not be complacent.

13. The Committee inquired about the capacity for reablement services and the balance between patient flow and personalised care. The Service Manager for Hospitals in Adult Social Services explained that the discharge to assess model had been implemented to ensure decisions were made in patients' homes, allowing for better reablement opportunities. She acknowledged the challenges but emphasised the importance of system-wide collaboration to maximise resources and support patients effectively.

KEY POINTS OF OBSERVATION & RECOMMENDATIONS

14. Below are four key points/themes of observation that the Committee has in relation to Winter Planning. These four key points of observation relate to some of the themes of discussion during the meeting on 12 September, and have also been used to shape the recommendations made by the Committee. Beneath each observation point is a specific recommendation being made by the Committee.

Reducing time spent in emergency departments: As winter approaches, healthcare systems, in the United Kingdom as well as worldwide, brace for the inevitable surge in patients seeking emergency care. The colder months bring a variety of seasonal illnesses and injuries, from influenza and respiratory infections to slips and falls, that

significantly increase the pressure on emergency departments (EDs). In this context, the implementation of clear plans and processes is crucial to manage patient flow, reduce waiting times, and ensure that patients receive timely and effective care.

Winter is synonymous with a spike in health-related issues. Influenza, and other respiratory ailments become more prevalent, particularly amongst vulnerable populations such as the elderly, young children, and those with pre-existing conditions. Additionally, the winter season sees an increase in accidents related to adverse weather conditions. These factors collectively contribute to a higher volume of patients in EDs, often applying pressure on healthcare providers and leading to longer waiting times and, potentially, poorer health outcomes.

The Committee believes that effective triage is the cornerstone of managing patient flow in emergency departments. Clear and well-defined triage protocols ensure that patients are assessed quickly and accurately based on the severity of their conditions. By prioritising cases that require immediate attention, healthcare providers can allocate resources more efficiently, and ensuring that all patients receive appropriate care in a timely manner. This would not only improve patient outcomes but also enhances overall ED efficiency.

Furthermore, clear plans and processes facilitate better communication and coordination among healthcare teams. During peak times, the ability to quickly and accurately share information about patient status, resource availability, and treatment plans is essential. Standardised communication protocols and regular briefings can help ensure that all team members are on the same page, reducing errors and delays in patient care. Additionally, coordination with other departments and external healthcare providers can potentially help manage patient overflow and improve continuity of care.

Moreover, there is also a point about potentially utilising data analytics to effectively predict and forecast the levels and type of demand that will rise during the winter months. This could also help to inform the level of preparedness of Eds in terms of their resource allocation/capacity.

Recommendation 1: *To continue to ensure that clear plans and processes are in place to help reduce time spent in emergency departments by patients during the winter months when pressures are likely to be higher.*

Balancing patient flow with efficacy of care: In the modern healthcare environment, achieving a balance between efficient patient flow and personalised care is paramount. This delicate balance ensures that patients receive tailored treatment while healthcare facilities operate smoothly and effectively. The Committee understands the challenge of optimising patient flow. This involves reducing lengths of stay in hospital as well as in step-down units. Nonetheless, it is vital that achieving greater patient flow does not compromise the quality of individualised

care each patient requires. Accomplishing this balance demands good strategic planning, resource management, and a deep commitment to patient-centred care.

Many patients who were initially admitted into hospital, or who were placed in step-down beds, often suffer from challenging conditions that would involve ongoing care and support. It is also the case that such patients will remain vulnerable and that they would therefore require ongoing/routine monitoring. It is therefore crucial that if vulnerable patients are discharged, three things are considered:

1. Their process of discharging should not be based purely on the need to maintain efficient patient flow.

2. Any risk of the emergency being repeated is assessed, discussed with a letter sent to primary care who can action any recommendation in a timely way.

3. That if it is deemed appropriate for them to not be in a hospital or step-down setting, that they receive the utmost care and support at home that they may require. Careful consideration should be given to the amount of resource available for this.

Hence, while optimising patient flow, it is imperative to maintain the individualised care that patients need. Whilst health settings are likely under pressure, it is critical to prevention and patient safety that patients are kept at the centre. Firstly, care plans should be as comprehensive as possible; and should be detailed and personalised in a manner that they address the unique needs of each patient. Secondly, there should be clear and effective communication with patients. Engaging in open and empathetic dialogue with patients and their families to understand their preferences and concerns is necessary. Thirdly, continuity of care is also paramount, and it should be ensured that patients experience seamless transitions between different care settings through careful coordination and follow-up.

Balancing patient flow with personalised care is a complex yet achievable goal. By implementing strategic measures and fostering a culture of patient-centeredness, services can ensure that they provide high-quality care efficiently and support future prevention of emergency. This balance not only enhances patient outcomes but also optimises the operational effectiveness of healthcare institutions.

Recommendation 2: *To continue to ensure a careful balance between providing patient flow on the one hand (including through reducing lengths of stay across step down beds), whilst continuing to provide the personalised care that each patient needs.*

Maximising primary care capacity: As winter approaches, primary care services, especially General Practitioner (GP) services, face increased pressure due to seasonal illnesses and a general increase in healthcare

needs. Maximising the capacity of primary care to handle this surge is essential to maintain the quality of care and ensure that patients receive timely and effective treatment.

Maximising staff capacity is a vital aspect of maximising overall primary care capacity. There are a couple of steps that could be taken to achieve this:

1. Recruitment and Training: To meet the heightened demand, recruiting additional healthcare professionals, including locum GPs, nurse practitioners, and allied professionals whose role and competencies are appropriate and clear and well communicated to patients is crucial. Providing targeted training for existing staff on managing common winter ailments can further enhance the workforce's preparedness.

2. Flexible Scheduling: Adopting flexible scheduling practices, such as extended hours and weekend clinics, can alleviate pressure during peak times. Rotating shifts and offering overtime can also help distribute the workload more evenly among staff.

Furthermore, effective triage systems can be efficient and help prioritise patients based on the severity of their conditions. This can help ensure that those with urgent needs are seen promptly, while less critical cases can be managed through alternative means such as phone consultations or advice services. However, the Committee urges that GP practices are consistent and as careful as possible in applying this logic. Some patients may genuinely require a prompt and an in-person appointment, and careful judgement should be used to ensure that such patients do not lose the opportunity of being offered this. People with long-term conditions are more likely to be experts in their lived experience and know if a risk is urgent. The elderly and other vulnerable groups on patient lists who may be likely less able to use new systems well or to advocate need to be carefully considered. Patients with mental health issues or other sensitive issues may be less likely to share information except with a trusted professional. Evidence-based training for triage and inclusive of lived experience should be used.

In addition, strengthening the link between primary and secondary care is important. Strengthening these links can facilitate smoother patient transitions and reduce hospital admissions. Regular communication and potentially shared care protocols/procedures can enhance coordination between different levels of care. This can also help ensure that patients are seen and followed up in ways that would prevent them being lost or unnecessarily held in-between primary and secondary care services. Systems that help identify patients and particular populations of patients that have repeat emergencies can help prevention through improved risk management during an emergency and communication of risk and management plan from acute to primary care.

Moreover, utilising data analytics to monitor patient demand and service performance can also help to inform resource allocation and identify areas for improvement. Primary care services can be in a more ideal position to forecast the levels and types of demand that could arise during the winter, and can plan accordingly. Regular feedback from patients and staff can also offer valuable insights.

Recommendation 3: *To maximise capacity within primary care (particularly with GP services) to cater for any increased pressure during the winter.*

Preparations for increased infection rates: As we continue to grapple with the challenges posed by infectious diseases both locally and nationally, it is imperative that we proactively prepare for potential surges in infection rates. Healthcare facilities must be prepared to handle a sudden influx of patients. This involves increasing the capacity of hospitals, emergency rooms, and intensive care units. Additionally, establishing temporary healthcare facilities and isolation centers can help manage overflow situations.

It is important that healthcare facilities are prepared to handle a sudden influx of patients. This involves increasing the capacity of hospitals, emergency rooms, and intensive care units. Additionally, ensuring the availability of essential medical supplies and equipment, such as personal protective equipment (PPE), ventilators, and testing kits, is crucial. Providers should maintain stockpiles of these supplies and avert the prospects of shortages.

Furthermore, establishing a robust vaccination infrastructure is critical for efficient vaccine administration. Consideration should also be given to setting up vaccination centers and mobile units that would increase capacity. Engaging communities in preparedness efforts is a key learning from the pandemic. Community-based organisations, local leaders, and volunteers can play a significant role in being aware in advance of emergency planning and part of that plan. Roles such as disseminating information, identifying vulnerable populations, and supporting vaccination campaigns should be given consideration. This relates to a broader point that the Committee is recommending around communicating with residents to help them understand the importance of vaccines and in helping them to understand how to go about getting vaccinated.

Recommendation 4: *To ensure that adequate preparations are in place for a potential surge in infection rates, and to secure the availability of vaccinations. It Is recommended that relevant system partners clearly communicate with the public in relation to both viral infection patterns as well as how residents can reduce the likelihood of spreading/contracting diseases.*

Legal Implications

15. Health Scrutiny powers set out in the Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide:
 Power to scrutinise health bodies and authorities in the local area
 Power to require members or officers of local health bodies to provide information and to attend health scrutiny meetings to answer questions
 Duty of NHS to consult scrutiny on major service changes and provide feedback on consultations.

16. Under s. 22 (1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 'A local authority may make reports and recommendations to a responsible person on any matter it has reviewed or scrutinised'.

17. The Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

Annex 1 – Scrutiny Response Pro Forma

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October 2024

REPORT OF: THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (HOSC):

Medicine Shortages:

REPORT BY: HEALTH SCRUTINY OFFICER, OXFORDSHIRE COUNTY COUNCIL, DR OMID NOURI

INTRODUCTION AND OVERVIEW

1. At its meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (HOSC) received two reports providing an update on medicine shortages; one from the BOB Integrated Care Board, and another from Oxford University Hospitals NHS Foundation Trust (OUH).

2. The Committee felt it crucial to receive an update on the causes of medicine shortages (be they international, national, or local), and the measures being taken by local partners to seek to address these shortages for Oxfordshire.

3. This item was scrutinised by HOSC given that it has a constitutional remit over all aspects of health as a whole; and this includes the availability and accessibility of medicines and residents' ability to access these. Upon commissioning this item, some of the points the Committee sought to investigate involved the following:

   - The national context of medicine shortages.
   - The reasons behind the increase in medicine shortages.
   - The extent to which medicine shortages are impacting Oxfordshire.
   - If there any particular medicines that are affected by the shortages.
   - Whether there any particular populations groups/those with specific conditions that could be most affected by the shortages.
   - Details of any impact assessments that have been conducted nationally or locally.
   - The steps being taken locally to address medicine shortages.

SUMMARY

4. The Committee would like to express thanks to Julie Dandridge (Head of Primary Care Infrastructure and Pharmacy BOB ICB), Claire Critchley (Medicines Optimisation Lead Pharmacist), David Dean (Chief Executive Officer for Community Pharmacy Thames Valley), Bhulesh Vadher (Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust), and Rustam Rea (Consultant at Oxford University NHS Hospital Trust) and Leyla Hannbeck (CEO of the Independent Pharmacies Association) for attending this item and for answering questions from the Committee on the issue of Medicine Shortages.

5. The Head of Primary Care Infrastructure and Pharmacy highlighted the multifaceted root causes of medicine shortages and the significant impact on patients and healthcare providers. She noted the anxiety patients face when their usual medications are unavailable and the challenges for pharmacists and clinicians in managing these shortages.

6. The Committee inquired about the main complexities causing medicine shortages. They asked about the international context of manufacturing capacity and whether the impacts of this had now been addressed. The CEO of the Independent Pharmacies Association responded, explaining that global manufacturing capacity issues, dependency on raw materials from countries like China and India, and geopolitical factors contributed to the problem. She also mentioned the impact of Brexit and the UK's pricing strategies, which make it less attractive for manufacturers to supply medicines to the UK. This included the UK Vpass system which allowed a financial clawback from manufacturers and that the UK had some of the cheapest generic medicines and was therefore a less attractive market for supply. She highlighted the increased demand for certain medications, such as HRT and ADHD treatments, which exacerbated the shortages. National protocols were in place for serious medical shortages, although when alternatives were identified, these could then be in high demand and go into shortage.

7. The Committee then asked how NHS contracts and pricing strategies impacted medicine availability. The Chief Executive Officer for Community Pharmacy Thames Valley explained that the national contract for community pharmacies had remained unchanged for seven years, creating financial pressures that had led to 5 pharmacies closing every week in the UK and 15 community pharmacies closed in Oxfordshire over 5 years. He noted that the contract drove down prices, discouraging manufacturers from supplying the UK market and causing pharmacies to dispense many items at a loss.

8. The Committee sought clarification on distribution issues contributing to shortages and whether these issues were national or local in scope and what measures could be taken to address them. The Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust explained that the distribution network itself was not the problem; rather, it was the availability of stock from wholesalers and manufacturers. He described the sophisticated systems in place within hospital pharmacies to manage stock and

share resources regionally, contrasting this with the less coordinated systems in community pharmacies. An exemplar was the regional coordination of epidurals and there were several situations were solutions had to be found.

9. The Committee asked about the impact of medicine shortages on individual patients, particularly those with conditions requiring specific medications. The Clinical Director of Pharmacy and Medicines Management at Oxford University NHS Hospital Trust provided examples of how shortages forced the use of alternative or unlicensed products, which could lead to further shortages. He emphasised the randomness of these shortages and the various factors that could cause them, such as manufacturing issues or supply chain disruptions. The CEO of the Independent Pharmacies Association explained that while national protocols, such as the serious shortages protocol, allowed pharmacists to switch medicines during shortages, high demand still led to product shortages, as seen with antibiotics and Hormone Replacement Therapy (HRT) medicines. Despite pharmacists' extensive knowledge, they were unable to make simple prescription changes without prescriber approval, which added to the workload of healthcare professionals and caused delays for patients. The CEO advocated for regulatory changes to allow pharmacists to make minor remedial prescriptions, such as substituting different dosages of the same medicine, to improve efficiency.

10. The Committee raised concerns about the impact on patients with "cliff edge" conditions where the absence of the right and timely medication could be life-threatening and so prior to Brexit had been stockpiled e.g. anti-seizure medication and insulin. The Medicines Optimisation Lead Pharmacist explained the national and local mitigations in place, including systems to manage shortages and ensure alternative medications are available. She noted that while stockpiling was not done locally, there were national reserves for critical medications. Various systems were implemented locally to address shortages, including providing information on alternative medicines, although this could lead to further shortages. Collaboration between primary and secondary care was essential, with efforts to import supplies locally when necessary. The ICB gave an example of a system-wide approach to shortages of palliative care medicines, where all doctors and nurses were aware of where they could access supply; and they agreed there was scope to extend this approach to other areas.

11. The Committee asked about the recognition of where alternatives were sub-optimal because a patient on a long-term medication was very used to taking a particular formulation e.g. elderly or someone with learning disability and where alternatives were sub-optimal because of lack of biological efficacy.

12. There was discussion of stockpiling. That across the whole system there was a discouragement of stock-piling

13. The Committee asked whether the issue of medicine shortages had impacted the workload of the clinical side of the NHS, and if this was being monitored. The Consultant at OUH highlighted the increased clinical and pharmacy

burdens due to drug shortages, which necessitated additional resources and adjustments in patient care, particularly in managing diabetes medication.

14. The Committee inquired about the global vulnerability to supply chain issues, and whether production could be brought into the UK to improve resilience. The Clinical Director of Pharmacy and Medicines Management noted that the UK's pharmaceutical industry had been offshored over the years, making it challenging to bring manufacturing back. He suggested that while it would be beneficial to increase local production, it was not entirely within the government's control as it would depend on pharma companies wishing to invest in the UK market.

15. The Committee questioned the communication and coordination efforts between Community Pharmacies to mitigate the risks associated with medicine shortages. The Chief Executive Officer for Community Pharmacy Thames Valley explained that pharmacies across BOB frequently shared stock via messaging groups to ensure patients received their medications. However, this practice added to pharmacists' workload, with each spending about a day a week locating stock. The Medicines Optimisation Lead Pharmacist described the various communication channels used to keep healthcare providers informed, including regular updates on the ICB and OUH websites and newsletters. She acknowledged the challenges of keeping information current due to the rapidly changing situation.

16. Regarding communications with the public, the ICB spoke about a campaign aimed at patients discouraging stock-piling. The Committee suggested that for some patients with long-term conditions, holding some medication stock might be considered a safe option, and it was really important that communications were contextualised for patients. The ICB were aware that some practices would prescribe for one month only, but that there was no ICB policy about that. The length of prescription should be in response to the particular condition and context for the patient. Community-based medication reviews were given as really important opportunities for medicines optimisation where it would be possible to plan the appropriate timescale for prescriptions with patients with long-term conditions.

KEY POINTS OF OBSERVATION & RECOMMENDATIONS

17. Below are some key points/themes of observation that the Committee has in relation to local impacts and the work concerning medicine shortages from this session. These observations have also been shaped from hearing about medicines shortages and impacts in other scrutiny sessions e.g. palliative care and epilepsy.

18. The Committee was acutely aware that the issue of medicines shortages was a matter of high public concern but was also complex, and these complexities were either not in the public domain or readily accessible. The Committee wished to praise local NHS leaders working on medicines for the creative way they have sought solutions and also to empathise with frontline community pharmacists and health professionals for dealing with shortages on a day-to-

day basis. Whilst the Committee made no recommendation regarding national enablers, the national and global context clearly needs to significantly improve in light of evidence at this session and national policy and media reports e.g https://www.nuffieldtrust.org.uk/news-item/patients-face-new-normal-of-medicines-shortages-as-uk-hampered-by-supply-issues-and-impact-of-eu-exit; https://www.pharmaceutical-technology.com/news/uk-charities-condemn-continued-drug-shortages/.

19. The OUH medicines lead explained that there were no problems in the past years when the UK had a strong pharmaceutical industry. Whilst it was accepted that rebuilding that may not be within the government's control, national leaders could work to improve the attractiveness to manufacturers of supplying patients in the UK and could support the sustainability of community pharmacies. Whilst the Committee has made no national recommendation, the local recommendations made requests of the ICB and providers to escalate to national policy makers the urgent need for medicines security for the UK and key enablers for this. Of particular note is the Independent Pharmacies Association (IPA) evidence that there is an urgent need for transparency regarding work to discuss the challenges with the view to solutions and that urgent mitigations include changing regulations to allow community pharmacists to make minor changes to prescriptions without having to resort back to the clinical prescriber.

20. The five key points of observation below relate to some of the local themes of discussion and have also been used to shape the recommendations made by the Committee.

Support for patients with cliff-edge conditions: In the healthcare sector, ensuring the safety and well-being of patients is paramount. Recognising and identifying patients with cliff-edge conditions (those who are at significant risk of severe health deterioration in the event of treatment disruption) is a critical aspect of patient care. Cliff-edge conditions were recognised in the lead up to Brexit as requiring special provision and are defined as medical conditions which can be immediately life-threatening if there is any interruption in treatment with a rapid and potentially irreversible deterioration in a patient's health and emergency. Common examples include but are not limited to:

- Life-threatening chronic illnesses requiring the right continuous medication (e.g., diabetes, epilepsy, asthma).
- Life-threatening acute conditions (e.g., certain types of cancers, severe infections).
- Critical post-operative or post-treatment conditions requiring constant medical support.

The Committee heard that community pharmacy teams regularly see distressed patients who cannot get hold of their medicines who need to travel from one pharmacy to another in the hope of getting hold of their

regular medicine and this was also heard in the scrutiny session that followed on epilepsy from the epilepsy clinical team. It is noted that the mental health of patients with these conditions is likely to deteriorate if they are worrying or having to travel large distances regularly to find their medicine, and that deteriorations in mental health was known in some of these conditions to worsen outcomes. This will include many that are especially vulnerable because they are not able to drive and unable to use public transport easily.

Healthcare systems and providers should do their utmost to identify patients with cliff-edge conditions. This could be through regular patient assessments and medical reviews, using electronic health records to flag high-risk patients, and through collaboration amongst specialists to ensure accurate diagnosis and treatment plans.

Furthermore, every effort should be made to maintain adequate stock levels of critical medications and supplies for those patients with cliff-edge conditions. Relevant system partners should work closely to ensure that those patients with cliff-edge conditions are swiftly and appropriately identified in the event of medicine shortages, and to have mitigations in place so as to reduce the risk of these patients experiencing harm in the event of disruptions to medicines supplies. In the absence of national enablers, it is critical that communications at a local level with patients with cliff-edge conditions about stock-piling medications are responsive to their need for enough medical supply to provide security and prevent anxieties.

Recommendation 1: *To ensure that policies are in place to recognise and identify patients with cliff-edge conditions, and to ensure that mitigations are in place to reduce the risk of harm to these patients in the event of supply disruptions.*

Coordination to mitigate risks with medicine shortages: The Committee is pleased to hear that there are various communication channels being utilised to keep healthcare providers informed, including regular updates on the ICB and OUH websites and newsletters, on updates relating to medicine shortages. It is vital that there are continued efforts not only to have open and transparent updates, but that these updates are timely given the ever-changing and rapidly developing dynamics (globally, nationally, and regionally) that could impact on medicine availability. It is also vital for there to be user-friendly avenues for regular sharing of stock information between pharmacies across the BOB footprint. This could help to ensure that risks associated with shortages in a particular locality are mitigated as much in advance as possible.

In addition, there are other potential steps that could be taken to mitigate risks including, establishing multiple supply sources to prevent dependency on a single supplier. Whilst this may not always be easy to achieve, particularly on a regional or local level, exploring such avenues could prove valuable in reducing the prospects of shortages stemming

from dependencies on single suppliers. There is also a point about regularly reviewing and updating supply chain protocols to adapt to changing circumstances.

Good coordination amongst and between system partners as well as national policymakers could help set the foundations for prompt responses to medicine shortages. The Committee urges for the development comprehensive contingency plans to address potential supply disruptions. Clear communication, coordination, and transparency can help with:

- Potentially creating emergency response teams to manage supply chain issues swiftly and efficiently.
- Developing alternative treatment plans in case of medication shortages.
- Ensuring clear communication channels with patients and their families regarding potential risks and mitigation measures.

Recommendation 2: *To ensure effective communication, coordination, and transparency within and between the local and national levels to help mitigate risks associated with medicine shortages. It is recommended that there is escalation to national levels as to the importance of national transparency with community pharmacy and patient stakeholders.*

Tackling excessive workloads: Upon commissioning this item, the Committee was keen to understand the potential impacts that medicine shortages could have on staff workload. The concern is that medicine shortages could increase additional burdens on the already substantial workloads that clinical or administrative staff are required to deal with. The Committee is concerned to hear of the increased clinical and pharmacy burdens due to drug shortages, and how this necessitated additional resources and adjustments in patient care, particularly in the management of diabetes medication.

One of the immediate impacts of medicine shortages on healthcare staff is the increase in administrative duties. Pharmacists, for instance, spend a considerable amount of time identifying alternative medications, updating electronic health records, and communicating with suppliers. The Committee heard that medicines supply issues take on average 2-3hrs per day of community pharmacy teams' time and on many occasions have led to abuse and violence against pharmacy teams.

This additional burden takes away valuable time that could be spent on other core duties, thereby reducing the overall efficiency of healthcare delivery.

When essential medications are unavailable, healthcare providers must spend additional time managing patients. This involves explaining the

situation to patients, discussing alternative treatments, and monitoring for potential side effects of substitute medications. Nurses and doctors often find themselves spending more time on each patient, which can lead to longer wait times and decreased patient throughput. Furthermore, the increased administrative and patient management duties as a result of medicine shortages could contribute to increased stress levels among healthcare staff. The constant need to find quick solutions to unforeseen problems can lead to burnout, a condition already prevalent among healthcare workers. Burnout not only affects the well-being of the staff but also compromises the quality of patient care.

Therefore, there is a need for staff to be adequately supported in the event of medicines shortages so as to help avert the prospect of staff burnout or work overload. In such contexts, consideration should be given to securing additional resource if need be so as to be able to tackle additional demands or burdens generated by medicine shortages.

Recommendation 3: *To work on reducing any prospect of additional excessive workloads on both clinical and administrative staff in the event of medicine shortages, and to provide meaningful support for staff as well as additional resource if need be for the purposes of tackling any additional demand/burdens. It is recommended that there is escalation to the national level as to the extent of workload across all health settings in the management of shortages and to seek national enablers.*

Digital database and information sharing: The prompt and accurate identification of medicine supply issues is essential for ensuring that patients receive the treatment they need. One of the key strategies to achieve this goal is the effective sharing of information and maintaining transparency among healthcare professionals. Information sharing allows healthcare providers to access up-to-date data on medicine availability, impending shortages, and alternative sources. When healthcare professionals have timely access to such information, they can make informed decisions, avoid prescribing unavailable medications, and prevent treatment disruptions. Effective communication and information sharing foster coordination among various stakeholders, including healthcare providers, pharmacists, and suppliers. This collaboration can help to ensure a cohesive approach to managing medicine supply issues, allowing for quicker responses and problem-solving.

The Committee urges system partners to explore the adoption of a digital local database to help professionals to easily identify where supply issues exist. This can serve as a centralised hub for storing and accessing information related to medicine supply. This database can include real-time data on stock levels, supply chain disruptions, and alternative suppliers, which can be easily accessed by healthcare professionals. Such a database can also enhance monitoring and reporting capabilities, allowing for the quick identification of emerging supply issues. Alerts and notifications can be set up to inform relevant parties of potential shortages, ensuring proactive measures are taken to

mitigate risks. In addition, a digital local database could open an avenue for advanced data analytics that can be employed to analyse trends, predict future supply challenges, and potentially even optimise inventory management. This predictive capability can significantly reduce the occurrence of unexpected shortages and improve overall supply chain resilience.

Furthermore, increasing transparency in medicines shortages is well recognised as critical to improvements and security of supply. The Committee was concerned about UK security of supply and the evidence about real gaps in national transparency with community pharmacy, patient and other key stakeholders. It noted that the UK is no longer part of the European Medicines Agency that provides public information on crisis preparedness and management and the work of the medicine shortages working group across Europe. Although the ICB had website information `Public Urged to Manage Prescriptions Responsibly` which urged patients to avoid stockpiling, Health Watch and the Committee members felt strongly that improved communications with the public would be a good investment to enhance transparency at a local level and empower the public to make informed decisions about their use of prescriptions.

Recommendation 4: *To continue to improve sharing of information and transparency, engaging across all health settings, including through a potential digital local database, for helping professionals to easily identify where supply issues exist. It is recommended that there is escalation to the national level on the need for; leadership on transparency with all stakeholders and the public; attracting the pharmaceutical industry to the UK market; and ensuring the sustainability of community pharmacy through improvements to the community pharmacy contract.*

Improving communication and coproduction with patients: Effective communication and coproduction with patients are crucial elements in the provision of high-quality pharmacy services and optimisation of medicines. This is especially true for patients with cliff-edge or long-term conditions, who often face unique challenges regarding the availability of medicines and the management of their health. By involving these patients in the conversation and using tools such as checklists for cliff-edge conditions and/or FAQs, pharmacies can enhance patient care, improve medication adherence, and foster a more collaborative healthcare environment. The use of medication reviews in a community-based setting might be an especially good setting for this and a good investment in prevention. Given that cliff-edge conditions refer to health issues that can suddenly worsen or escalate without timely intervention, these conditions often require immediate access to medications and close monitoring. Examples include severe asthma, epilepsy, and certain mental health disorders. Effective communication with these patients is critical to ensure they have rapid access to necessary treatments and understand their management plans.

Developing a comprehensive FAQ section can address common patient concerns and provide quick access to important information. FAQs could develop on the patient information leaflet already supplied with each medication by a pharmacy company (medication side effects, storage instructions, what to do in case of a missed dose), and include for example how to manage multiple medications, information on what to do if you have a cliff-edge condition and do not have an emergency supply, helpful signposting information. One of the most fundamental aspects of improving communication with patients is using clear and accessible language and a FAQ could help with that. FAQs in easy read for people with learning disability and different languages could save pharmacies and health professionals significant time. This resource could ideally be available both online and in printed formats within the pharmacy.

Furthermore, digital communication tools, such as email, text messaging, and patient portals and patient communication Apps for specific conditions can enhance communication with patients. These tools can be used to send reminders about medication refills, provide updates on the availability of medicines, and offer tailored checklists or educational content about managing conditions and self-care. They also allow for more immediate and convenient contact between patients and pharmacists.

Moreover, coproduction should not only inform how pharmacy services are designed/delivered, but should ideally also mean patients should be involved as active partners healthcare decisions and treatment options.

Pharmacists should be enabled to encourage patients to share their preferences and concerns regarding their treatment plans. This collaborative approach helps to tailor treatments to individual needs and increases patient satisfaction and adherence. In addition, establishing patient advisory groups can provide valuable insights into the needs and preferences of patients with cliff-edge or long-term conditions. These groups can offer feedback on pharmacy services or suggest improvements. Regular meetings and open forums for discussion can create a sense of community and partnership. The third sector is an important partner to support the NHS with co-production, helping avoidance of medical jargon and providing health information in plain language. The third sector is also well networked in respect of specific cliff-edge and long-term conditions. This ensures that patients fully understand their condition and the importance to them of their treatment and supports adherence. Liaison with Health Watch and specialist third sector health organisations for cliff-edge conditions would support a co-produced improvement.

Recommendation 5: *To work on improving communication and coproduction with patients, and involving the third-sector for those with cliff-edge or long-term conditions, regarding pharmacy services and the availability of medicines (including through the use of frequently asked questions). It is also recommended that patients are*

signposted to any support that could be available from pharmacy services and the wider voluntary sector.

Legal Implications

21. Health Scrutiny powers set out in the Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide:
    - Power to scrutinise health bodies and authorities in the local area
    - Power to require members or officers of local health bodies to provide information and to attend health scrutiny meetings to answer questions
    - Duty of NHS to consult scrutiny on major service changes and provide feedback on consultations.

22. Under s. 22 (1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 'A local authority may make reports and recommendations to a responsible person on any matter it has reviewed or scrutinised'.

23. The Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

Annex 1 – Scrutiny Response Pro Forma

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October 2024

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OXFORDSHIRE COUNTY COUNCIL

REPORT OF: THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (HOSC):

Epilepsy Services:

REPORT BY: HEALTH SCRUTINY OFFICER, OXFORDSHIRE COUNTY COUNCIL, DR OMID NOURI

INTRODUCTION AND OVERVIEW

1. At its meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (HOSC) received reports providing an update on epilepsy services. Two reports were received, one main report from Oxford University Hospitals NHS Foundation Trust, and another brief report from NHS England South-East. This section provides a brief overview of the recent activities of the Committee around epilepsy as well as around the valproate policy and the background to the recent scrutiny session on 12 September 2024.

2. The Committee had received written evidence at its previous public meeting on 16 January 2024 from:

   - SUDEP Action and Epilepsy Action correspondence.
   - Correspondence from Professor Marian Knight, University of Oxford.

3. The letter from Professor Knight, concerned the findings of MBRRACE national surveillance of pregnant mothers and their unborn with a near doubling of sudden deaths against a backdrop of the introduction of the Pregnancy Prevention Programme. The third sector raised a red flag about the likely local safety impacts on residents and impacts on all stakeholders of a new national framework that valproate must not be started in new patients (male or female) younger than 55 years, unless two specialists independently consider and document that there is no other effective or tolerated treatment. It alerted to this being a very dramatic shift in clinical practice https://assets.publishing.service.gov.uk/media/65ae8f33fd784b0010e0c688/January_DSU_PDF.pdf

4. The Committee wrote to Steve Brine MP, Chair of the Parliamentary Health Select Committee in January 2024, requesting national scrutiny of the MHRA alert, the proposed timescales for implementation, the lack of a national impact assessment, and the lack of resources to support the new requirements; and received a response that it was included on the list of potential scrutiny items for the Select Committee.

5. The Committee also liaised with the ICB with a view to an update about the ICB response to the alert and the required local action plan and consideration of the suggestion that delay is sought to implementation because of the severe

pressures in the NHS and until adequate resources can be made available to local systems. This was based on an understanding of the likely local impacts.

6. In April 2024, the ICB updated the Committee that a task force comprising consultants, specialist nurses, medicines safety officers, and representatives from charities and patients with lived experience had worked on a local impact assessment. In April, the Committee received the ICB local impact assessment on the MHRA Pregnancy Prevention Update November 2023. The impact report that was shared with Committee members and the public outlined that there were unavoidable consequences, and current services were ill-equipped to handle the implementation. Specifically, it was anticipated that approximately 2855 outpatient appointments would be lost due to the new requirements and predicted increased mortality and greater co-morbidity including emergency situations.

7. The Committee wrote to Victoria Atkins MP, the then Secretary of State for Health (copied to the Chair of the Parliamentary Health Select Committee), to bring the local ICB impact assessment to her attention and to request that until the likely impacts and risks of phase 1 of the policy are assessed and safety addressed, that they allow the local NHS to delay implementation. The Committee received a response from the Department of Health that due to the General Election, this would have to be brought to attention after this had happened.

8. The Committee felt it crucial to receive an update on the current state of epilepsy services, and national and local contexts in which this service operates.

9. Between the January update and the Scrutiny item on 12 September, the MHRA issued a second update extending the Pregnancy Prevention Programme to another anti-seizure medication Topirimate https://www.gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme. In September there was an announcement of a third update, this time adding requirements for boys and men additional to those that were announced in January and applying the September update to all boys and men regardless of age https://www.gov.uk/drug-safety-update/valproate-use-in-men-as-a-precaution-men-and-their-partners-should-use-effective-contraception

10. This item was scrutinised by HOSC given that it has a constitutional remit over all aspects of health as a whole; and this includes the availability or accessibility of epilepsy services, as well as the national and local impacts of the Pregnancy Prevention Programme valproate policy. Upon commissioning this item, some of the points the Committee sought to investigate involved the following:

    - The effects of epilepsy as a condition on patients and families; and the health inequalities implications surrounding this.

    - Whether there are any high-risk groups that have been identified within Oxfordshire.

- Insights into the Oxfordshire epilepsy workforce, including full-time equivalent neurologists and specialists; and on trends of demands on clinical time and where these pressures stem from.

- Whether there are any community-based epilepsy services in Oxfordshire (and if there are any GPs with a specialist interest in epilepsy across the County).

- Details of any training on epilepsy for GPs and community-based professionals.

- Data on waiting times and any trends against recommended NICE good practice including first seizure clinic; follow-up appointments; new tertiary patients; as well as waiting times for the ketogenic diet for children with severe epilepsy.

- Insights into the new regulation on Valproate and Topirimate. What the impact on patients will be of the accelerated Valproate regulation.

- Given that the MHRA also announced that the Prevent programme will apply to Topirimate; what data outcomes are required locally for reporting nationally, and is any other data collected locally on outcomes of patients with epilepsy?

- Details around the steps taken thus far to progress the Oxford University Hospitals NHS Foundation Trust proposal to consider specialist clinics (including epilepsy) for Wantage Community Hospital. One outcome of coproduction and engagement was that epilepsy was included in the long list this year that was shared with the public in July.

- Who is leading on patient safety and at what levels of governance locally has consideration and assurance been given of the patient safety of people with epilepsy and their families including the adequacy of resource, funding, workforce and training for the Oxfordshire epilepsy service (in light of population-health needs and the added work and nature of the MHRA regulations on Valproate and Topirimate, and the context of medicines shortages).

- The support being provided to tackle sudden death in epilepsy, suicide and other epilepsy-related premature mortality in Oxfordshire.

- Whether there are any plans to continue to develop and to improve epilepsy services moving forward, and if there is any planned coproduction with the voluntary sector in Oxfordshire and patients with epilepsy and their families.

11. A summary of the 12 September scrutiny session, key observations and considerations follow. It became clear from HOSC scrutiny that there were

especially severe local impacts due to poor provision of the epilepsy service and because of unfunded and unbalanced national mandatory policies. This is also being brought to the attention of Cabinet and senior officers at Oxfordshire County Council, who are responsible for commissioning and provider arrangements for children and adults of people with epilepsy with learning disability or autism; and because of public health responsibilities relating to this population that is experiencing serious and worsening health inequalities.

12. These observations also informed a set of recommendations (outlined below) that have been issued to the BOB Integrated Care Board, Oxford University Hospitals NHS Foundation Trust, and NHS England South East region (The Committee has also written with recommendations to Karin Smyth MP, health minister and to Layla Moran MP, Chair of the Parliamentary Health and Social Care Committee).

SUMMARY

13. The Committee would like to express thanks to Professor Arjune Sen (Consultant Neurologist, OUH), Jackie Roberts (Lead Learning Disability Epilepsy Specialist Nurse, OUH), Rohini Rattihalli (Consultant Paediatric Medicine, OUH), Marcus Neale (Epilepsy Specialist Nurse, OUH), Rustam Rea (Consultant, OUH), Jane Adcock (Consultant Neurologist, OUH), Janice Craig (Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB), Rachael Corser (Chief Nurse, BOB ICB) and Sarah Fishburn (Senior Clinical Quality Improvement Manager, NHS England) for attending the meeting and answering questions from the Committee on the topic of epilepsy services.

14. Kristi McDonald, a registered speaker, shared her personal experience with epilepsy and the impact of the new Pregnancy Prevention regulations on her life. She highlighted the severe neglect and ignorance faced by epilepsy patients. She described the complexities of living with epilepsy, the mental health impacts, and the recent tightening of policies on sodium valproate and topiramate. She criticised the policy for stripping away informed consent and shared decision-making and breaching human rights, sharing examples of how the policy had harmed other patients.

15. The Committee then asked Professor Sen to introduce the epilepsy team and provide an overview of epilepsy and the service. The Consultant Neurologist explained that everyone experiences abnormal electrical discharges in the brain and that 1 in ten will experience a seizure in their lifetime requiring investigation. Epilepsy is a neurological disorder characterized by a network of electrical discharges which leads to recurrent seizures. It is a largely hidden disability. Each individual is likely to have some known triggers to seizures and the worsening of risk factors can be flagged and mitigated. The epilepsies often carry significant associated co-morbidities and when not well managed a large socio-economic impact.

16. There were significant and escalating demands on the service, including severe shortages of specialist nurses and neurologists and long waiting times for

patients. OUH serves a local population of 762,500 (and additional tertiary 2 million catchment) with waiting lists that are not safe for patients. NICE recommends a two-week waiting time for a first seizure, but at OUH this is a 9 month wait (tertiary referral one year). Children with epilepsy not controlled by medication who could benefit from the Ketogenic diet are waiting 3 years. New referrals to the epilepsy nurse service had tripled and requests from GPs for written guidance and letters had increased ten-fold in 3 years.

17. Access to treatment and anti-seizure medications has become extremely challenging. There were shortages of anti-seizure medications with some patients in Oxfordshire having to travel a long distance two weeks before their medicine was due so as not to run out of a source of supply.

18. Most concerning was the vast impact from the Medicines and Healthcare products Regulatory Agency (MHRA) regulations on the service, including the need for additional patient appointments and two clinical signatures (including a review of all patients who are seizure-free with a view to switching of medication from Valproate or Topirimate anti-seizure medications). The numbers of prescriptions are closely monitored. Clinicians confirmed the ICB local impact assessment report which had found an inequality of access to medication by girls and women and the likely harms. The consultant paediatrician spoke of the harrowing experience of a sister and a brother both living with epilepsy but with the sister experiencing physical and mental health crisis because of lack of access to Valproate https://www.channel4.com/news/fears-over-dangerous-change-in-prescription-rules-for-epilepsy-drug.

19. The Oxfordshire epilepsy clinical team were now undertaking excessive working during periods of leave, early mornings and late evenings because of these national demands and the welfare of the team was affected. There were immediate impacts and there was the enduring impact direct and indirect on patient safety and on recruitment and retention. The programme was also now extended to boys and men for the first time effecting 1045 boys and men in Oxfordshire and neither this or the extension of the programme to Topirimate had yet been factored in to any consideration of what was needed to sustain the service. The Oxfordshire epilepsy service was not in a position to implement safely.

20. There were only 2 full-time equivalent neurologists in the service. Whilst NICE recommends 9 epilepsy specialist nurses per 500,000 the Oxford service only has 3.6. The Committee received evidence that there was extremely poor provision for the Oxfordshire epilepsy service compared with other OUH services for similar `cliff-edge' long-term conditions and that it also fared very badly in comparison with similar services elsewhere like Sheffield. The Committee asked why the Oxfordshire epilepsy team was significantly under-resourced compared to other areas with similar populations, and what the historical context and funding situation behind this disparity were. The Epilepsy Specialist Nurse and the consultants reflected on the historical inequalities between epilepsy and neurology and other conditions and the postcode lottery across the UK since the late 1990s and the increasing complexities around

epilepsy service commissioning. Despite prioritising patient care, the nurse highlighted the difficulties in sustaining services due to insufficient resources, staffing, and funding; especially when national programmes like the Pregnancy Prevention Programme did not come with national funding.

21. The Committee asked about the potential for improving services and NHS performance on epilepsy. The Epilepsy Specialist Nurse discussed the setup of a satellite clinic in Brackley, which reduced travel times for patients significantly. The epilepsy team had worked in co-production with a population in South Oxfordshire to produce an outline plan of how a community-based clinic in Oxfordshire could benefit patients and staff during 2025 but would need workforce capacity to progress this. Progressing this plan was now negatively impacted by the requirement of two clinical signatures and additional appointments mandated nationally.

22. The Committee asked about the rise in demand for services for patients with learning disabilities and epilepsy. The Lead Learning Disability Epilepsy Specialist Nurse had been working closely with Oxford Health and Oxford University Hospitals to streamline services for patients in Oxfordshire. There were two learning disability teams, each with experienced Band 6 and Band 7 nurses. These teams primarily supported individuals with epilepsy and other health conditions, ensuring medication compliance and addressing potential risks like SUDEP. A significant focus of her concern was on the challenge of transition from childrens' to adult services, with more action needed to facilitate smooth transitions through transition clinics.

23. The Consultant Paediatrician spoke about the complexities of managing epilepsy in children, particularly those with learning disabilities and particularly with the confusion and complexity of communications with parents concerning the Pregnancy Prevention Programme. She discussed the need for personalised risk-benefit assessments for patients and the lack of a national framework to guide these decisions at the same time that there was a mandatory national framework for protection of a future unborn population.

24. There were widespread and shared concerns across all witnesses about the accelerations to the Pregnancy Prevention Programme including the governance processes at the MHRA. The Committee received evidence from one of the epilepsy clinical leads for NICE who spoke about the robust governance processes required at NICE when making recommendations about clinical practice and about medicines. NICE required a public and transparent evidence-based process from the start which involved third sector patient and clinical stakeholders and public consultation over a prolonged period. The Committee heard from the clinical team and from patients that this hadn't happened with the MHRA Pregnancy Prevention Programme Updates and that when there was stakeholder engagement it was on implementation including materials for updates. The feedback from patient organisations was ignored on most and certainly on critical aspects. These included that the aggregated regulation and national materials were mandatory without regard for different and especially vulnerable populations e.g. for children, the LGBTQ community and people with learning disability and epilepsy.

25. Kristi McDonald said that the national regulations and patient materials were unbalanced and felt hostile to living patients with a worsening of stigma and discrimination. The national framework and materials were not inclusive of patient preferences and there was no right of appeal. The MHRA national framework and NHS ignored essential information and existing safety empowerment tools valued by herself and other patients and recommended by MBRRACE and NHS RightCare Epilepsy Toolkit. The clinical team was clear professional organisations had complained too. The processes did not however allow for public transparency on stakeholder feedback. The Committee noted evidence from a patient that in a recent MHRA private briefing session accountability was explained as ministerial and across the whole health eco-system but that accountability for individualised decisions made under the policy rested with clinicians. The Committee heard about widespread international concern that the UK Pregnancy Prevention Programme was now extreme with insufficient evidence and without a national framework to ensure proportionality with patient safety needs and the preferences of the individual.

26. The Committee asked the Medicines Optimisation Lead Pharmacist and the The Senior Clinical Quality Improvement Manager at NHS England about the impact of the accelerated mandatory MHRA policies. The NHSE manager explained she had been specially seconded and was spending most of her time on it because of the impacts and complexities. The development of strong teamwork across the region and the ICB and all stakeholders had been encouraging with shared understanding of negative local impacts and development of local mitigations where these were possible. There had been whole system escalation to the NHS and MHRA because the increase in clinical and administrative workload across specialist and community NHS providers from the national mandatory requirements had not been funded and because of widespread and shared concerns across the South-East Region about undermining of basic NHS principles of informed consent, shared and balanced decision-making, evidence-based decision-making, transparency and impact on medication choices, family planning, patient safety and health inequalities.

27. The NHSE said they had met with families across the South-East that had been denied Valproate and had received evidence of patient harms from stakeholders. Access to the MHRA was difficult but they had now been informed that MHRA focused on drug safety, stating that while they regulate medication, it is the NHS's responsibility to implement these regulations and deal with impacts. The risk to the local NHS identified by the ICB local impact statement on severe local impacts on waiting lists, the service and residents was on the divisional risk register and was highlighted regularly at national meetings. At a recent national meeting the focus was on reduction of prescribing and absence of any balancing metric including outcomes for patients. The NHSE gave evidence they had written to all professional regulators and had requested clarity on accountability. The GMC had responded that regarding clinicians they would take account of exercise of the duty of candour and raising of concerns at an institutional level.

KEY POINTS OF OBSERVATION:

28. Below are some key points/themes of observation that the Committee has in relation to epilepsy services. These points of observation relate to some of the themes of discussion during the meeting on 12 September, and have also been used to shape the recommendations being made by the Committee to NHSE South East Region, BOB ICB, and Oxford University Hospitals NHS Foundation Trust.

29. The Committee recognised that all people experience abnormal electrical brain discharges and that 1 in 10 people will experience a seizure in their lifetime that will need investigation, but that with someone diagnosed with epilepsy it is a network of electrical discharges. Seizures can range from brief lapses of attention called absence seizures to full convulsive or generalised seizures. The place and the time of day or night are important. Each person may experience different triggers for their epilepsy and will have a different exposure to safety issues.

30. Whilst there are over forty different types of epilepsy 70% of people can be seizure-free if properly diagnosed and treated. Yet the World Health Organisation report had highlighted epilepsy as a public health emergency in 2021 Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology. The World Health Organization (WHO) has identified a significant treatment gap in epilepsy care, particularly in low- and middle-income countries, where up to 75% of people with epilepsy may not receive the treatment they need[1].

31. Public Health England found deaths in neurology with an increasing trend pre-pandemic when all other causes fell. Deaths in epilepsy were premature and three times more likely in deprived areas and a recent systematic review in the Lancet found this was the case for mid and high deprivation areas. https://assets.publishing.service.gov.uk/media/5a941945e5274a5b87c2fe47/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf https://www.sciencedirect.com/science/article/pii/S2468266724001324

32. The report by Economist impact in 2024 found neurology clinics struggling more than other NHS services with waiting lists raising by 76% between 2021 and 2023 Neurology crisis costing UK £96bn – Economist report (epilepsy.org.uk) showing that the availability of such specialists is seriously limited, even in high-income places and the Committee found that the Oxford epilepsy service was especially poorly served when contrasted with other similar services across the UK and with Western Europe where there was a ratio of 1 neurologist per 12,000 population.

33. The Committee recognises epilepsy as a treatable `cliff-edge condition` affecting 1 per cent of the population that often presents as an emergency (or sudden fatality for at least 21 people a week (EB | Epilepsy & Behavior |

[1] New WHO brief sets out actions needed to improve lives of people with epilepsy

Prevent 21: SUDEP Summit | ScienceDirect.com by Elsevier). Deaths can result from Sudden Unexpected Death in Epilepsy (SUDEP) or from accident or status or suicide. The Committee heard evidence from lived experience that empowerment of people living with the condition and their families is a priority, but that awareness and support for people having access to good practice safety communication tools from the third sector was not happening. This meant that people living with epilepsy and health and care professionals were not being helped to appreciate individualised worsening of risk factors for Sudden Unexpected Death in Epilepsy (where an otherwise healthy person with epilepsy would die suddenly, often in their sleep), or risks of injuries, accidents and/or deteriorating mental health drowning or suicide so that there could be a plan to mitigate.

34. The impact of epilepsy extends beyond the seizures themselves. Children and adults also face absence from school, loss of driving licence, loss of employment and emergencies due to physical and mental health crisis. Stigmatisation, discrimination, mental health issues such as anxiety and depression are well established. Children experience severe inequalities https://www.rcpch.ac.uk/resources/epilepsy12-round-3-methodology-datasets and in 2024 epilepsy was included in Core20PLUS5 as a priority for tackling health inequalities in children https://www.england.nhs.uk/wp-content/uploads/2022/11/core20plus5-cyp-infographic-v2.pdf

35. 53% of people with epilepsy are economically inactive far worse than for autism, severe learning disabilities and mental health conditions; and this is not related to skills or qualifications https://www.epilepsy.org.uk/news/high-rate-of-economic-inactivity-in-epilepsy

36. The Midlands region has prioritised epilepsy and in people with learning disability and autism. 1 in 5 people with learning disability or autism have epilepsy. This population dies ten years younger than people with a learning disability or autism with another co-morbidity and has taken action https://www.england.nhs.uk/midlands/2023/11/15/nhs-england-funded-project-aims-to-reduce-the-epilepsy-risks-faced-by-people-with-learning-disabilities/, https://sudep.org/epilepsy-safety/learning-disability-resources/. The need for a focus on prevention in the community and avoidance of A and E and costly inpatient settings for people with learning disability and autism is at the core of the Oxfordshire charity supporting campaigners with learning disability with their Don't lock me up' and `We can't wait' campaigns https://mylifemychoice.org.uk/campaigns/. The Committee heard that children and adults with a learning disability are likely to find the MHRA accelerated regulations on the Pregnancy Prevention Programme confusing and given this group is at high risk from their epilepsy the impacts need consideration and management because they are significant.

37. A recent national confidential enquiry into adult patients presenting to A and E found a gap in risk check, communication and follow up action for the many thousands of adults with epilepsy who present to and who are then discharged back into the community NCEPOD - Epilepsy: (2022). 1% of A and E

attendances are for epilepsy, 30% of patients did not receive any advice. For patients who had not seen a specialist in the previous 12 months the referral rate was only 35%, a lower rate than those who had. 23% were on no medication for their seizures and 44% only on one medication https://www.nashstudy.org.uk/ Adults also face loss of driving licence, loss of employment and emergencies due to both physical and mental health crisis.

38. Access to the right medication at the right time needs urgently to be improved as the impact of not accessing this can be catastrophic. Medication needs to be personalised as it can take some years for patients to have their epilepsy stabilised. National guidance on switching across different versions of the same drug is clear that for one category of medication there should be maintenance of supply and for another category the need for supply should be based on clinical judgement and consultation with patient and/or carer, taking into account factors such as seizure frequency and treatment history and patient/carer-related factors https://www.gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products. However the Committee found there is no national framework to guide the switching or non-commencement of Valproate or Topirimate in children and adults who have seizures that are likely to respond most effectively to Valproate or Topirimate.

39. Based on the written and verbal evidence given to the Committee, there was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June). In addition to the summary of evidence we noted:

    a. Valproate taken whilst pregnant is one of medications that carries a high teratogenic potential with a 11% risk of congenital malformations and a 30-40% risk of neurodevelopmental disorders.

    b. A systematic review in June 2024 of 923 studies was amongst other scientific papers this year which found reassuring evidence that paternal exposure to anti-seizure medication at conception is unlikely to pose any major risk of adverse outcomes for the unborn and there was insufficient evidence for regulatory action https://jnnp.bmj.com/content/early/2024/08/17/jnnp-2024-334077.abstract; Paternal Valproate Treatment and Risk of Childhood Neurodevelopmental Disorders: Precautionary Regulatory Measures Are Insufficiently Substantiated - Garey - 2024 - Birth Defects Research - Wiley Online Library.

    c. Valproate also happens to be the most potent medication to treat generalised epilepsies should girls and women have preferences to be safe from SUDEP and other harms and able to lead their best lives The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for

generalised and unclassifiable epilepsy: an unblinded randomised controlled trial - The Lancet; https://pubmed.ncbi.nlm.nih.gov/31831600/.

d. A study in Brain 2024 is noted which found the risk of emergency attendance, hospital admission, injuries, burns and new on-set depression was 1 to 7% higher for patients withdrawn from valproate than in those remaining ON valproate https://academic.oup.com/brain/article/147/10/3426/7657740; and a paper in the Journal of Neurology in June 2024 estimated that 21,000–28000 people in the UK will be exposed to the potential hazards of breakthrough seizures. https://link.springer.com/article/10.1007/s00415-024-12436

e. The evidence from lived experience at HOSC is also supported by a thematic examination of the voices of 19 people with epilepsy and their lived experience of the direct damage of avoiding valproate or topiramate, including SUDEP https://medrxiv.org/cgi/content/short/2024.09.06.24313040v1

Below are two more specific observations that the Committee has, which have shaped the recommendations being made to the NHSE South East Region, BOB ICB, and Oxford University Hospitals NHS Foundation Trust. These observations have also a recommendation separately being made to Oxfordshire County Council's cabinet:

A. Securing more resource for epilepsy services:

This all underscores the need for inclusion of epilepsy in work programmes of the NHS and local authorities as part of tackling inequalities in commissioning and provision of care and support for people to live their best lives. Improved awareness across the system would help tackle the invisibility of this population that has always had limited access to services and which have worsened further as a result of escalating demands and national policies on medicines. More resources to train healthcare and residential providers in epilepsy care and to even explore the potential establishment of comprehensive care centres with view to:

Improved outcomes- Early and accurate diagnosis would mean 7 out of 10 people would be seizure free on the right medication and could be managed well in the community. This would mean increased capacity to support treatment and care of people needing interventions to reduce the frequency and severity of seizures. This, in turn, enhances the overall quality of life for individuals with epilepsy and their families.

Reducing the treatment gap and health inequalities have been identified nationally and by the WHO- By ensuring that more individuals have access to the necessary medications and care, we can move towards equitable healthcare for all people with epilepsy, regardless of their geographic location or socioeconomic status.

Reducing mental health burden- Epilepsy often coexists with mental health conditions, making integrated care essential. Allocating resources to provide mental health support within an epilepsy service better integrated into primary care and the community can address the psychological and emotional needs of patients, leading to better overall health outcomes.

Economic benefits- Enabling individuals with epilepsy to lead productive lives, will increase workforce participation and reduce school absences. Securing more resources for epilepsy services can also contribute to reducing the stigma associated with the condition. Targeted public awareness campaigns and education programs with schools, workplaces, citizen advice centres and the public can change societal attitudes and promote understanding and acceptance of epilepsy and support so that epilepsy is recognised as a disability and one that will only require minimal reasonable adjustment. This, in turn, can lead to more inclusive communities and workplaces. Proper support for children and adults with learning disability with epilepsy and autism or both to access the intervention they need for their epilepsy and their wider educational needs in the community close to their family will reduce the need for expensive out of county placements or special need schools. Effective epilepsy management can reduce healthcare costs associated with emergency care and hospitalizations. 1 in 5 people with learning disability and/or autism has epilepsy and the co-morbidities of epilepsy include mental health and for the older population stroke. Identifying risk in A and E and developing community-based prevention would decrease admissions, which can be lengthy for the most vulnerable group within this population. Therefore, the importance of securing further resources for epilepsy services cannot be overstated. From improving patient outcomes and reducing the treatment gap to fostering societal acceptance and economic benefits, the advantages are manifold. By prioritising epilepsy care and investing in the necessary resources, we can enhance the lives of millions of individuals living with epilepsy and build a more inclusive and compassionate society.

B. Prioritising patient safety:

Managing epilepsy involves not only addressing the medical aspects but also ensuring patient safety, which is paramount for both those affected and their families.

For the general population with epilepsy, it is critical that cultural assumptions and myths are tackled. It is vital for there to be signposting to awareness of empowerment information and tools to support engagement with the public sector, especially the NHS, local authorities, schools, and with employers, and to support self-care and support with risk assessments and reasonable adjustments where these are needed, or a safe home environment. There are very few things that just because you have epilepsy you cannot do e.g. working at heights, around unguarded machinery or near open unsupervised water.

For people with learning disability or autism and epilepsy it is also important that cultural assumptions and myths are tackled and treatment and care is individualised and based on accurate information about epilepsy:

SEND and schools: mental health and SEND staff awareness of third sector support for families and for schools.

Commissioning and providing of residential care: awareness of good practice guidelines

Annual Learning Disability Check to include use of existing digitalised patient safety check**.**

Safe Environment: Modification of the home environment to reduce hazards, such as installing a shower instead of a bath, adjustments in the kitchen and advice on high-risk activities e.g. climbing a ladder. Consideration of interventions such as information on range of night monitors.

Additionally, according to a study published in the journal of Epilepsy and Behaviour, epilepsy can have profound impacts on mental and emotional health[2].

The Committee also heard from lived experience about how existing anxieties about seizures and social stigma and discrimination had worsened with recent national policy and how the emotional toll on families was significant. Anti-epileptic drugs (AEDs) are a cornerstone of epilepsy treatment. Access to the right medicine at the right time and adherence to prescribed medication regimens is vital for controlling seizures. Steps to enhance medication safety could include:

- Education health and care professionals: Improved awareness across professionals who work in community based or emergency settings who may be alongside people with epilepsy of the importance of ensuring the patient is at the centre of decision-making, and of SUDEP and other epilepsy risks, and the positive impacts of care that includes the patient benefiting from the right medication in a timely way and other interventions and support if needed. Consideration of multi-disciplinary support including peer group support, counselling and therapy to help mitigate psychological impacts.

- Education for patients and families: Educating the patient, family, and community about epilepsy can reduce stigma and foster a more supportive environment. Signposting to information and empowerment tools to support self-advocacy, self-care and open communication with healthcare providers about any issues or changes in seizure patterns. Signposting to support networks available to access peer group support and practice advice.

[2] EB | Epilepsy & Behavior | Journal | ScienceDirect.com by Elsevier

RECOMMENDATIONS

40. In light of its findings and observations (including those outlined above), the Committee issues the following recommendations to the BOB Integrated Care Board, Oxford University Hospitals NHS Foundation Trust, and to NHS England South East region:

For the ICB and Oxford University Hospitals NHSFT to:

- *Give priority to patient safety for people with epilepsy and their families in Oxfordshire, and to the welfare of the Oxfordshire epilepsy team, and to set out how that priority will be addressed through their governance and management at a board level. The governance and management of these priorities should also be inclusive of people with lived experience and their charity representatives, as well as their concerns regarding tailored and balanced communications and the use of existing empowerment tools.*

- *To secure further funding and resource for epilepsy services.*

For NHS England South East Region to:

- *Give support to the ICB and Oxford University Hospitals NHS Foundation Trust to help achieve the above prioritisations.*

Legal Implications

41. Health Scrutiny powers set out in the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide:
 Power to scrutinise health bodies and authorities in the local area
 Power to require members or officers of local health bodies to provide information and to attend health scrutiny meetings to answer questions
 Duty of NHS to consult scrutiny on major service changes and provide feedback on consultations.

42. Under s. 22 (1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 'A local authority may make reports and recommendations to a responsible person on any matter it has reviewed or scrutinised'.

43. The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the Committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

Annex 1 – Scrutiny Response Pro Forma

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November 2024

OXFORDSHIRE COUNTY COUNCIL

Cllr J Hanna OBE

Chair, Oxfordshire Health Overview and Scrutiny Committee

12 November 2024

Dear Karin Smyth MP,

Epilepsy and the Valproate Policy:

At its public meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (JHOSC) held an item on Epilepsy services. The current state of epilepsy services were discussed, with insights into national and local contexts being provided. Three MHRA national alerts during 2024 around the Pregnancy Prevention Programme with accelerated and new restrictions on anti-seizure medications were also a key aspect of the discussion.

The timeliness of the need for urgent action and consideration of business cases currently under consideration, warrant the Committee sharing some of our draft findings as well as the recommendations that were formally accepted at the Committee on 12 September. The Committee had received written evidence at previous Committees in January that have been shared as attachments to the email containing this letter from:

- SUDEP Action and Epilepsy Action
- Marian Knight, Professor of Professor of Maternal and Child Population Health, Oxford

The Committee wrote to Steve Brine MP, Chair of the Parliamentary Health Scrutiny Committee in January 2024, requesting national scrutiny of the MHRA alert, the proposed timescales for implementation, the lack of a national impact assessment, and the lack of resources to support the new requirements. We received a response that it was included on the list of potential scrutiny items for the Select Committee.

The Committee also liaised with the ICB with a view to an update about the ICB response to the alert and required local action plan and consideration of the suggestion by SUDEP Action and Epilepsy Action that delay is sought to implementation because of the severe pressures in the NHS, and until adequate resources can be made available to local systems. This was based on an understanding confirmed at our meeting on 12 September of the severe likely local impacts that had been brought to the attention of the MHRA, ministers, the NHS, the Patient Safety Commissioner and the Parliamentary Health and Care Select Committee since a surprise MHRA drug safety update in December 2022 https://assets.publishing.service.gov.uk/media/6399fcf4e90e072aefe10288/Dec-2022-DSU-PDF.pdfof December 2022

In April, the ICB updated the Committee that a task force comprising consultants, specialist nurses, medicines safety officers, representatives from charities and patients with lived experience had worked on a local impact assessment. In April the committee received:

- The ICB Local impact assessment on the MHRA Pregnancy Prevention Update November 2023 *(This is also attached to the email containing this letter)*

The impact report that was shared with Committee members and the public outlined that there were unavoidable consequences, and current services were ill-equipped to handle the implementation.

Specifically, it was anticipated that approximately 2855 outpatient appointments would be lost due to the new requirements and that "*naturally, this resource impact will result in less patients being prescribed valproate; this impact will be seen in greater mortality, greater morbidity including ED pressure resulting from uncontrolled epilepsy*" and warned that the impact of further expected updates for men and boys would be additional and severe.

The Committee wrote to Victoria Atkins MP, the then Secretary of State for Health (copied to the Chair of the Parliamentary Health Select Committee), to bring the local ICB impact assessment to her attention and to request that until the likely impacts and risks of phase 1 of the policy are assessed and safety addressed, that they allow the local NHS to delay implementation. The Committee received a response from the Department of Health that because of the General Election this would have to be brought to attention after this.

An epilepsy item was added for the June JHOSC agenda and received petitions from the public from Dr Judy Shakespeare and Kristi McDonald (who spoke about the harms that she and other women were experiencing). On the request of Oxford University Hospitals NHS Foundation Trust that they be given the opportunity to liaise with the ICB, the substantive epilepsy item was deferred until 12 September.

Evidence and outcomes of the 12th September JHOSC meeting epilepsy item:

The Committee received written evidence, and it also heard evidence during the epilepsy session on 12th September from:

- Kristi McDonald, expert by lived experience
- Professor Arjune Sen- Consultant Neurologist, OUH.
- Dr Jane Adcock- Consultant Neurologist, OUH.
- Jackie Roberts- Lead Learning Disability Epilepsy Specialist Nurse, OUH.
- Dr Rohini Rattihalli- Consultant Paediatric Medicine, OUH.
- Marcus Neale- Epilepsy Specialist Nurse, OUH.
- Dr Rustam Rea- Consultant, OUH Trust representative.
- Janice Craig- Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB
- Sarah Fishburn, NHSE South East Region.

The Committee found the evidence relating to serious concerns and harms because of local impacts from national policy updates on the Pregnancy Prevention Programme were shared across all NHS stakeholders, and that stakeholders had been escalating these internally for some time. There was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June) and patient safety harms across the South-East Region. Shared concerns about

evidence-base, lack of public consultation, lack of a national framework for the protection of children and adults who ought to be offered Valproate and Topirimate and the range of direct and indirect impacts. There was unanimous recognition of the need for urgent action in support of the local epilepsy service. Evidence was received that the epilepsy clinical team were working unsustainable clinical hours so that they avoided worsening of waiting lists for clinics, and their welfare was seriously impacted.

The Committee was shocked by the dire situation and issued the following recommendations to Oxford University Hospitals NHS Foundation Trust and NHS England South-East region on 12 September:

1. For the ICB and Oxford University Hospitals NHSFT to:

- *Give priority to patient safety for people with epilepsy and their families in Oxfordshire, and to the welfare of the Oxfordshire epilepsy team; and to set out how that priority will be addressed through their governance and management at a board level. The governance and management of these priorities should also include co-production with patients with lived experience and their charity representative; and address their concerns regarding tailored and balanced communications and the importance of signposting to existing empowerment tools recommended by MBRRACE (national surveillance on maternal deaths), NHS RightCare, as well as the recommendations from other NHS regions.*
- *To secure further funding and resource for epilepsy services. It is also recommended that managers involved in consideration of the current business case before the Trust take account of the JHOSC findings and the recommendations of the Committee and its full support for the business case as a necessary first step in addressing patient safety and welfare, the sustainability of the Oxfordshire epilepsy service, and wider impacts on public services.*

2. For NHSE South East Region to*: Give support to the ICB and Oxford University Hospitals NHS Foundation Trust to help achieve the above prioritisations.*

The Committee urges you to suspend the MHRA regulatory updates of 2024 pending an independent national review of the UK's Pregnancy Prevention Programme.

Yours sincerely,

Cllr Jane Hanna OBE

Chair, Oxfordshire JHOSC, OCC
Jane.hanna@oxfordshire.gov.uk

APPENDICES

Attached by email: Letter SUDEP Action/Epilepsy Action; Letter Marian Knight attached to Local Impact Assessment attached

Considerations of the Committee about:

a) Epilepsy needs and Service.

b) The local impact of MHRA updates 2024 on the Pregnancy Prevention Programme on the epilepsy workforce and patient safety.

A. Considerations of the JHOSC on Epilepsy Needs and Service

On the basis of the written and verbal evidence given to the committee, there was strong evidence supporting:

1. Lack of awareness of epilepsy and stigma. The committee recognised that all people experience abnormal electrical brain discharges and that 1 in 10 people will experience a seizure in their lifetime, but that with someone diagnosed with epilepsy it is a network of electrical discharges. Whilst there are many different epilepsies, 70% of people can be seizure-free if properly diagnosed and treated.

2. Lack of awareness and communication of SUDEP and risks of epilepsy. The Committee's recognition of epilepsy as a treatable `cliff-edge condition` affecting 1 per cent of the population that often presents as an emergency (or sudden fatality for at least 21 people a week (EB | Epilepsy & Behavior | Prevent 21: SUDEP Summit | ScienceDirect.com by Elsevier). Deaths can result from Sudden Unexpected Death in Epilepsy (SUDEP) or from accident or status or suicide. Children and adults also face absence from school, loss of driving licence, loss of employment and emergencies due to physical and mental health crisis.

3. People with epilepsy and their families can also face injuries, lost school days, loss of driving licence, loss of employment, loss of mental well-being.

4. Clinical and lived experience evidence of stigmatisation still experienced in 2024 at all levels of institutions. The World Health Organisation report Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology is noted as is the Chief Medical Officer annual report 2001 and 2002 which evidenced this hostile culture contributing to avoidable deaths and harms in epilepsy https://image.guardian.co.uk/sys-files/Society/documents/2003/07/03/report2002.pdf

5. The epilepsy service not in a position to take on new national mandatory actions safely. OUH serves a local population of 762,500 (and additional tertiary 2 million catchment) with waiting lists that are not safe for patients. NICE recommends a two-week waiting time for a first seizure, but at OUH this is a 9 month wait (tertiary referral one year). Children with epilepsy not controlled by medication who could benefit from the Ketogenic

diet are waiting 3 years. New referrals to the epilepsy nurse service had tripled and requests from GPs for written guidance and letters had increased ten-fold in 3 years.

6. The adult service only has 2 Full-time equivalent neurologists for this population in contrast with 1 per 12,000 in Western Europe. Whilst NICE recommends 9 epilepsy specialist nurses per 500,000 the Oxford service only has 3.6. The report by Economist impact in 2024 found neurology clinics struggling more than other NHS services with waiting lists raising by 76% between 2021 and 2023 Neurology crisis costing UK £96bn – Economist report (epilepsy.org.uk). The Committee received evidence that there was extremely poor provision for the Oxfordshire epilepsy service compared with other OUH services for similar `cliff-edge' long-term conditions and that it also fared very badly in comparison with similar services elsewhere like Sheffield. The Committee was concerned to understand why there were these inequalities between different services and between postcodes. It was explained that the present funding of posts was based on national specialist commissioning arrangements, and these were based on historical allocations of NHS posts to individual hospital trusts going back decades.

7. The gap in any primary care service or any specialist primary care clinician across Oxfordshire or the ICB with an interest or role in epilepsy against a backdrop of the cut of epilepsy from the GP Quality Outcomes Framework in 2013. The epilepsy team had worked in co-production with a population in South Oxfordshire to produce an outline plan of how a community-based clinic in South Oxfordshire could benefit patients and staff during 2023 but would need workforce capacity to progress this.
   Reports reveal a national issue with a gap in risk check, communication and follow up action for the many thousands of adults with epilepsy who present to and are discharged back into the community NCEPOD - Epilepsy: (2022).

B. The local impact of MHRA updates 2024 on workforce capacity and patient safety

Based on the written and verbal evidence given to the committee, there was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June). Evidence included:

1.Access to treatment and anti-seizure medications is now extremely challenging. There were shortages of anti-seizure medications with some patients in Oxfordshire having to travel a long distance two weeks before their medicine was due so as not to run out of a source of supply. It was noted that neither Valproate nor Topirimate were in short supply.

2. Valproate taken whilst pregnant is one of medications that carries a high teratogenic potential with a 11% risk of congenital malformations and a 30-40% risk of neurodevelopmental disorders.

3. Valproate also happens to be the most potent medication to treat generalised epilepsies should girls and women have preferences to be safe from SUDEP and other harms and able to lead their best lives The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for generalised and unclassifiable epilepsy: an unblinded randomised controlled trial - The Lancet; https://pubmed.ncbi.nlm.nih.gov/31831600/

4. The ICB local impact assessment report attached found an inequality of access to this medication by girls and women and the MBRRACE report analysing deaths of pregnant mothers and their unborn has found a near doubling of SUDEP against a backdrop of the introduction of the Pregnancy Prevention Programme with women uninformed about the risks of SUDEP (Letter Professor Knight attached). The clinical team alerted the Committee to the harrowing experience of a sister of a sister and a brother both living with epilepsy and the impact of this inequality on the safety and life of the sister https://www.channel4.com/news/fears-over-dangerous-change-in-prescription-rules-for-epilepsy-drug. The sister is part of a published thematic examination of the voices of 19 people with epilepsy and their lived experience of the direct damage of avoiding valproate or topiramate, including SUDEP https://medrxiv.org/cgi/content/short/2024.09.06.24313040v1

5. The latest UK regulation since 2024 requires two clinical signatures for Valproate and numbers of prescriptions are closely monitored. The programme had been extended to boys and men for the first time in 2024. The Committee heard from the clinical team about International concern, including from the team that generated the data being used that the MHRA Pregnancy Prevention Programme is an outlier using insufficient evidence and lack of balance to rationalise an extreme mandatory policy without a national framework to tailor to include the clinical needs and preferences of the individual.

6. A systematic review in June 2024 of 923 studies was amongst other scientific papers this year which found reassuring evidence that paternal exposure to anti-seizure medication at conception is unlikely to pose any major risk of adverse outcomes for the unborn and there was insufficient evidence for regulatory action https://jnnp.bmj.com/content/early/2024/08/17/jnnp-2024-334077.abstract; Paternal Valproate Treatment and Risk of Childhood Neurodevelopmental Disorders: Precautionary Regulatory Measures Are Insufficiently Substantiated - Garey - 2024 - Birth Defects Research - Wiley Online Library.

7. A study in Brain 2024 is noted which found the risk of emergency attendance, hospital admission, injuries, burns and new on-set depression was 1 to 7% higher for patients withdrawn from valproate than in those remaining ON valproate https://academic.oup.com/brain/article/147/10/3426/7657740; and a paper in the Journal of Neurology in June 2024 estimated that 21,000–28000 people in the UK will be exposed to the potential hazards of breakthrough seizures.
https://link.springer.com/article/10.1007/s00415-024-12436

8. Lived experience evidence that the national regulations and patient materials were unbalanced and felt hostile to living patients with a worsening of stigma and discrimination. Kristi McDonald found the national framework and materials were not inclusive of patient preferences and there was no right of appeal. There was no signposting from the NHS or the MHRA to an EpsMon App that had helped her to know her individualised risks and self-advocate. The MHRA national framework and NHS ignored essential information and existing safety empowerment tools valued by patients and recommended by MBRRACE and NHS RightCare Epilepsy Toolkit. She had been involved in a national research meeting where there was discussion about developing a new national App and she did not understand why this was happening. The NHSE said they had met with families across the South-East that had been denied Valproate and had received evidence of patient harms from SUDEP Action.

9. The aggregated regulation and national materials were mandatory without regard for different populations e.g. for children, the LGBTQ community and people with learning disability and epilepsy the MHRA regulations were especially complex. Whilst there was a national framework and materials for protection which extended to hypothetical unborn children, the paediatric team gave evidence there was no national framework for the protection of children or adults living with epilepsy who ought to be offered Valproate or Topirimate to control their seizures and it was unclear who nationally had a responsibility for that.

10. Widespread and shared concerns across the South-East Region about undermining of basic NHS principles of informed consent, shared and balanced decision-making, evidence-based decision-making, transparency specifically in relation to a vulnerable population of patients needing anti-seizure medication for epilepsy or mental health. This included concern about the validity of the second signature in the context of the framework not requiring patient involvement and there being no appeal.

11. The risk to the local NHS identified by the ICB local impact statement severe local impacts on waiting lists, the service and residents was on the divisional risk register and was highlighted regularly at national meetings. The latest surprise update from the MHRA in September 2024 would impact 1045 boys and men in Oxfordshire and this had not yet been factored in to any consideration of what was needed to sustain the service. Nor had the new update on Topirimate.

12. The Committee heard directly from the Oxfordshire epilepsy clinical team who were undertaking excessive working during periods of leave, early mornings and late evenings because of these national demands and the welfare of the team was affected. There were immediate impacts and there was the enduring impact direct and indirect on patient safety and on recruitment and retention.

13. All stakeholders including the region and the ICB were clear that the increase in clinical and administrative workload from the national mandatory requirements had not been funded. The provider Trust representative explained that the impact of the national demands fell purely on the Trust which was affected by cuts year on year and that there was an urgent need for NHS national specialist funding arrangements to tackle the problem and make resource available.

14. There was a widespread impact across management teams in the NHSE and ICB and Trusts of managing the demands of the Pregnancy Prevention Programme. The NHSE manager explained she had been specially seconded and was spending most of her time on it because of the impacts and complexities. The development of strong teamwork across the region and the ICB and stakeholders had been encouraging with development of some local mitigations where these were possible and whole system escalation to the NHS and MHRA.

15. Access to the MHRA was difficult for NHS regions taking many months. When they raised concerns, they were told that although the MHRA was leading the regulatory change, their focus was entirely on the safety of the drug i.e they regulated the medicine not the NHS and any concerns of impacts were for the NHS to resolve. The MHRA view was that there were no deaths associated with the policy. At a recent national meeting the focus was on

reduction of prescribing. There was an absence of any balancing metric including outcomes for patients.

16. Concerns for the welfare of patients, clinicians, bereaved families and their charity representatives including the threat from the Prevent regulatory regime to proposals for piloting a community-based specialist epilepsy clinic in Wantage to support prevention because of lack of capacity.

17. Widespread and shared concerns about the governance processes at the MHRA. The committee heard that the 2024 updates required the most dramatic change in clinical practice for decades and yet updates were usually briefed to stakeholders as a fait accompli. In 2022 there had been no public consultation or consultation with third sector patient and clinical organisations before there was an MHRA drug safety announcement and organisations had complained. There had been three updates in 2024 alone, with the September 2024 update on additional regulations for men and boys a surprise for all stakeholders. The Committee received evidence from one of the epilepsy clinical leads for NICE who compared the robust governance processes required at NICE with the MHRA processes. NICE required a public and transparent evidence-based process from the start which involved third sector patient and clinical stakeholders and public consultation over a prolonged period.

18. The Committee evidence was that third sector epilepsy patient and clinical organisations had raised likely harms from the policy and urged consultation and a rethink since December 2022. It was noted that outcome from engagement had not been included in a statements from ministers to Parliament Sodium Valproate - Hansard - UK Parliament, neither was a plea for a radical rewrite of national materials for clinicians and patients referred to in the statement of engagement with stakeholders in the public impact report https://www.gov.uk/government/publications/valproate-review-of-safety-data-and-expert-advice-on-management-of-risks

19. Concerns about accountabilities for deaths and harms under the UK Pregnancy Prevention Programme or the management of harms and support for patients, bereaved families and clinicians. The committee noted evidence from Kristi McDonald that in the MHRA recent private briefing session about the latest update, accountability was explained as ministerial and across the whole health eco-system but that accountability for individualised decisions made under the policy rested with clinicians. The NHSE gave evidence they had written to all professional regulators and had requested clarity on accountability. The GMC had responded that regarding fitness to practice they would take account of exercise of the duty of candour and raising of concerns at an institutional level.

OXFORDSHIRE COUNTY COUNCIL

Cllr J Hanna OBE

Chair, Oxfordshire Health Overview and Scrutiny Committee

12 November 2024

Dear NHS England Specialist Commissioning Team,

Epilepsy and the Valproate Policy:

At its public meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (JHOSC) held an item on Epilepsy services. The current state of epilepsy services were discussed, with insights into national and local contexts being provided. Three MHRA national alerts during 2024 around the Pregnancy Prevention Programme with accelerated and new restrictions on anti-seizure medications were also a key aspect of the discussion.

The timeliness of the need for urgent action and consideration of business cases currently under consideration, warrant the Committee sharing some of our draft findings as well as the recommendations that were formally accepted at the Committee on 12 September. The Committee had received written evidence at previous Committees in January that have been shared as attachments to the email containing this letter from:

- SUDEP Action and Epilepsy Action
- Marian Knight, Professor of Professor of Maternal and Child Population Health, Oxford

The Committee wrote to Steve Brine MP, Chair of the Parliamentary Health Scrutiny Committee in January 2024, requesting national scrutiny of the MHRA alert, the proposed timescales for implementation, the lack of a national impact assessment, and the lack of resources to support the new requirements. We received a response that it was included on the list of potential scrutiny items for the Select Committee.

The Committee also liaised with the ICB with a view to an update about the ICB response to the alert and required local action plan and consideration of the suggestion by SUDEP Action and Epilepsy Action that delay is sought to implementation because of the severe pressures in the NHS, and until adequate resources can be made available to local systems. This was based on an understanding confirmed at our meeting on 12 September of the severe likely local impacts that had been brought to the attention of the MHRA, ministers, the NHS, the Patient Safety Commissioner and the Parliamentary Health and Care Select Committee since a surprise MHRA drug safety update in December 2022 https://assets.publishing.service.gov.uk/media/6399fcf4e90e072aefe10288/Dec-2022-DSU-PDF.pdfof December 2022

In April, the ICB updated the Committee that a task force comprising consultants, specialist nurses, medicines safety officers, representatives from charities and patients with lived experience had worked on a local impact assessment. In April the committee received:

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The impact report that was shared with Committee members and the public outlined that there were unavoidable consequences, and current services were ill-equipped to handle the implementation.

Specifically, it was anticipated that approximately 2855 outpatient appointments would be lost due to the new requirements and that "*naturally, this resource impact will result in less patients being prescribed valproate; this impact will be seen in greater mortality, greater morbidity including ED pressure resulting from uncontrolled epilepsy*" and warned that the impact of further expected updates for men and boys would be additional and severe.

The Committee wrote to Victoria Atkins MP, the then Secretary of State for Health (copied to the Chair of the Parliamentary Health Select Committee), to bring the local ICB impact assessment to her attention and to request that until the likely impacts and risks of phase 1 of the policy are assessed and safety addressed, that they allow the local NHS to delay implementation. The Committee received a response from the Department of Health that because of the General Election this would have to be brought to attention after this.

An epilepsy item was added for the June JHOSC agenda and received petitions from the public from Dr Judy Shakespeare and Kristi McDonald (who spoke about the harms that she and other women were experiencing). On the request of Oxford University Hospitals NHS Foundation Trust that they be given the opportunity to liaise with the ICB, the substantive epilepsy item was deferred until 12 September.

Evidence and outcomes of the 12th September JHOSC meeting epilepsy item:

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- Professor Arjune Sen- Consultant Neurologist, OUH.
- Dr Jane Adcock- Consultant Neurologist, OUH.
- Jackie Roberts- Lead Learning Disability Epilepsy Specialist Nurse, OUH.
- Dr Rohini Rattihalli- Consultant Paediatric Medicine, OUH.
- Marcus Neale- Epilepsy Specialist Nurse, OUH.
- Dr Rustam Rea- Consultant, OUH Trust representative.
- Janice Craig- Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB
- Sarah Fishburn, NHSE South East Region.

The Committee found the evidence relating to serious concerns and harms because of local impacts from national policy updates on the Pregnancy Prevention Programme were shared across all NHS stakeholders, and that stakeholders had been escalating these internally for some time. There was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June) and patient safety harms across the South-East Region. Shared concerns about

evidence-base, lack of public consultation, lack of a national framework for the protection of children and adults who ought to be offered Valproate and Topirimate and the range of direct and indirect impacts. There was unanimous recognition of the need for urgent action in support of the local epilepsy service. Evidence was received that the epilepsy clinical team were working unsustainable clinical hours so that they avoided worsening of waiting lists for clinics, and their welfare was seriously impacted.

The Committee was shocked by the dire situation and issued the following recommendations to Oxford University Hospitals NHS Foundation Trust and NHS England South-East region on 12 September:

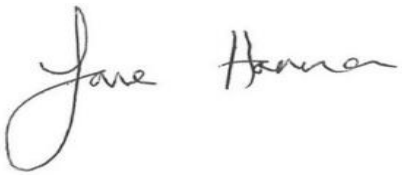
1. For the ICB and Oxford University Hospitals NHSFT to:

- *Give priority to patient safety for people with epilepsy and their families in Oxfordshire, and to the welfare of the Oxfordshire epilepsy team; and to set out how that priority will be addressed through their governance and management at a board level. The governance and management of these priorities should also include co-production with patients with lived experience and their charity representative; and address their concerns regarding tailored and balanced communications and the importance of signposting to existing empowerment tools recommended by MBRRACE (national surveillance on maternal deaths), NHS RightCare, as well as the recommendations from other NHS regions.*
- *To secure further funding and resource for epilepsy services. It is also recommended that managers involved in consideration of the current business case before the Trust take account of the JHOSC findings and the recommendations of the Committee and its full support for the business case as a necessary first step in addressing patient safety and welfare, the sustainability of the Oxfordshire epilepsy service, and wider impacts on public services.*

2. For NHSE South East Region to*: Give support to the ICB and Oxford University Hospitals NHS Foundation Trust to help achieve the above prioritisations.*

The Committee urges for further funding to be allocated to epilepsy services. In addition, we urge you to escalate to ministers to support the suspension of the MHRA regulatory updates of 2024 pending an independent national review of the UK's Pregnancy Prevention Programme. The Committee has also written to Karin Smyth MP to urge this suspension, as well as to Layla Moran MP (Chair of Parliamentary Health and Care Select Committee) to request national scrutiny of this. The Committee also urges NHSE specialist commissioning to meet with local system partners to enable a solution to the unsafe and unequal provision of funding to the Oxfordshire epilepsy service.

Yours sincerely,



Cllr Jane Hanna OBE

Chair, Oxfordshire JHOSC, OCC
Jane.hanna@oxfordshire.gov.uk

APPENDICES

Attached by email: Letter SUDEP Action/Epilepsy Action; Letter Marian Knight attached to Local Impact Assessment attached

Considerations of the Committee about:

a) Epilepsy needs and Service.

b) The local impact of MHRA updates 2024 on the Pregnancy Prevention Programme on the epilepsy workforce and patient safety.

A. Considerations of the JHOSC on Epilepsy Needs and Service

On the basis of the written and verbal evidence given to the committee, there was strong evidence supporting:

1. Lack of awareness of epilepsy and stigma. The committee recognised that all people experience abnormal electrical brain discharges and that 1 in 10 people will experience a seizure in their lifetime, but that with someone diagnosed with epilepsy it is a network of electrical discharges. Whilst there are many different epilepsies, 70% of people can be seizure-free if properly diagnosed and treated.

2. Lack of awareness and communication of SUDEP and risks of epilepsy. The Committee's recognition of epilepsy as a treatable `cliff-edge condition` affecting 1 per cent of the population that often presents as an emergency (or sudden fatality for at least 21 people a week (EB | Epilepsy & Behavior | Prevent 21: SUDEP Summit | ScienceDirect.com by Elsevier). Deaths can result from Sudden Unexpected Death in Epilepsy (SUDEP) or from accident or status or suicide. Children and adults also face absence from school, loss of driving licence, loss of employment and emergencies due to physical and mental health crisis.

3. People with epilepsy and their families can also face injuries, lost school days, loss of driving licence, loss of employment, loss of mental well-being.

4. Clinical and lived experience evidence of stigmatisation still experienced in 2024 at all levels of institutions. The World Health Organisation report Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology is noted as is the Chief Medical Officer annual report 2001 and 2002 which evidenced this hostile culture contributing to avoidable deaths and harms in epilepsy https://image.guardian.co.uk/sys-files/Society/documents/2003/07/03/report2002.pdf

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4. The ICB local impact assessment report attached found an inequality of access to this medication by girls and women and the MBRRACE report analysing deaths of pregnant mothers and their unborn has found a near doubling of SUDEP against a backdrop of the introduction of the Pregnancy Prevention Programme with women uninformed about the risks of SUDEP (Letter Professor Knight attached). The clinical team alerted the Committee to the harrowing experience of a sister of a sister and a brother both living with epilepsy and the impact of this inequality on the safety and life of the sister https://www.channel4.com/news/fears-over-dangerous-change-in-prescription-rules-for-epilepsy-drug. The sister is part of a published thematic examination of the voices of 19 people with epilepsy and their lived experience of the direct damage of avoiding valproate or topiramate, including SUDEP https://medrxiv.org/cgi/content/short/2024.09.06.24313040v1

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9. The aggregated regulation and national materials were mandatory without regard for different populations e.g. for children, the LGBTQ community and people with learning disability and epilepsy the MHRA regulations were especially complex. Whilst there was a national framework and materials for protection which extended to hypothetical unborn children, the paediatric team gave evidence there was no national framework for the protection of children or adults living with epilepsy who ought to be offered Valproate or Topirimate to control their seizures and it was unclear who nationally had a responsibility for that.

10. Widespread and shared concerns across the South-East Region about undermining of basic NHS principles of informed consent, shared and balanced decision-making, evidence-based decision-making, transparency specifically in relation to a vulnerable population of patients needing anti-seizure medication for epilepsy or mental health. This included concern about the validity of the second signature in the context of the framework not requiring patient involvement and there being no appeal.

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13. All stakeholders including the region and the ICB were clear that the increase in clinical and administrative workload from the national mandatory requirements had not been funded. The provider Trust representative explained that the impact of the national demands fell purely on the Trust which was affected by cuts year on year and that there was an urgent need for NHS national specialist funding arrangements to tackle the problem and make resource available.

14. There was a widespread impact across management teams in the NHSE and ICB and Trusts of managing the demands of the Pregnancy Prevention Programme. The NHSE manager explained she had been specially seconded and was spending most of her time on it because of the impacts and complexities. The development of strong teamwork across the region and the ICB and stakeholders had been encouraging with development of some local mitigations where these were possible and whole system escalation to the NHS and MHRA.

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reduction of prescribing. There was an absence of any balancing metric including outcomes for patients.

16. Concerns for the welfare of patients, clinicians, bereaved families and their charity representatives including the threat from the Prevent regulatory regime to proposals for piloting a community-based specialist epilepsy clinic in Wantage to support prevention because of lack of capacity.

17. Widespread and shared concerns about the governance processes at the MHRA. The committee heard that the 2024 updates required the most dramatic change in clinical practice for decades and yet updates were usually briefed to stakeholders as a fait accompli. In 2022 there had been no public consultation or consultation with third sector patient and clinical organisations before there was an MHRA drug safety announcement and organisations had complained. There had been three updates in 2024 alone, with the September 2024 update on additional regulations for men and boys a surprise for all stakeholders. The Committee received evidence from one of the epilepsy clinical leads for NICE who compared the robust governance processes required at NICE with the MHRA processes. NICE required a public and transparent evidence-based process from the start which involved third sector patient and clinical stakeholders and public consultation over a prolonged period.

18. The Committee evidence was that third sector epilepsy patient and clinical organisations had raised likely harms from the policy and urged consultation and a rethink since December 2022. It was noted that outcome from engagement had not been included in a statements from ministers to Parliament Sodium Valproate - Hansard - UK Parliament, neither was a plea for a radical rewrite of national materials for clinicians and patients referred to in the statement of engagement with stakeholders in the public impact report https://www.gov.uk/government/publications/valproate-review-of-safety-data-and-expert-advice-on-management-of-risks

19. Concerns about accountabilities for deaths and harms under the UK Pregnancy Prevention Programme or the management of harms and support for patients, bereaved families and clinicians. The committee noted evidence from Kristi McDonald that in the MHRA recent private briefing session about the latest update, accountability was explained as ministerial and across the whole health eco-system but that accountability for individualised decisions made under the policy rested with clinicians. The NHSE gave evidence they had written to all professional regulators and had requested clarity on accountability. The GMC had responded that regarding fitness to practice they would take account of exercise of the duty of candour and raising of concerns at an institutional level.

OXFORDSHIRE COUNTY COUNCIL

Cllr J Hanna OBE

Chair, Oxfordshire Health Overview and Scrutiny Committee

12 November 2024

Dear Layla Moran MP,

Epilepsy and the Valproate Policy:

At its public meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (JHOSC) held an item on Epilepsy services. The current state of epilepsy services were discussed, with insights into national and local contexts being provided. Three MHRA national alerts during 2024 around the Pregnancy Prevention Programme with accelerated and new restrictions on anti-seizure medications were also a key aspect of the discussion.

The timeliness of the need for urgent action and consideration of business cases currently under consideration, warrant the Committee sharing some of our draft findings as well as the recommendations that were formally accepted at the Committee on 12 September. The Committee had received written evidence at previous Committees in January that have been shared as attachments to the email containing this letter from:

- SUDEP Action and Epilepsy Action
- Marian Knight, Professor of Professor of Maternal and Child Population Health, Oxford

The Committee wrote to Steve Brine MP, Chair of the Parliamentary Health Scrutiny Committee in January 2024, requesting national scrutiny of the MHRA alert, the proposed timescales for implementation, the lack of a national impact assessment, and the lack of resources to support the new requirements. We received a response that it was included on the list of potential scrutiny items for the Select Committee.

The Committee also liaised with the ICB with a view to an update about the ICB response to the alert and required local action plan and consideration of the suggestion by SUDEP Action and Epilepsy Action that delay is sought to implementation because of the severe pressures in the NHS, and until adequate resources can be made available to local systems. This was based on an understanding confirmed at our meeting on 12 September of the severe likely local impacts that had been brought to the attention of the MHRA, ministers, the NHS, the Patient Safety Commissioner and the Parliamentary Health and Care Select Committee since a surprise MHRA drug safety update in December 2022 https://assets.publishing.service.gov.uk/media/6399fcf4e90e072aefe10288/Dec-2022-DSU-PDF.pdfof December 2022

In April, the ICB updated the Committee that a task force comprising consultants, specialist nurses, medicines safety officers, representatives from charities and patients with lived experience had worked on a local impact assessment. In April the committee received:

- The ICB Local impact assessment on the MHRA Pregnancy Prevention Update November 2023 *(This is also attached to the email containing this letter)*

The impact report that was shared with Committee members and the public outlined that there were unavoidable consequences, and current services were ill-equipped to handle the implementation.

Specifically, it was anticipated that approximately 2855 outpatient appointments would be lost due to the new requirements and that "*naturally, this resource impact will result in less patients being prescribed valproate; this impact will be seen in greater mortality, greater morbidity including ED pressure resulting from uncontrolled epilepsy*" and warned that the impact of further expected updates for men and boys would be additional and severe.

The Committee wrote to Victoria Atkins MP, the then Secretary of State for Health (copied to the Chair of the Parliamentary Health Select Committee), to bring the local ICB impact assessment to her attention and to request that until the likely impacts and risks of phase 1 of the policy are assessed and safety addressed, that they allow the local NHS to delay implementation. The Committee received a response from the Department of Health that because of the General Election this would have to be brought to attention after this.

An epilepsy item was added for the June JHOSC agenda and received petitions from the public from Dr Judy Shakespeare and Kristi McDonald (who spoke about the harms that she and other women were experiencing). On the request of Oxford University Hospitals NHS Foundation Trust that they be given the opportunity to liaise with the ICB, the substantive epilepsy item was deferred until 12 September.

Evidence and outcomes of the 12th September JHOSC meeting epilepsy item:

The Committee received written evidence, and it also heard evidence during the epilepsy session on 12th September from:

- Kristi McDonald, expert by lived experience
- Professor Arjune Sen- Consultant Neurologist, OUH.
- Dr Jane Adcock- Consultant Neurologist, OUH.
- Jackie Roberts- Lead Learning Disability Epilepsy Specialist Nurse, OUH.
- Dr Rohini Rattihalli- Consultant Paediatric Medicine, OUH.
- Marcus Neale- Epilepsy Specialist Nurse, OUH.
- Dr Rustam Rea- Consultant, OUH Trust representative.
- Janice Craig- Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB
- Sarah Fishburn, NHSE South East Region.

The Committee found the evidence relating to serious concerns and harms because of local impacts from national policy updates on the Pregnancy Prevention Programme were shared across all NHS stakeholders, and that stakeholders had been escalating these internally for some time. There was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June) and patient safety harms across the South-East Region. Shared concerns about

evidence-base, lack of public consultation, lack of a national framework for the protection of children and adults who ought to be offered Valproate and Topirimate and the range of direct and indirect impacts. There was unanimous recognition of the need for urgent action in support of the local epilepsy service. Evidence was received that the epilepsy clinical team were working unsustainable clinical hours so that they avoided worsening of waiting lists for clinics, and their welfare was seriously impacted.

The Committee was shocked by the dire situation and issued the following recommendations to Oxford University Hospitals NHS Foundation Trust and NHS England South-East region on 12 September:

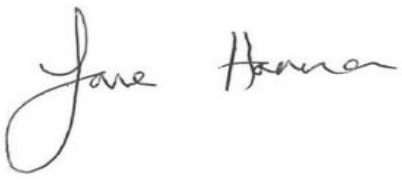
1.For the ICB and Oxford University Hospitals NHSFT to:

- *Give priority to patient safety for people with epilepsy and their families in Oxfordshire, and to the welfare of the Oxfordshire epilepsy team; and to set out how that priority will be addressed through their governance and management at a board level. The governance and management of these priorities should also include co-production with patients with lived experience and their charity representative; and address their concerns regarding tailored and balanced communications and the importance of signposting to existing empowerment tools recommended by MBRRACE (national surveillance on maternal deaths), NHS RightCare, as well as the recommendations from other NHS regions.*
- *To secure further funding and resource for epilepsy services. It is also recommended that managers involved in consideration of the current business case before the Trust take account of the JHOSC findings and the recommendations of the Committee and its full support for the business case as a necessary first step in addressing patient safety and welfare, the sustainability of the Oxfordshire epilepsy service, and wider impacts on public services.*

2. For NHSE South East Region to*: Give support to the ICB and Oxford University Hospitals NHS Foundation Trust to help achieve the above prioritisations.*

The Committee also agreed unanimously to recommend to the Parliamentary Select Committee that the Committee embark on thorough and ongoing scrutiny of the Pregnancy Prevention Programme. We have written to Karen Smith MP and to NHS specialist commissioning.

Yours sincerely,



Cllr Jane Hanna OBE

Chair, Oxfordshire JHOSC, OCC
Jane.hanna@oxfordshire.gov.uk

APPENDICES

Attached by email: Letter SUDEP Action/Epilepsy Action; Letter Marian Knight attached to Local Impact Assessment attached

Considerations of the Committee about:

a) Epilepsy needs and Service.

b) The local impact of MHRA updates 2024 on the Pregnancy Prevention Programme on the epilepsy workforce and patient safety.

A. Considerations of the JHOSC on Epilepsy Needs and Service

On the basis of the written and verbal evidence given to the committee, there was strong evidence supporting:

1. Lack of awareness of epilepsy and stigma. The committee recognised that all people experience abnormal electrical brain discharges and that 1 in 10 people will experience a seizure in their lifetime, but that with someone diagnosed with epilepsy it is a network of electrical discharges. Whilst there are many different epilepsies, 70% of people can be seizure-free if properly diagnosed and treated.

2. Lack of awareness and communication of SUDEP and risks of epilepsy. The Committee's recognition of epilepsy as a treatable `cliff-edge condition` affecting 1 per cent of the population that often presents as an emergency (or sudden fatality for at least 21 people a week (EB | Epilepsy & Behavior | Prevent 21: SUDEP Summit | ScienceDirect.com by Elsevier). Deaths can result from Sudden Unexpected Death in Epilepsy (SUDEP) or from accident or status or suicide. Children and adults also face absence from school, loss of driving licence, loss of employment and emergencies due to physical and mental health crisis.

3. People with epilepsy and their families can also face injuries, lost school days, loss of driving licence, loss of employment, loss of mental well-being.

4. Clinical and lived experience evidence of stigmatisation still experienced in 2024 at all levels of institutions. The World Health Organisation report Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology is noted as is the Chief Medical Officer annual report 2001 and 2002 which evidenced this hostile culture contributing to avoidable deaths and harms in epilepsy https://image.guardian.co.uk/sys-files/Society/documents/2003/07/03/report2002.pdf

5. The epilepsy service not in a position to take on new national mandatory actions safely. OUH serves a local population of 762,500 (and additional tertiary 2 million catchment) with waiting lists that are not safe for patients. NICE recommends a two-week waiting time for a first seizure, but at OUH this is a 9 month wait (tertiary referral one year). Children with epilepsy not controlled by medication who could benefit from the Ketogenic

diet are waiting 3 years. New referrals to the epilepsy nurse service had tripled and requests from GPs for written guidance and letters had increased ten-fold in 3 years.

6. The adult service only has 2 Full-time equivalent neurologists for this population in contrast with 1 per 12,000 in Western Europe. Whilst NICE recommends 9 epilepsy specialist nurses per 500,000 the Oxford service only has 3.6. The report by Economist impact in 2024 found neurology clinics struggling more than other NHS services with waiting lists raising by 76% between 2021 and 2023 Neurology crisis costing UK £96bn – Economist report (epilepsy.org.uk). The Committee received evidence that there was extremely poor provision for the Oxfordshire epilepsy service compared with other OUH services for similar `cliff-edge' long-term conditions and that it also fared very badly in comparison with similar services elsewhere like Sheffield. The Committee was concerned to understand why there were these inequalities between different services and between postcodes. It was explained that the present funding of posts was based on national specialist commissioning arrangements, and these were based on historical allocations of NHS posts to individual hospital trusts going back decades.

7. The gap in any primary care service or any specialist primary care clinician across Oxfordshire or the ICB with an interest or role in epilepsy against a backdrop of the cut of epilepsy from the GP Quality Outcomes Framework in 2013. The epilepsy team had worked in co-production with a population in South Oxfordshire to produce an outline plan of how a community-based clinic in South Oxfordshire could benefit patients and staff during 2023 but would need workforce capacity to progress this.
   Reports reveal a national issue with a gap in risk check, communication and follow up action for the many thousands of adults with epilepsy who present to and are discharged back into the community NCEPOD - Epilepsy: (2022).

B. The local impact of MHRA updates 2024 on workforce capacity and patient safety

Based on the written and verbal evidence given to the committee, there was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June). Evidence included:

1.Access to treatment and anti-seizure medications is now extremely challenging. There were shortages of anti-seizure medications with some patients in Oxfordshire having to travel a long distance two weeks before their medicine was due so as not to run out of a source of supply. It was noted that neither Valproate nor Topirimate were in short supply.

2. Valproate taken whilst pregnant is one of medications that carries a high teratogenic potential with a 11% risk of congenital malformations and a 30-40% risk of neurodevelopmental disorders.

3. Valproate also happens to be the most potent medication to treat generalised epilepsies should girls and women have preferences to be safe from SUDEP and other harms and able to lead their best lives The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for generalised and unclassifiable epilepsy: an unblinded randomised controlled trial - The Lancet; https://pubmed.ncbi.nlm.nih.gov/31831600/

4. The ICB local impact assessment report attached found an inequality of access to this medication by girls and women and the MBRRACE report analysing deaths of pregnant mothers and their unborn has found a near doubling of SUDEP against a backdrop of the introduction of the Pregnancy Prevention Programme with women uninformed about the risks of SUDEP (Letter Professor Knight attached). The clinical team alerted the Committee to the harrowing experience of a sister of a sister and a brother both living with epilepsy and the impact of this inequality on the safety and life of the sister https://www.channel4.com/news/fears-over-dangerous-change-in-prescription-rules-for-epilepsy-drug. The sister is part of a published thematic examination of the voices of 19 people with epilepsy and their lived experience of the direct damage of avoiding valproate or topiramate, including SUDEP https://medrxiv.org/cgi/content/short/2024.09.06.24313040v1

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HEALTH OVERVIEW AND SCRUTINY COMMITTEE

21st November 2024

Report by Corporate Director for Public Health and Communities on Healthy Weight

1. RECOMMENDATION

The Committee is RECOMMENDED to

a) Consider the contents of the report and put relevant questions to the Director of Public Health, Cabinet Lead Member and supporting officers (noting the contribution to the report from the ICB who will be in attendance)
b) Note the key actions required and support their progression

2. Executive Summary

Living with excess weight poses a significant challenge to living a healthy life. It is one of the leading causes of preventable early deaths, increasing the risks for a wide range of health conditions, including Type 2 diabetes and some cancers. It is also associated with worse mental health and lower educational attainment in children and needing to take more sick leave in adults. On average living with obesity reduces someone's life expectancy by around three years with severe obesity shortening life by as much as lifelong smoking – by up to 10 years.

Reducing excess weight is a priority for Oxfordshire's Health Improvement Board and the Health and Wellbeing Board and was the focus of the Director Public Health Annual Report 22/23. A related Health Needs Assessment (HNA) in 2023 made more than 20 recommendations[1]. This body of work led to a key change of focus to give a greater emphasis on eating more healthily and enabling this through the wider environment within which food purchasing and consumption occurs. The work happening in this space has previously benefited from the input of HOSC members as part of the HOSC meeting in Sept 2023

An Oxfordshire Whole Systems Approach (WSA) to healthy weight action plan is in place focussing on four key areas: prevention, healthy weight environment, support and system. Updated recommendations following the HNA gave a greater focus on prevention and wider changes to the environment to encourage and facilitate access to healthier food. It remains important to maintain an offer of effective support to people who are already experiencing excess weight.

It should be noted that the actions associated with a WSA to healthy weight are unlikely to have an immediate effect, requiring time and resource to implement and for sustainable change to be seen. To make significant progress input is required from a broad range of partners.

3. Background

3.1 Mortality and morbidity

In Oxfordshire, latest data shows that of four years olds entering Reception year, just less than one in five are overweight or obese, rising to around one third in year 6, and more than half of adults.

[1] Oxfordshire County Council (2023) Health Needs Assessment for Promoting Healthy Weight. Available here

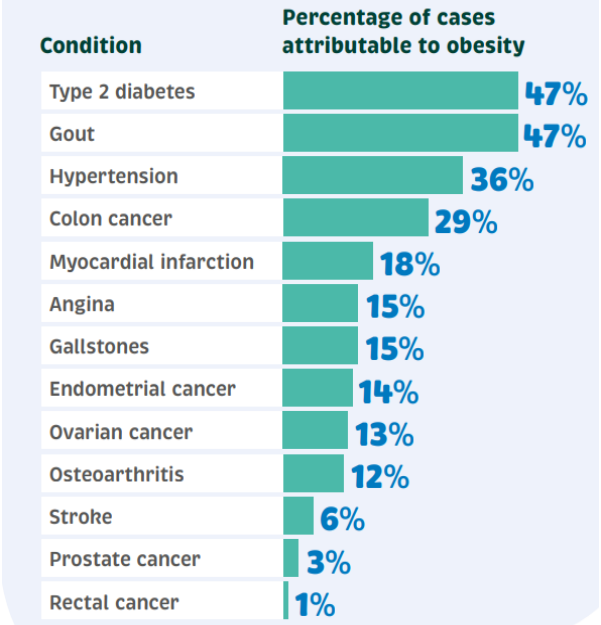
On average, obesity reduces someone's life expectancy by around three years with severe obesity shortening life by as much as lifelong smoking – up to 10 years. Tackling the risk factors for obesity reduces the risk of more than 20 long term conditions, increases economic productivity and reduces demand on health and social care services.

As shown in Table 1 below, the risk of developing some diseases are much higher in people living with obesity. For example, there is a 12.7 times greater risk of developing Type 2 diabetes amongst women who are obese than women who are not. Table 2 shows the percentage of cases in England attributable to obesity.

Table 1: **Relative risk factors for men and women living with obesity, compared to those not living with obesity, of developing selected diseases[7].**

Condition	Men	Women
Type 2 diabetes	5.2	12.7
Hypertension (high blood pressure)	2.6	4.2
Myocardial Infarction (heart attack)	1.5	3.2
Cancer of the colon	3	2.7
Ovarian cancer	N/A	1.7
Osteoarthritis	1.9	1.4
Stroke	1.3	1.3

Table 2: **Percentage of cases in England attributable to obesity**



Excess weight impacts negatively on both physical and mental wellbeing of children and adutls as demonstrated in Figure 1:-

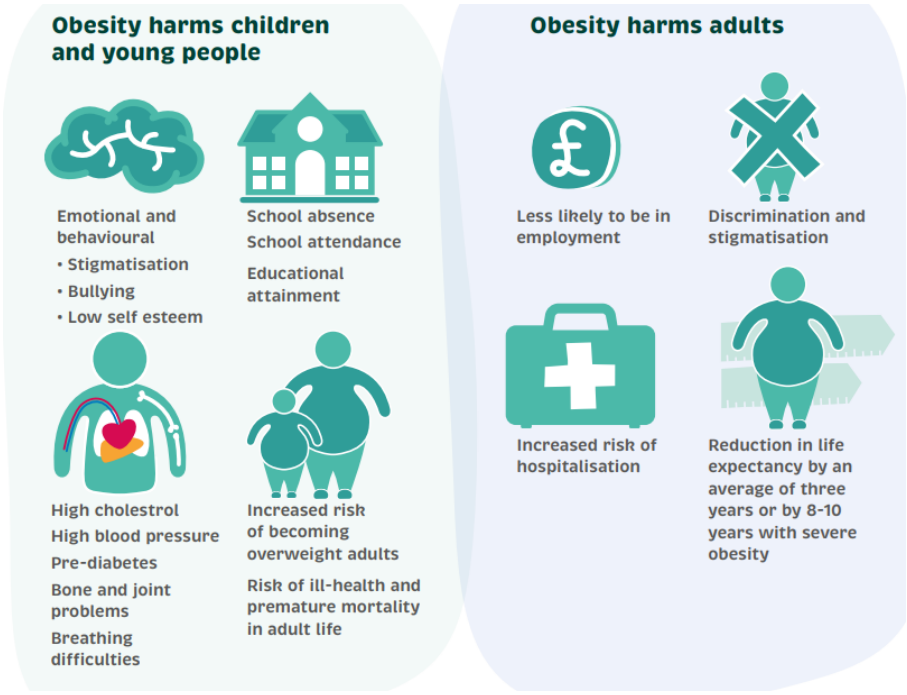


Figure 1: Obesity harms children and young people and obesity harms adults

3.2 Pregnancy

The risks of unhealthy diets and obesity start before conception. Children living with obesity are five times more likely to become adults with obesity, and more likely to become parents with obesity in their turn. Experiencing excess weight in pregnancy is a risk factor for a number of health issues for women, their baby, and their childbirth experience. These include gestational diabetes and hypertension, pre-eclampsia, a large (or conversely a small) for gestational age baby, miscarriage, still birth and even death[2]. There is an increased risk of needing medical intervention during childbirth, resulting in increased recovery time, challenges with breastfeeding and risk to bonding experience with their baby as well as poorer mental health outcomes.

Having parents that have increased BMI results in an increased risk of BMI for the child. Having an obese mother increases the child risk of experiencing excess weight by over 40%, see Figure 2.

[2] NICE (201) Weight management before, during and after pregnancy. Available here

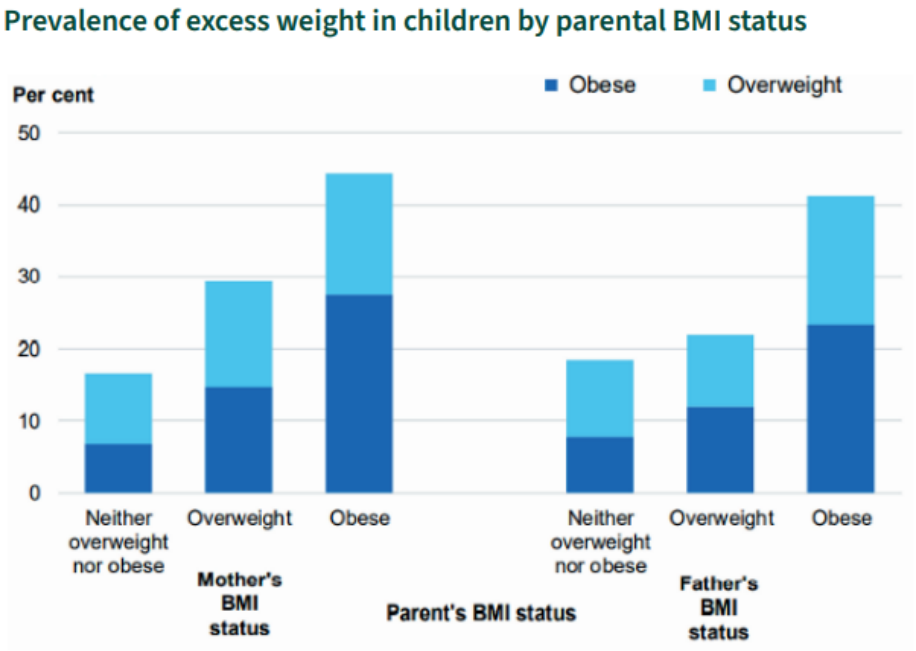


Figure 2: Figure showing increased risk of overweight for child according to weight status of mother and father

Local data found between March 2022 and Feb 2023, over 1900 pregnant women had a BMI of 30 or over at the time of booking in Oxfordshire (within the first 12 weeks of pregnancy).

3.3 The National Picture

3.3.1 Costs

The estimated annual costs of obesity in the UK are £58billion, rising to £62 billion with unemployment benefits related to obesity are added[3]. This equates to around 3% of the UK GDP[4]. National costs of obesity on health services are estimated to be £6.5billion and related to increased visits to GP, hospital admission rates and medications and community services[5].

There are increased hospital and social care costs associated with obesity related conditions such as musculoskeletal, digestive disorders and circulatory diseases. In the UK, excess weight is strongly associated with higher annual rates of hospital admissions with over one million of these annually having obesity as a main or contributing factor.

3.4 A Summary of trend in Oxfordshire

In the previous report to HOSC detail was given about trend for the following groups in Oxfordshire; children, adults, adults in areas of deprivation, and pregnant women, noting there was a rise in rates of overweight and obesity during the COVID-19 pandemic.

[3] Frontier Economics (2022) Estimating the full costs of obesity. Available here
[4] ONS. 2022. Gross Domestic Product: chained volume measures: Seasonally adjusted £m - Office for National Statistics (ons.gov.uk) https://www.ons.gov. uk/economy/grossdomesticproductgdp/timeseries/abmi/pn2
[5] PHE. 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/907966/PHE_insight_Excess_weight_and_COVID-19__FINAL.pdf

3.41 Children

In Oxfordshire, latest data (23/24) shows that of 4 years olds entering Reception Year in Oxfordshire just less than one in five (19.3%) are overweight or obese, rising to around one third in year 6, (32%). Figures for year R fell in 22/23 remaining very similar in 23/24. For year 6 they fell a little from 34% to 31% then back to 32% in year 6. Figures for year 6 remain just above pre-pandemic levels (Table 3) .

Oxfordshire	21/22	22/23	23/24
Year R	20%	19%	19%
Year 6	34%	31%	32%
Adult	60%	58%	-

Table 3- Oxfordshire children's obesity data from the National Childhood Measurement Programme 21/22 to 23/24

Overall, rates in Oxfordshire remain below the England average (figure 3).

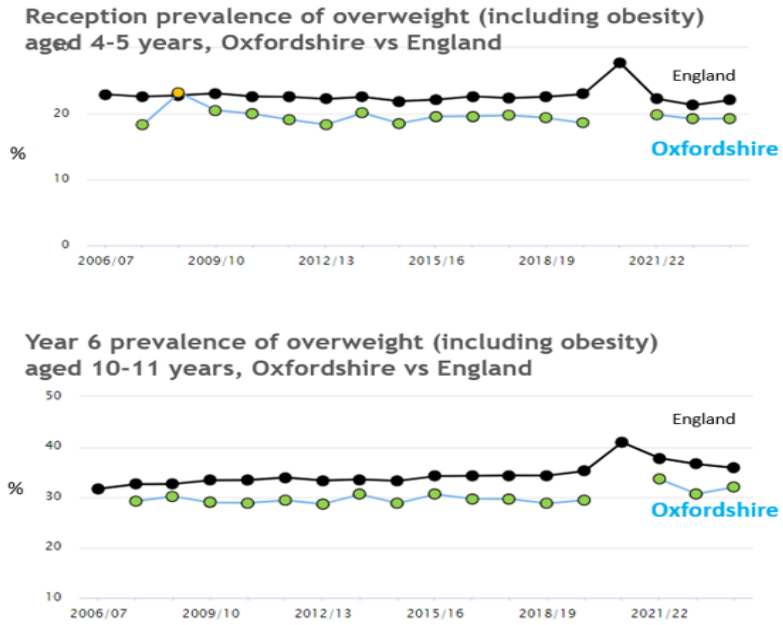


Figure 3: year on year prevalence of overweight and obesity in children and summary of recent data

As figures 4 and 5 show, there is some variation by District but changes this year are not statistically significant. Later in the inequalities section further detail will be given about smaller areas within Districts

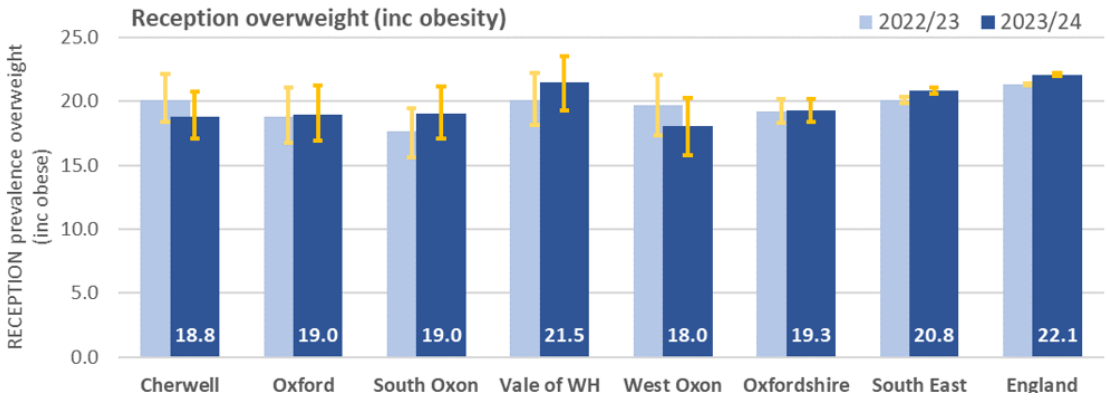


Figure 1: City and Districts reception prevalence overweight (inc obesity)

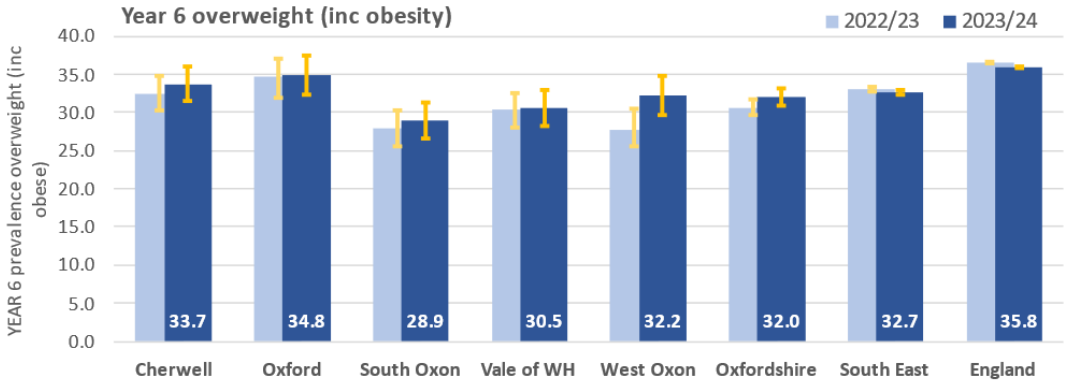


Figure 2: City and Districts year 6 prevalence overweight (inc obesity

3.42 Adults

Overall, in Oxfordshire, latest data from the annual population survey (22/23) found 57.8% of adults to be overweight or obese, a reduction of around 2% from the previous year.

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Figure 6 shows there is variation by District but all areas have more than half of their adult population living with excess weight with ranges from 53.9% (Oxford City) to 60.3% (South and Vale). .

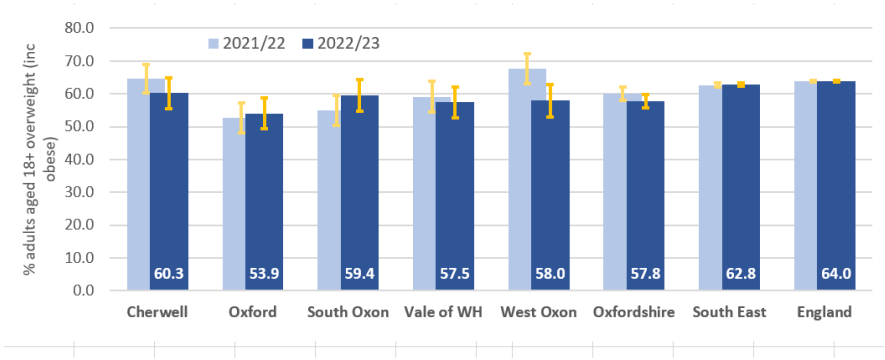

Figure 3: adults classified as overweight (inc obesity) across City and Districts

3.5 Inequalities

The differences in excess weight across Oxfordshire are likely to be due to a combination of both differences in socio-economic deprivation, ethnicity, as well as the age profile of people living in different parts of the county.

Some ethnic groups are more likely to experience excess weight. For example, national rates show 48.1% of black Caribbean and 49.6% of black African Year 6 children experiencing overweight or obesity, and 68% of black adults are overweight or obese.

While Oxfordshire's overall rates of overweight and obesity in childhood remain lower than the England average, some areas have similar (amber) rates than the England average overall and some have much higher (red) rates, see Figure 7. This year for year 6, four areas ranked worse than the England average. These areas with worse rates have featured over a long period of time. It is notable that Blackbird Leys and Greater Leys previously featured but we have seen a move for them from worse than to similar to England average this year.

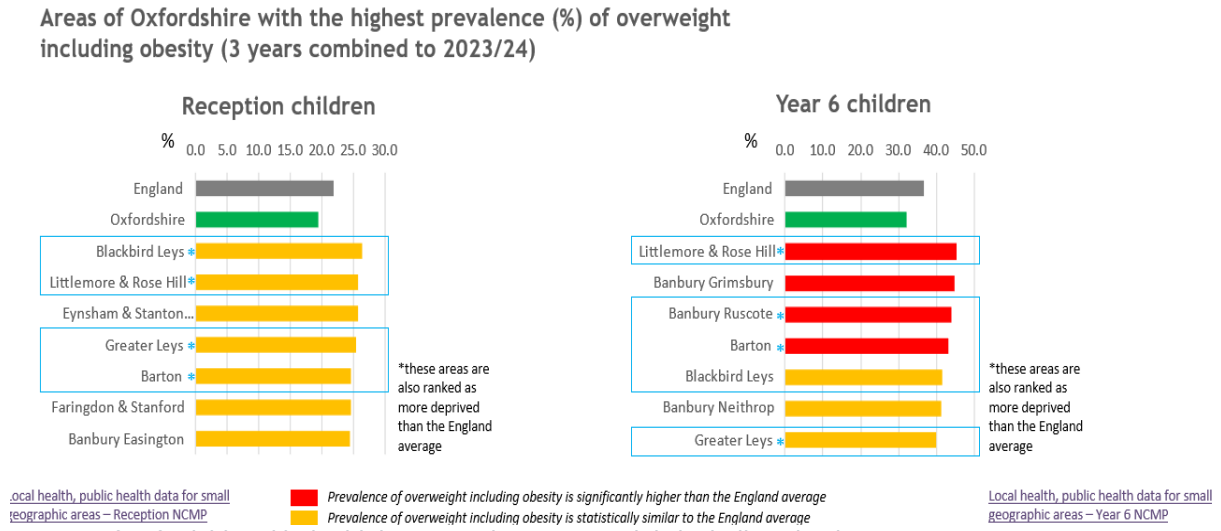

Figure 4- areas of Oxfordshire with the highest prevalence overweight including obesity

We know that areas of greatest socio-economic deprivation have residents with the lowest rates of fruit and vegetable consumption finding it harder to access healthier food locally but easier to access hot food takeaways.

While undertaking some work across the whole of Oxfordshire, over the past year we have honed down our approach to focus on specific geographical areas where there have been consistently worse levels of excess weight in children. This year the focus has predominantly been on Blackbird Leys/Greater Leys area.

Below is more detail about some of the programmes of work that will initially be focussed in these areas before being rolled out if they are positively evaluated: -

Good Food Retail Project: Delivered by a retail expert organisation to engage local convenience shops to offer healthier options to their customers. Shops are assessed against the 100 healthier lines framework, agree an action plan and receive free stock drops to trial. Phase 1 took place in Blackbird Leys where there is a price premium in local shops compared to Tesco of +30%. The number of healthier lines available increased by 19% and on average the stores stocked 12 more healthier lines. Evaluation as to the difference this has made to shopping habits is underway.

Strategic school food and physical activity advisor: Develop policy and programmes to encourage healthier eating and more physical activity for a whole school approach (and linked early years settings). To date the focus has been on engaging schools in priority areas, setting up a schools' forum and holding an Oxfordshire Schools Conference on healthy and active young

people bringing local cross sector (VCS, NHS and Education) and national partners together (Youth Sports Trust, Veg Power) .

School Cooking project: To develop and deliver an interactive school-based cooking programme in priority areas in Oxfordshire linking to wider community (in line with best practice). Working primarily with Primary (Year 5 and 6) and linked Secondary Schools. To commence Nov. 2024.

A 'Healthier out of Home' post: In Trading Standards, working on identifying what support can be provided to existing businesses supplying food in the takeaway industry to support a healthier offer that meets both business and health needs.

Healthy Weight in Early Years: Our new healthy weight provider will be piloting a programme called HENRY (Health Exercise and Nutrition for the Really Young) in Early Years settings.

4.0 Oxfordshire's Whole Systems Approach to Healthy Weight

The causes of excess weight are complex, resulting less from individual behaviours and more from the many factors which collectively make up an obesogenic environment. No single organisation has the knowledge tools or power to solve it and so a 'whole system' approach is needed to make change happen. Actions will not show immediate affect and may time some time to implement and for change to be seen. Following the HNA (2023) the Oxfordshire WSA action plan (appendix) was refreshed.

An overview of the process towards the development of WSA was noted in the previous update to HOSC and is summarised in the table below.

July 2019	Guidance towards a Whole System Approach to Obesity Issued[6]. Oxfordshire Health Improvement Board endorse WSA for Oxfordshire
2020/21	More than 125 stakeholders in Oxfordshire work together towards a collective approach to developing Oxfordshire WSA
2022/23	Health Needs Assessment completed by public health Healthy Weight Needs Assessment 2023 Full report | Oxfordshire Insight
2023	Whole Systems Approach action plan refreshed (appendix) . Outcomes influence Health and Wellbeing Strategy for Oxfordshire.

Actions in the WSA action plan centre around the below four areas of focus. While acknowledging the importance of continuing to provide evidence-based comprehensive support services to help residents living with overweight and obesity to be a healthy weight, increased focus is needed on the wider healthy weight environment.

[6] PHE (2019) Whole systems approach to obesity: a guide to support local approaches to promoting a healthy weight. Available here

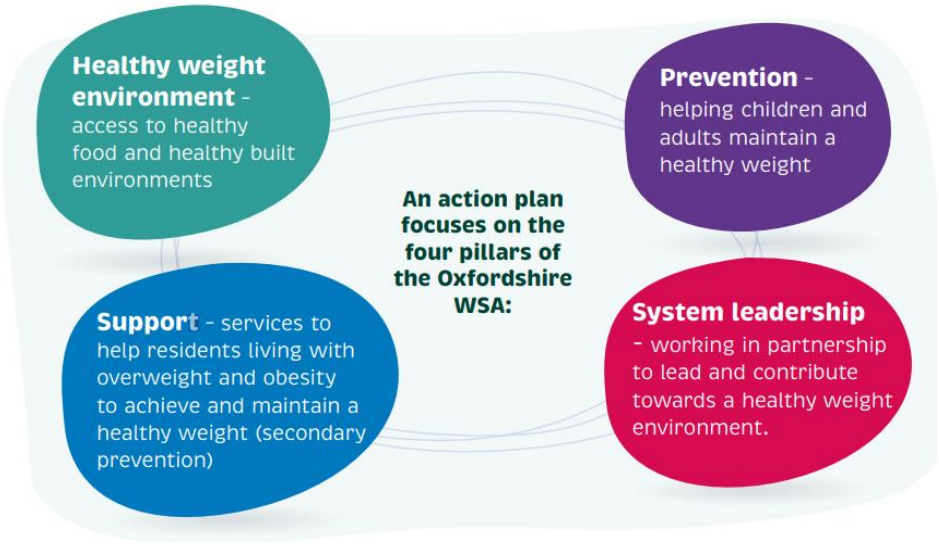

Figure 5: Figure showing the four pillars of the whole system approach to healthy weight for Oxfordshire

Progression of the WSA is reported to the Oxfordshire Health Improvement Board and actions are reflected in the new Health and wellbeing Strategy for Oxfordshire 2024-2030. Particularly notable in the Health and Wellbeing Strategy are the priorities, ambitions and actions below:-

Priority 3: Healthy people and healthy places

The length and quality of people's lives in Oxfordshire should not be negatively impacted by exposure to tobacco, alcohol, or unhealthy weight. People in Oxfordshire should live in healthy environments where they can thrive free from these harms.

Our ambitions

Between now and 2030, we want to see:

- Improved access to healthy food, especially in priority neighbourhoods.
- Whole school approaches to food and healthy weight.
- Effective implementation of Oxfordshire's Food Strategy.

Immediate actions

- Where possible shift the environment toward being more healthy – advertising healthy options, and explore the feasibility of restricting new hot food takeaways.
- Improve uptake of Healthy Start initiative and ensure support is in place for key groups like pregnant women.

In the appendix we present a more detail on the work in plan and progress at 2024.

The remaining focus of this report is on two areas of the whole systems approach: 'Support' and 'Healthy Weight Environment'.

4.1: A summary of policy initiatives to support a healthy weight environment.

"When we live surrounded by fast food outlets, and nearby shops sell limited healthy food - and it's more expensive - it makes it harder to eat well. This can lead to poorer health."

The healthy weight action plan highlights the need to change the healthy weight environment, A key element to note in this area of work is that in areas of greatest deprivation children are flooded by views of and access to unhealthy food. In these areas access to hot food takeaways and views

of adverts advertising high fat salt and sugar products are disproportionately prominent. As described in section 3.5, the Good Food Retail Project and the 'Healthier out of Home' work have been designed to intervene in this issue and we expect to role out beyond Blackbird Leys in future.

In addition there are a variety of opportunities to tackle this is at District/City Council level through distinct policy areas

- **Local Plans**: restricting the number of new hot food takeaways in high prevalence geographical areas or close to schools
- **Healthier Advertising Policies** to promote heathier food options over foods that are high in fat salt and sugar.
- **Street Trading Policies** considering proximity to schools during opening times

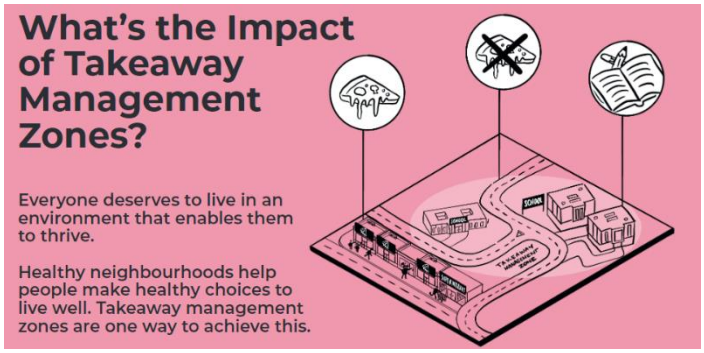

Figure 6:impact of takeaway management zones

Local Plans

Nationally, one in four places to buy food are fast food outlets, and almost one in five meals are eaten outside the home[7]. Out-of-home meals contain significantly higher intakes of sugar, fat and salt and portion sizes tend to be bigger, as well as usually being cheap and easily available[8].. There is robust evidence linking availability of fast-food outlets to excess childhood weight.

In January 2024, Oxfordshire had 513 takeaway food outlets[4]. In some areas of Oxfordshire there are more than double the number of takeaway outlets per 1000 population than the England average. Takeaway outlets tend to be located closer to people's homes in the most deprived wards of the county where we see the highest levels of obesity[5] and in some of our areas with the highest levels of childhood obesity, fast food outlets are shown to be frequently located within 400m of primary and secondary schools.

More than half of local authorities in England now have planning policies in place to address the proliferation of hot food takeaways. Recent work being undertaken by the City and District Councils to renew their Local Plans has provided an opportunity to engage with local planning teams to include such policies for Oxfordshire. A number of conversations have taken place with planners and other influential council staff about scope for including a policy that restricts clustering of new hot food takeaways and information bespoke to each District has been provided.

The current situation is that despite the provision of detailed information including evidence to support these policies, planners in most Districts have been reluctant to include such a policy and may have been influenced by the nature of the National Planning Policy Framework against which local plans need to be aligned. In the regulation 19 versions of their Local Plans both the City Council and South & Vale District Councils have decided not to include such a policy. Cherwell have a draft policy as one of its preferred policy options and we are awaiting confirmation that it

[7] 2022-23 Director of Public Health annual report | Oxfordshire County Council
[8] Health matters: obesity and the food environment - GOV.UK (www.gov.uk)
[4][4] Feat (feat-tool.org.uk)
[5] 2022-23 Director of Public Health annual report | Oxfordshire County Council

has been included in the in the final Plan due for publication in December 2024. We are continuing to work with West Oxfordshire District Council to try and influence their Plan.

Healthier Advertising Policies

The advertising of unhealthy food has been shown to drive over-consumption. "Food marketing and advertising promotes consumption of what is available … That intake is not compensated for, so when children snack in response to food marketing, they do not then consume less at the next eating opportunity to balance out their energy intake; additional energy is added. Research has found have shown that to be somewhere in the region of 50 additional calories. We know from epidemiological evidence that it takes somewhere between only 40 and 70 additional calories per day to contribute to weight gain in children[9]

For children growing up in this frenzy of advertising, exposure to HFSS products normalises these highly processed, unhealthy foods and drinks and research shows this influences their food choices[10]. HFSS marketing is linked to a strong preference for HFSS products,[11] more snacking[12], eating more calories[13] and HFSS products replacing healthier foods[14], leading to lower consumption of fruit and vegetables and higher sugar content.

Over the last few years, local authorities across the UK have shown an interest in introducing Healthier Food Advertising policies in their own advertising spaces with twenty known to have policies in place. Evidence shows this does not negatively affect income from advertising.

The aspiration is for Oxfordshire County, City and Districts Councils is to have healthier advertising policies in place that promote healthier food options over foods that are high in fat, salt and sugar**.** It does this by switching the spotlight away from unhealthy food across council owned advertising spaces (phone boxes, billboards, roundabouts, lampposts) and through council advertising contracts.

In Oxfordshire, Oxford City Council are retendering their bus stop advertising contract with appropriate criteria to discourage HFSS advertising and are currently exploring how they might implement an overarching policy. Work is ongoing across other Districts with a key challenge being identifying who would lead on such a policy.
In order to further progress both of the above, this area of work will be reviewed at the Health and Wellbeing Board as it progress the implementation of the new Health and Wellbeing Strategy.

[9] Recipe for health: a plan to fix our broken food system, quote from Professor Emma Boyland committees.parliament.uk/oralevidence/14569/html/ evidence food, diet and obesity, March 2024. Available here.
[10] Ferguson CJ, Muñoz ME, Medrano, MR. Advertising Influences on Young Children's Food Choices and Parental Influence The Journal of Paediatrics. 2012; 160(3):452–455.
[11] Boyland EJ, Harrold JA, Kirkham TC, Corker C, Cuddy J, Evans D, Dovey TM, Lawton CL, Blundell JE, Halford JCG. Food commercials increase preference for energy-dense foods, particularly in children who watch more television. Pediatrics. 2011; 128(1):93-100
[12] Boyland EJ, Nolan S, Kelly B, Tudur-Smith C, Jones A, Halford JCG, Robinson E. Advertising as a cue to consume: a systematic review and meta-analysis of the effects of acute exposure to unhealthy food or non-alcoholic beverage advertising on intake in children and adults. American Journal of Clinical Nutrition. 2016. 103:519-533
[13] Boyland EJ, Whalen R, Christiansen P, McGale L, Duckworth J, Halford J, Clark M, Rosenburg G, Vohra J. See it, want it, buy it, eat it: how food advertising is associated with unhealthy eating behaviours in 7 -11 year old children [online]. Cancer Research UK. 2018
[14] Thomas, C, Hooper L, Petty R, Thomas F, Rosenburg G, Vohra J. 10 years on: New evidence on TV marketing and junk food consumption amongst 11–19-year-olds 10 years after broadcast regulations [online]. Cancer Research UK. 2018

4.2 Support for individuals in Oxfordshire to achieve a healthy weight

It remains important to provide support for people with excess weight to reach a healthier weight. Detail of the current situation in Oxfordshire is below.

Services for individuals who need support to reach a healthy weight are split into four tiers as depicted in figure 10.

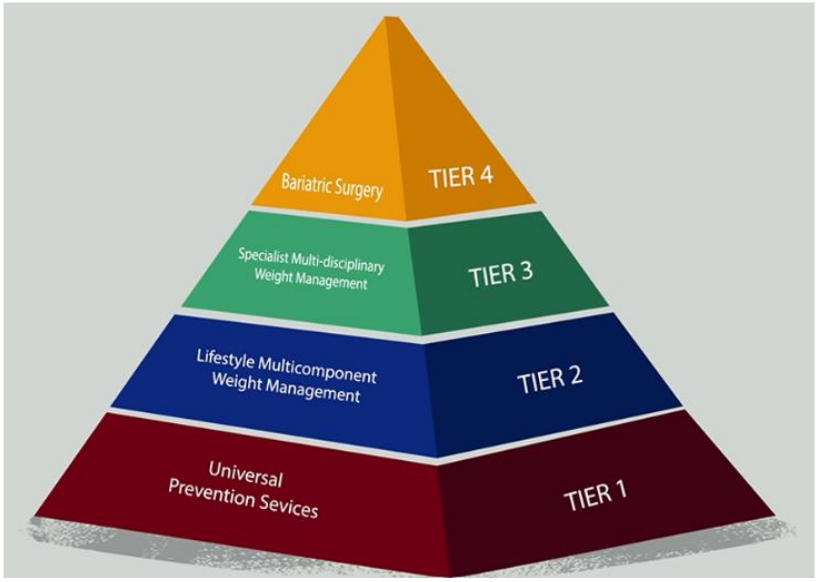

Figure 7: healthy weight tiers for individuals who need support

Local authorities are responsible for commissioning tiers 1 and 2. ICB'S are responsible for commissioning tiers 3 and 4.

Tier 1 includes "Behavioural – Universal interventions (prevention and reinforcement of healthy eating and physical activity messages) . Tier 2: time limited lifestyle weight management services which include community-based diet, nutrition, lifestyle and behaviour change support, normally in a group setting environment. All services are developed and delivered in line with National Institute for Healthcare Excellence (NICE) Guidance.

From September 2024 a new all age healthy weight service, BeeZee Oxfordshire is in place Home Page - Free Healthy Lifestyle Services | Oxfordshire. The previous service was an adult only service though a service for children aged 4–12-year-olds was piloted with good outcomes. The new service has capacity to work with 5000 adults and 200 children and families. People can refer themselves or be referred if they have a BMI over 28 (or lower for some ethnic groups and some co-morbidities).

- BeeZee Families: a 12-week family focused programme (online or in person) with fun activities and expert support on nutritious snacks, easy meals and getting active,
- BeeZee adults: designed to help adults lose weight in a healthy way and keep it off for good.
- Gutless: a bespoke programme developed for men recognising the challenges they face when managing their health and fitness.
- Slimming World: offers members support, commitment and accountability to help boost happiness, self-esteem and slimming success.

From 2025 a staged approach to piloting the following will be delivered all of which will be co-produced.

- Early years and maternity
- Young people aged 13-18
- Ethnic Minority groups
- Mild-moderate mental health conditions.

Tier 3 and Tier 4 weight management services are commissioned by BOB ICB. The following update has been provided by ICB colleagues.

Tier 3 specialist weight management services are recommended by NICE to manage obesity, prevent further complications of excess weight and need for bariatric surgery. They are not a statutory requirement. A Tier 3 specialist weight management service is a multi-disciplinary team approach to weight management including dietitian, medical, psychological, and physical activity professionals. Programmes are typically 12-month programme and until recently they were a prerequisite for a patient to be eligible for bariatric surgery, however this guidance has recently changed and this is no longer the case for providers contracted by BOB ICB.

Oxfordshire residents can access the tier 3 service at Luton and Dunstable hospital. Patients can be referred to the service if they meet the following criteria:

- Has a BMI of over 35* with obesity related co-morbidities, have failed to lose weight and maintain weight reduction within Tier 1 and Tier 2, despite engagement and compliance **OR**
- Has a BMI of over 40* without specified co-morbidities, and only after failure of Tier 1 and Tier 2 services, despite engagement and compliance.

In the last financial year approximately 200 patients from Oxfordshire entered the Luton and Dunstable service. There is currently a waiting time of 8 months for a patient to commence the programme.

Within this service, eligible patients can be offered medications for weight loss (Wegovy and Saxenda) although these medications are currently prioritised as a phased approach to NICE guidance. Only very high priority patients for whom weight loss medications can offer greatest benefit will be eligible for medications such as Wegovy and Saxenda at Luton and Dunstable.

Medications prescribed for weight management and obesity is a rapidly evolving area. Last year, NICE approved the use of Semaglutide (Wegovy) for adults with a BMI of at least 35 and one weight-related health condition (such as diabetes or high blood pressure). Both Wegovy and Saxenda are not available for prescription from primary care as they require specialist weight management services including nutrition, physical activity and behaviour change support. We are aware that our primary care services are experiencing frequent request for medications. The ICB is currently considering how they develop a pathway for these medications and are mindful that further drugs will be approved by NICE later this year. NHSE are considering funding and support for ICBs to implement pathways for medications as it is acknowledged that the demand has significant resource implications.

There are national providers of the tier 3 services who are not commissioned by the ICB, yet provide remote tier 3 weight management including provision of weight loss medications services to patients in line with National Guidelines and the NHS Constitution. GPs in BOB ICB <u>can</u> refer residents who meet the criteria to a remote specialist tier 3 weight management service should they invoke their right to choose.

To compare across BOB, the ICB commissioned a Tier 3 service in Buckinghamshire. This has capacity for 116 patients per year and currently has a waiting list of 300 patients (24 month wait). Berkshire West does not have access to a local service commissioned by the ICB.

Tier 4

The Tier 4 bariatric surgery service at Oxford University Hospital is no longer active. Oxfordshire patients are referred out of county, commonly to Royal Berkshire Hospital, Luton and Dunstable or Ashford St Peter. The ICB is progressing a provider collaborative model which proposes to include a hub and spoke model for bariatric surgery with Royal Berkshire Hospital leading the service across BOB with the priority of making services more equitable and consistent.

For children and young people, the ICB are delivering a national pilot for Complications from Excess Weight (CEW) clinics from Helen and Douglas House (OUH). This is a holistic approach to treating conditions related to obesity in children and young people (CYP). There is capacity for 40 patients across BOB.

The three aims of the service are to:

- Identify the factors involved in the development of severe obesity. Assessment should be holistic with equal consideration for mental health, physical health and social needs.
- Treat complications associated with severe obesity and coordinate / refer onto other services where required.
- Consider an individualised holistic plan. This may include interventions such as family-based therapy, behavioural coaching, dietary strategies, and mental health support. This aims to address health inequalities by considering culturally appropriate factors and a personalised approach.

Children receive holistic treatment and person-centred care packages developed with their family, which could include mental health treatment, coaching and advice around a healthy diet

The ICB recently explored a deep dive into weight management services across BOB ICB and has recommended that they work closely with public health colleagues to prioritise a preventative approach to healthy weight especially amongst families, children and young people. It is also proposed that the ICB's strategic commissioning directorate lead a workstream to explore the transformation of our weight management services.

5 Corporate Policies and Priorities

This report reflects priorities both in the Oxfordshire County Council Corporate Plan and Oxfordshire Health and Wellbeing Strategy.

Climate action – physical activity contributes towards a healthy weight with active travel (walking and cycling) being an element of this. Takeaway food contributes to additional waste and littering. can contribute to additional waste and littering.

Tackle inequalities – excess weight affects some communities, particularly those in areas of socio-economic deprivation and people of black, Asian and ethnic populations more than others.

Prioritise the health and wellbeing of residents – becoming a healthy weight supports residents to reduce their risk of long-term conditions such as diabetes, cardiovascular disease and musculoskeletal issues, resulting in improved chance of longer, disability free, life

Support carers and the social care system – adults aged 65 and over with a BMI of 40+ are over twice as likely to use formal social care than a person with a BMI in the healthy range[15]. Social care costs are estimated to be a total of 12% of the overall costs obesity to the UK system (data not available at an Oxfordshire level).

Preserve and improve access to nature and green spaces – reducing the proliferation of fast food outlets will support reduction in associated litter/waste that is often not biodegradable. It would also support a more diverse high street in large villages, towns and Oxford City.

Create opportunities for children and young people to reach their full potential – habits and behaviours formed during early years (first 1000 days) influence those into later life[16]. Experiencing excess weight as a child means they will be twice as likely to becoming overweight/obese in adulthood[17] and associated health risks, as well as reduce attainment within school, and impact poorly on mental health and wellbeing.

Work with local businesses and partners for environmental, economic and social benefit – healthy weight is everyone's business as demonstrated by a systems wide approach. There is opportunity to make environmental and social change to local communities through the identified environmental actions addressing fast-food proliferation, improving access to healthier, affordable food (particularly in areas of socio-economic deprivation) and supporting healthier food (vs high fat salt sugar). Creating a more diverse high street will further support the economic benefit of local places.

6. Financial Implications

Funding for the Tier 2 healthy weight services, as well as other initiatives (Healthy Start social marketing, School Food Advisor, creating Active Schools Framework, some physical activity programmes) comes from the ringfenced Public Health Grant. Other partner organisations fund their healthy weight work directly and partnership work across the system takes officer time/resource.

[15] LGA (2020) Social care and obesity. Available here
[16] UNICEF (2013) The first 1000 days of life: The brain's window of opportunity. Available here
[17] Singh et al (2008) Trackling of childhood overweight into adulthood: a systematic review of the literature. Available here https://doi.org/10.1111/j.1467-789X.2008.00475.x

4. Appendices

6.1 Appendix 1: Recommendations from Healthy Weight Health Needs Assessment

20230824 HNA Recommendations Su

6.2 Appendix 2: Whole systems approach to healthy weight action plan 23/24

20230823 WSA Action Plan Summary.

6.3 Appendix 3: Oxfordshire WSA To excess weight: Work undertaken or in progress update 2024

Oxfordshire WSA To excess weight underta

2 Summary list of recommendations

For a comprehensive list of recommendations with rationale see Appendix 11.14.

KEY OBJECTIVE 1

System - address healthy weight inequalities in everything we do

1. Prioritise actions based on, and measure progress against, addressing healthy weight inequalities.
2. Ensure our policies, strategies, communications, campaigns, and weight support programmes avoid perpetuating weight stigma and use co-production approaches in the design of weight support services

KEY OBJECTIVE 2

Prevent - To prevent excess weight, start early

A substantial proportion of children are already affected by excess weight by the time they start Reception. From national data, we know that the majority of these children will still be affected by overweight in Year 6 and see that health inequalities in excess weight already start developing from this early age. This highlights the need to promote a healthy weight in parents during pregnancy, breastfeeding, through early years providers and in school settings. Residents identified being exposed to healthy eating habits and a cooking culture at home early in life as key factors that support their motivation to cook themselves later in life. The research evidence suggests childhood Physical Activity (PA) levels predict PA levels later in life (for example levels later in childhood, during adolescence and adulthood).

3. Collate up-to-date small area data to assess for inequalities in breastfeeding initiation and continuation within Oxfordshire, taking action to address inequalities if required
4. a) Work with early years providers to assess current food provision against, and understand facilitators and barriers to adherence to, national nutritional guidance and work to improve adherence where it is currently low
   b) Understand the opportunities for breastfeeding support, promotion of the Healthy Start scheme and increasing children's confidence to engage in physical activity through these settings
5. Review the evidence on programmes to prevent childhood obesity aimed at children aged 0-3 years to identify those that have been demonstrated to have longer term impacts on enabling healthier diets and physical activity.
6. Ensure a continued focus on increasing uptake of the Healthy Start scheme across Oxfordshire via the OCC Healthy Start working group action plan and District Food Action Working Groups
7. Implement a 'whole school approach' to promote healthier eating and physical activity in schools, prioritising areas with high excess weight prevalence amongst children.

KEY OBJECTIVE 3

Environment - Enable healthy weight by building healthy places and environments

In community engagement, residents described the constant exposure to less healthy foods through neighbourhoods, social media and advertising as making it easy for less healthy dietary habits to develop. It is estimated that nationally around one in five meals are eaten outside of the home. Meals from out-of-home food outlets tend to have higher levels of saturated fats, sugar, and salt, and lower levels of essential micronutrients. National data show that less affluent areas have a higher concentration of fast-food outlets. Research has found that the proportion of school pupils regularly purchasing food outside of school is much higher in these areas, with the most commonly purchased foods including chips, sandwiches, sweets and chocolate. This highlights the importance of healthy food environments around schools as well as within schools.

8. Use available levers to restrict advertising of less healthy food in public sector spaces and externally owned spaces across Oxfordshire

9. Introduce planning policy to limit proliferation of less healthy food vendors, prioritising areas with the highest levels of excess weight and around schools

10. Use levers within licensing to increase exposure to healthier foods and limit exposure to less healthy foods

11. Use evidence-based levers to support and incentivise local food outlets to provide a healthier food offer

12. Ensure Government Buying Standard-based criteria are used in the procurement of food and catering services by public sector facilities

13. a) Identify and act on opportunities to increase the healthiness of the food offer provided by Community Food Services
b) Ensure information on best practice for addressing stigma associated with accessing services and improving accessibility is shared between Community Food Services

14. Develop Local Cycling and Walking Infrastructure Plans in all market towns in Oxfordshire

15. Work with partners to implement the priorities of the Local Transport and Connectivity Plan and review progress in achieving its targeted aims of increasing walking and cycling. Including work with Local Enterprise Partnerships to ensure physical activity is integrated into local economic growth and infrastructure plans

16. Sustain support for cycling and walking activation programmes, especially aiming to increase engagement amongst those who are least active, and evaluate their impact and reach

17. Support community engagement activities to improve the quality of existing green spaces in order to increase use of green space in the population groups known to be at the highest risk from low physical activity levels

18. Consider the added value a workplace wellbeing programme for Oxfordshire could contribute to improving healthy eating and increasing physical activity (as well as other health promoting behaviours such as smoking)

KEY OBJECTIVE 4

Prevent - Environment - Enable healthy weight by building healthy places and environments

19. a) Review existing cooking-related training to ensure it is meeting the specific needs identified by residents during community engagement.
b) Work with providers of cooking-related training to measure and increase uptake in key target groups (including those at important life transitions such as leaving home or becoming a new parent).

20. Use and expand upon existing evidence from community engagement with residents to ensure the active recreation offer in Oxfordshire aligns with activity preferences across different age groups

21. Ensure information about programmes that support physical activity (including what activities are available), healthy diet and weight support services, is promoted to the public and partners working with those at the greatest risk from excess weight

KEY OBJECTIVE 5:

Support - Ensure those living with excess weight are connected with healthy weight-promoting programmes and weight support services

Several weight management support programmes are offered in Oxfordshire for children and adults, as well as specific programmes for adults living with a mental health condition(s) (Gloji Mind+), residents from a Black, Asian or minority ethnic background and for men. Offers need to be joined up across the lifecourse.

22. a) Address the gap in provision at Tiers 3 and 4 in Oxfordshire. At Level 2 ensure support is provided for groups that experience a high prevalence of excess weight where gaps have been identified (those with learning disabilities, women peri-pregnancy, young people aged 12-18 years) alongside promoting prevention-orientated approaches in these groups
b) Develop a clear healthy weight care pathway for children and adults across all ages and commissioning bodies

23. a) Identify brief intervention approaches for excess weight that complement the MECC ('Making Every Contact Count') approach.
b) Identify professional groups who have a high amount of contact with groups at high risk of excess weight with whom to implement the MECC/brief intervention approaches to excess weight, monitoring the effectiveness of training where delivered.

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Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
Strategic Leadership	1	Maintain oversight of new guidance related to healthy weight - ensure regular review, dissemination and updates.	Core Group	Ongoing
	2	Develop a suite of outcomes/monitoring data related to healthy weight and a related trend/trajectory to enable monitoring	Core Group	Ongoing
	3	Ensure recommendations related to 2023 HNA for promoting healthy weight are embedded into action plan.	Core Group	End of 2023
	4	Ensure policies, strategies, communications, campaigns, and weight management programmes delivered in Oxfordshire avoid perpetuating weight stigma	Core Group	Ongoing
	5	Work towards relevant partners Adopting the Healthy Weight Declaration	Exec leads for District/City/County Councils & ICS	23/24 24/25
	6	Support the implementation of the Food Strategy for Oxfordshire. Ensure relevant recommendations are embedded in the healthy weight action plan and vice versa.	Good Food Oxford, Core Working Group	Y1- High Sep 2021-May 22
	7	Support the implementation of the Physical Activity Strategy and ensure relevant recommendations are embedded in the healthy weight action plan (and vice versa).	Active Oxfordshire /Public Health /5 DCs, Core Working Group	Y1- High, Launch May 2022

Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
Prevention	1	Review the evidence on programs to prevent childhood obesity aimed at children aged 0-3 years (or their families) to understand if any have been demonstrated to have longer term impacts on enabling healthier diets and being more physically active in children and their families.	Public Health/HW in Childhood Group	23/24 24/25
	2	Early Years. 1. Establish baseline level of knowledge, skills and capacity in relation to nutritionally balanced food provision amongst Early Years and Childcare Providers and develop plan to improve. 2. Work with early years providers to assess: - current food provision against national nutritional recommendations and understand facilitators and barriers to adhering to national recommendations	HW in Childhood Group	2023 24/25 to implement offer
	3	Breastfeeding: 1. Ensure accreditation to best practice standards for infant feeding (e.g. Unicef Baby Friendly Initiative/support with 'fussy eaters'). 2. Collate up-to-date small area data on breastfeeding initiation and at 6-8 weeks to assess for inequalities in breastfeeding continuation within Oxfordshire.	HW in childhood group	24/25
	4	Improve the uptake of Healthy Start vitamins and vouchers across the County, including promoting the service, communications and training for relevant frontline professionals and volunteers.	Healthy Start Working Group and City and Districts Food Action Working Groups - formed April 2023	Action plans for City/Districts end of May 2023

Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
	5	Amplify national and develop and promote local campaigns and programmes on healthy eating and food to partners and the public.	Food Sustainability and Health Group	Ongoing
	6	Develop a School Food and Physical Activity Advisor role to manage a suite of work for a 'whole school approach' to healthy weight/physical activity in identified targeted areas/schools.	Public Health and Children, Education and Families (CEF) at OCC	April 2023 - High - Q2 & Q3
Physical Activity – Oxfordshire on the Move	1	Development of You Move programme to support low-income families with a year-round physical activity offer across all 5 districts, building on the learning from Families, Active and Sporting Together.	Active Oxfordshire	Launched May 2022
	2	Support residents to find active recreation activities they enjoy by using insights collected on activity preferences to influence commissioning provision and ensure information about activities available is easily accessible	Active Oxfordshire	24/25
	3	Review and implement Creating Active Schools Framework with Oxfordshire schools to embed a whole school approach in addressing physical inactivity.	ACTIVE OXFORDSHIRE	Y1- High, launch Jan 2021

Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
Support	1	Develop a clear, streamlined healthy weight pathway for adults (Tier 1-4) and improve the integration and referral protocols across the pathway for adults and children.	ICB and Public Health	Y2- High 23/24
	2	Understand, monitor and promote opportunities within frontline settings to prompt healthy weight conversations and onward referral. Including Primary Care, Pharmacy, Adult Social Care and other frontline professionals by 1. Ensure information about support and programmes is promoted 2. Identify and target MECC training to certain roles.	MECC Lead. Core Group	TBC
	3	Evaluate and review findings of the child healthy weight pilot for Oxfordshire (Gloji Energy).	JS/DP/SC, HW in childhood group	July 2022 service launch 23/24 Service evaluation complete Used to inform the recommission of all age healthy weight service 24/25
	4	Commission a Tier 3 Weight Management Service for Adults (age 18 years and above)	ICB	May 2022 options paper submitted – progress paused?
	5	Explore the need for a Tier 3 Weight Management Clinic for Children and YP (age 2 up to 16 years old).	HW in childhood group/ICB	Y1 High . Sept 2022
	6	Understand the Tier 4 Gap (referral to Bariatric) which has been paused during COVID (provided by OUH)	ICB	23/24 24/25

Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
	7	Address gaps identified in HNA (learning disability, pregnancy, teens). Including exploring best practice and recommending local approach for both prevention and support	Public Health, OUH Maternity Lead & Dietetics LD lead within OCC and ICB.	23/24 24/25
Healthy Weight Environment	1	Complete mapping and gap analysis of existing activity, organisations, community assets and needs supporting **cooking and healthy eating** to inform future approach to interventions.	Good Food Oxfordshire Food Sustainability and Health Group	April 2023 (start of work) - December 2023 report with recommendations
	2	Work with providers of cooking-related training to measure and increase uptake in key target groups (including those important life transitions such as **leaving home or becoming a parent**).	Good Food Oxfordshire	
	3	Oxfordshire to achieve the **Sustainable Food Places** Gold award by 2025.	Good Food Oxfordshire, Food Sustainability & Health Group	Target of May 2025 to achieve Gold
	4	Deliver the **Oxfordshire Good Food Retail project** in target areas to improve the accessibility of healthier food options (convenience stores, wholesalers)	Public Health, Rice Marketing	23/24 24/25

Oxfordshire Whole System Approach to Healthy Weight
Action Plan 23/24

Pillar		ACTION	LEAD	PRIORITY AND TIMESCALE
	5	**Healthier food advertising** - reduce advertising of less healthy foods by 1. Conduct an assessment of advertising spaces in Oxfordshire and who owns those spaces 2. Identify levers to restrict advertising of less healthy food in public sector spaces and externally-owned spaces across Oxfordshire 3. Work with Sustain on a healthier food advertising policy	Public Health District, City and Town (& Parish?) Councils	23/24 24/25
	6	Introduce planning policy to limit proliferation of less healthy food vendors (ie **hot food takeaways - planning, street trading close to schools**).	Public Health, District, City Councils	23/24 24/25
	7	**Provision of healthier food in public sector facilities:** 1.Use Government Buying Standard-based criteria in the procurement of food and catering services by public sector facilities (excluding educational settings) 2. Review opportunities to embed these guidelines into contracts or leases	Oxfordshire County Council and ICB	23/24 24/25
	8	**Support local food outlets (hot food takeaways, mobile food vendors, shops) to provide a healthier food and drink offer -** utilising levers such as healthy catering/eating out award schemes, dedicated support/capacity roles and training to incentivise.	Public Health, District, City Councils	23/24 24/25

Oxfordshire WSA To excess weight: Work undertaken or in progress update 2024

Pillar	Actions completed to date (end of 22/23)	In Plan for 2024/25
Prevention	Develop and launch an Oxfordshire wide Healthy Start Programme Implement a pilot of Active Schools Framework for a whole school approach to physical activity, evaluation to be completed in 2024. Delivery of the evidence-based Healthy Smiles Accreditation Scheme to support good oral health in early years. Survey and focus groups with Early Years and Childcare settings to inform future approach of support; education, training and knowledge on healthy eating and food provision. Reviewed evidence based practice for prevention in early years Completed gap analysis for cooking and healthy eating activities across Oxfordshire underway. Amplified national and local campaigns on healthy eating and food for example Eat Them to Defeat Them, Switch Up Your Lunch	Provision of licenses (35 of 100 to date) for online Child Feeding Guide training including 'Fussy Eating' for Early Years, Healthcare Professionals and Home Start workers (working with vulnerable families) Evaluate the engagement and impact of the Healthy Start social marketing campaign commission and commence school cooking and healthy eating project to 31st October 2024 Work towards implementation of initiatives based on the evidence review related to early years. Pilot evidence based HENRY (Health Exercise and Nutrition for the Really Young) approach for Oxfordshire in target area Learning Disabilities Team, Oxford Health to pilot an approach to engage people, carers and providers to support healthy weight in people with learning disabilities Work with maternity to determine if further approach (beyond commissioned service) for pregnant women would be of benefit
Support	Commissioned a new all age healthy weight service with specific programmes where gaps were identified in the Health Needs Assessment	Develop a specific approach with maternity to provide bespoke support to pregnant women with very high BMI.

Oxfordshire WSA To excess weight: Work undertaken or in progress update 2024

Pillar	Actions completed to date (end of 22/23)	In Plan for 2024/25
	Revised content of National Child Measurement Programme letters and signposting leaflet including offer for parents Positively evaluated a pilot healthy weight support service for 4–12-year-olds and their parents/carers (planned continuation) Developed a physical activity programme to support adults with long-term conditions (Move Together) Developed and delivered physical activity opportunities for young people/families eligible/in receipt of benefits related free school meals (You Move) Social prescribers linking residents with active recreation opportunities	Learning Disabilities Team, Oxford Health to pilot an approach to engage people, carers and providers to support healthy weight in people with learning disabilities
Environment	Completed a community insight project, to explore residents' feelings about how where they live, work, learn and play could motivate or support them to attain and/or sustain a healthy weight. Reviewed and shared best practice around shifting advertising in the Oxfordshire from High, Fat, Salt and Sugar (junk food) to healthier food advertising. Reviewed and shared best practice with localised information for individual Districts/City to enable them to include wording in their local Plans to support potential restriction of new fast-food	Oxfordshire County Council Catering has signed up to Food for Life Served Here award to ensure they provide healthy and sustainable food in schools. Menus are being assessed to identify good practice and where adaption and improvement is needed. Expansion of Good Food retail Project to Banbury and delivery for 2 further years until 2027. Launch Workplace Wellbeing programme for Oxfordshire Biteback food youth voice project (launched October) – recruiting Community Food Champions aged 14–18-year-

Pillar	Actions completed to date (end of 22/23)	In Plan for 2024/25
	outlets within specific radius of schools or in areas of excess weight Established a post sitting in Trading Standards who is reviewing evidence and best practice on potential provision of an accreditation and support offer across Oxfordshire for existing food businesses/outlets Pilot Oxfordshire Good Food Retail project - to support convenience stores to improve access to healthier food options (in Blackbird Leys) Oxfordshire County Council Catering has signed up to Food for Life Served Here award to ensure they provide healthy and sustainable food in schools.	olds to learn about the food system, how it shapes what we eat and to give their views about what needs to change locally, a video and manifesto report to be shared with decision makers in Oxfordshire by February 2025. Assessment of OCC school catering menus are being assessed to identify good practice and where adaption and improvement is needed.Expression of interest submitted for Oxfordshire to NESTA's 'Location Based Testing Programme' Nesta | UK innovation agency for social good

Oxfordshire WSA To excess weight: Work undertaken or in progress update 2024

Pillar	Actions completed to date (end of 22/23)	In Plan for 2024/25
System Leadership *Figure 1: Pie charts indicati approach in 19/20 to 23/24*	Complete a comprehensive Health Needs Assessment and updated WSA action plan. Publication of the Countywide Food Strategy Part 1 Achieved Sustainable Food Places Silver Award for Oxfordshire Delivered a workshop for senior leaders to explore taking forward healthy food environment recommendations from HNA across the County Recruitment of strategic schools' food and physical activity advisor to work in schools in targeted priority neighbourhoods Support governance for the Oxfordshire Food Strategy, (SRO Ansaf Azhar, DPH), OCC Food Strategy action plan to be agreed. Food Action Working Group (FAWG) formed in each of the City/District area to develop a local action plan by end of 2023 Developed a WSA to physical activity in partnership with ICB, Active Oxfordshire and District Councils.	Re-establish and re-invigorate the WSA oversight group. Collecting evidance and impact of work for Sustainable Food Places Gold bid in 2026 Conclude whether the Healthy Weight Declaration (Food Active) would be an appropriate tool

healthwatch Oxfordshire

Your voice on health and care services

Report to the Oxfordshire Joint Health Overview Scrutiny Committee

November 2024

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1. Healthwatch Oxfordshire reports to external bodies

For all external bodies we attend our reports can be found online at: https://healthwatchoxfordshire.co.uk/our-reports/reports-to-other-bodies/

We attended Health and Wellbeing Board, Health Improvement Board, Children's Trust. We attend **Oxfordshire Place Based Partnership** meetings under Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB). We work together with the five Healthwatch groups at place across BOB ICB to give insight into committees at BOB ICB wide level, including BOB ICB Quality Committee, BOB ICB Health Overview Scrutiny Committee and BOB Integrated Care Partnership (BOB ICP).

2. Update since the last Health Overview Scrutiny Committee (HOSC) Meeting - Sept 2024:

Healthwatch Oxfordshire reports published to date:

All the following reports published since the last meeting can be seen here: https://healthwatchoxfordshire.co.uk/reports All reports are available in **easy read**, and word format.

- Report: '**People's Experiences of Leaving Hospital in Oxfordshire**' (Nov 2024). This was to enable us to gather insight into how the new models of hospital discharge are being experienced by the public, including the Discharge 2 Assess Pathway (D2A). We worked closely with health providers and commissioners and patients through this process and in ensuring recommendations would be built on to improve services, based on feedback from patients and their carers. In all, we heard from a total of 293 people:
  - 206 members of the public about their experiences of leaving hospital and any follow-on care and support they received after their stay
  - Including views of 22 unpaid carers
  - We also heard from 87 health and social care professionals from primary and secondary care and social care.

(**Note:** See published report on link above and additional powerpoint presentation presented to this HOSC Meeting).

- Report **'What you told us about hospitals'** (Oct 2024) summarising what we have heard via our feedback routes about OUH hospitals between August 2023 and July 2024.
- **Community Participatory Action Research** (CPAR2) (July 2024) The final report https://healthwatchoxfordshire.co.uk/reports and accompanying film https://youtu.be/5_P3MMGUirI of work on food and cost of living by community researchers from Oxford Community Action (OCA) was published in July. We held a follow on event, ***'Feeding Oxford, Ensuring Dignity and Access Amid Rising Costs'*** together with OCA, OX4 Food Crew, Oxford Mutual Aid, Waste2Taste and others at Rose Hill Community Centre on 17th October. Over 50 attendees from grassroots community, BOB ICB, Oxfordshire County Council (OCC), Oxford University Hospitals (OUH), Oxford City Council and others, took part in learning from voices of those with lived experience of food insecurity, and discussions as to next steps. Actions from the work have already begun, with pilot development of a 'social supermarket', embedded advice worker sessions in food service, initiation of community food growing and input into wider refresh of Oxfordshire Food Poverty Strategy. The report and film have also been shared in Oxford Mail, and BBC Radio Oxford as well as in presentations together with Oxford Community Action on community led research to Institute for Voluntary Action Research (IVAR), and to the ARC (Applied Research Collaboration) Thames Valley showcase event on 4 Nov.

- **Enter and View Visits**

Since the last meeting we made Enter and View visits to the following: White Horse Medical Practice, Faringdon; Ferendune Care Home, Faringdon and Boots Pharmacy, Corn Market, Oxford. We published the following reports: (https://healthwatchoxfordshire.co.uk/our-work/enter-and-view/) on Enter and View visits to the following services:

- Ambulatory Care Unit Churchill Hospital (Sept 2024)
- Oxford Eye Hospital (Sept 2024)
- Outpatients Wantage Community Hospital (Sept 2024)

All published Enter and View reports are available here: https://healthwatchoxfordshire.co.uk/our-work/enter-and-view and information https://healthwatchoxfordshire.co.uk/wp-content/uploads/2024/01/Enter-and-View-easy-read-information.pdf

Webinars: We held two Public Webinars:

- *'Healthcare closer to home'* with Dan Leveson, Director of Place – Oxfordshire (BOB ICB) and Karen Fuller Director of Adult Social Care (OCC) on 17 Sept.
- *'Designing services for men in mind'* 19th November 1-2pm. Held together with Oxfordshire Men's Health Partnership and Oxford Community Champions as part of the wider Oxfordshire Men's Health Partnership focus on men in November.
  To see recordings of all our webinars:
  https://healthwatchoxfordshire.co.uk/news-and-events/patient-webinars/

Our ongoing work:

- We held a survey on **Women's Health** services and received over 500 responses. The report on what we heard will be published in the new year.
- We continue ongoing **outreach** to groups and events across the county, including hospital stands, community groups and events e.g. play days, community events, and have been focusing on hearing about hospital discharge, men and women's health, as well as general listening.
- We have undertaken street and community insight gathering for **Wood Farm and Town Furze** to contribute to community health profile for the area, for Oxfordshire Public Health and Oxford City Council (part commissioned).

3. Key issues we are hearing from the public:

We hear from members of the public via phone, email, online feedback on services (https://healthwatchoxfordshire.co.uk/services), and when out and about. This enables us to pick up and raise with health and care providers and commissioners on emerging and current themes. Below are some examples of comments from the public on different issues.

Relating to this HOSC meeting agenda feedback from the public we have received includes:

ADHD medication and pathways – continues to be unclear for patients and for children moving into adult services, with little clear communication from BOB ICB about access, rights, where to turn and how to find information and support.

> "Son has ADHD and autism and in transition to adult services and support - but no support and don't know where to go - keep getting passed from a to b to c, and no-one wants to know- getting no support as a carer (mother) terrible impact on family lie 'terrible failure of support all round" (outreach at Witney Pride)
>
> "[I] would like to raise my disappointment that the practice will not agree to 'Shared Care' with private providers (or the NHS if I have understood correctly) for Adults with ADHD. I feel I am now in a postcode lottery situation to find a surgery that will take on my son's care to help us with the ongoing cost of his medication." (signposting email)

Maternity services in Oxfordshire:

Gathered from our current Women's Health survey, signposting calls, service feedback reviews and face to face outreach in the last four months.

- **Praise for midwifery teams and other maternity health and care professionals, including HV and EPAU:**
  "The midwifery team based out of Witney are particularly excellent and ensure continuity of care no matter who the appointment is with. They are efficient, compassionate and in my experience, always went above and beyond to assist me with any health issues I might have had. They have organised appointments and chased referrals and consultants to ensure the safe arrival and care of my baby. The team at the John Radcliffe (both midwives and consultants) have, on the whole, also been incredible. They saw me antenatally, while in labour, for an emergency c-section and again postnatally after being discharged. Many of the team there were brilliant and supported me with every choice, ensuring that I felt listened to and that I left the hospital fully recovered." (Online feedback)
  "The midwife consultant I was referred to listened to me and understood my concerns and helped me achieve the birth I wanted" (women's health survey)
  "Amazing maternity services at both Horton and the John Radcliffe" (Women's health survey)

"Helpful Health visitor, if they can get to know you before and visit after that does help" (women's health survey)
"I was very grateful to have access to the Early Pregnancy Assessment Unit and really appreciated the fact that this was separate from the main maternity care pathway. The staff were incredibly sensitive and caring, it was clear they understood that patients were facing anxiety and uncertainty and spoke with this in mind, e.g. unlike in the main maternity care pathway where the expectation is that you will be joyful and excited. It was also clear that there is specialist expertise in dealing with miscarriage which is very reassuring" (Women's health survey)

- **Waiting for care:**"*Early Pregnancy services overstretched - could not be seen at the hospital but the pregnancy unit had no availability so a long wait for a scan which I was very worried about*" (Women's health survey)
- **Issues with quality of care, lack of person-centred care:**
"*Midwives left me for hours on my own, it was a very hot day and they put me in a labour waiting room to be transferred from ground floor to the Spires with the excuse that the birth pool was being filled. I was throwing up all the time, only student midwives showed up and treated me like I was a guinea pig they were observing*." (Feedback centre review of Oxford Spires, July 2024)
"*I felt looked after with my physical health during my pregnancy but not my mental health*" (Women's health survey)
"*Health visitor appointments should be optional - and health visitors must be aware that visits to a newborn's home are unacceptable in some cultures for 6 weeks post-birth. Personally, I found those visits intrusive and unhelpful*."
(Women's health survey)
"*My diabetes was mismanaged when I was in labour. My blood sugars dropped I was denied food in case of theatre admission. I became unconscious my baby swallowed meconium. I had emergency c section.*"
(Feedback via HWE webform)
- **Lack of joined-up care:**
"There is a problem with the lack of continuity between the GP surgery, the midwives and the hospital. The GP surgery are seemingly unable to view the results and notes from the hospital or the midwifery team in a timely manner (if they're able to view them at all) which resulted in a delay in care on several occasions. One GP prescribed an antibiotic that the infection I had was resistant to as unable to view the results that the midwifery team had

received. This meant that I ended up being prescribed 4/5 different antibiotics for an infection that I then struggled to recover from." (Online feedback survey)

"The GP services and Midwifery services seem completely disconnected and there seemed to be very little information shared about any of my medical history - my miscarriages weren't properly recorded and I continued to receive pregnancy communications even when I was no longer pregnant and there seemed not to be any knowledge of these passed on to help inform my care in my current pregnancy." (Women's health survey)

- **Aftercare including 6-week check up:**

  "My surgical experience went well but my post surgery care was awful. I repeatedly requested pain relief which I was not given for hours and hours, there was not enough qualified staff for the amount of patients" (Feedback via HWE webform)

  "I was shocked to discover after the birth of this child that my GP surgery in Oxfordshire complete the 6-week check entirely online unless a clinician feels that the answers you give merit an in-person consultation or you request to be seen. I cannot believe that they feel it is appropriate to ask questions about the state of new mothers' mental health in a tick-box survey without seeing them in person. I also could not believe that this same form then actually required mothers to enter their current height & weight and informed them that their BMI is too high and that they therefore need to lose weight. At 6 weeks postpartum. When they have not been cleared to exercise or lift anything heavier than their baby." (Online feedback survey). (See also our report on maternal mental health - published Dec 2023).

  "*Support and checks after postpartum - I was shocked about the support and checks you get after giving birth. There needs to be more on pelvic care/ physio*" (women's health survey)

- **Other feedback** included issues with the Badger Notes app, a lack of support for people experiencing miscarriages, and difficulty accessing appointments due to cost of living impacts on fuel and maternity pay.

Healthy Weight – feedback on food environment among others:

"The GP suggested the mounjaro weight loss injections - they're not available on the NHS is South Oxfordshire, yet they are in Buckinghamshire and Berkshire which are the same trust." (feedback via HWE webform)

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healthwatch Oxfordshire

Your voice on health and care services

People's experiences of leaving hospital in Oxfordshire

November 2024

Contents

Executive Summary

"So the good care, it's not just about healthcare, it's about the quality of life and the relationship and everything – it's just priceless."
(Unpaid carer comment)

Over the past year, informed by national guidance, the Oxfordshire health and social care 'system' has been working to develop new pathways to care and support for people when they leave hospital. This has included a shift towards rehabilitation and care for people in their own homes or usual place of residence, as a way of supporting speedier recovery and independence. This in turn helps to relieve the pressure on acute hospital beds, by reducing hospital stays and associated negative impact on recovery. There is focus on providing 'joined-up care', with support services planning and working closely together around the patient.

Between May and September 2024, Healthwatch Oxfordshire reached out to hear from people in the county about their experiences of this care and support. We heard from people via a combination of online and paper surveys, face to face outreach, and interviews. We focused on patients returning home via two pathways – Pathway 0 (going home without additional social care) and Pathway 1 or Discharge to Assess (D2A) (going home with additional social care before being assessed for longer-term social care needs).

In all, we heard from a total of 293 people:

- **206 members of the public** about their experiences of leaving hospital and any follow-on care and support they received after their stay
- This included the views of **22 unpaid carers**
- We also heard from **87 health and social care professionals** from primary and secondary care and social care.

What people told us:

What's working well?

- Parts of the process are working well for some patients. People valued the support and care from health and care professionals. What was clear was that good, consistent communication, being involved in decision-making about their care, effective follow-up care and aftercare, and high-quality care all made their experience of care positive. Most people told us they were happy to be back in their own home.

- Health and care professionals are finding effective ways of working together around patients' needs. Central to this is the coordinated approach taken in the Transfer of Care Hub and in multidisciplinary teams, to help get more people home with the support they need.

What could be better?

- Some parts of the discharge process are not working well for everyone. There are challenges around consistent and clear communication, listening to people and involving their unpaid carers in decision making, delays in leaving hospital and getting care, and accessing follow-up care and aftercare from different services. There are also challenges around the quality and continuity of care provided.
- Some areas of joined-up communication across primary and secondary care can still be improved following discharge of a patient from hospital, including handing over care to GPs and district nursing teams.
- We heard that unpaid carers were not always included or did not feel listened to, and were not being offered support.
- Overall communication and information about the discharge support offer and expectations could be more accessible, both for patients and carers but also for the health and care professionals within the system.

Recommendations

We would like to make the following recommendations based on what we have heard. They focus on building on existing good practice to improve the experience of patients and unpaid carers as well as system working.

- Recommendations are for response for all system partners – including Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) with Oxfordshire Place-Based Partnership, Oxford University Hospitals (OUH), Oxford Health, Oxfordshire County Council (OCC) and home care providers – as to how they will address them.
- For noting by Oxfordshire GP Network, Age UK Oxfordshire and Carers Oxfordshire.

1. **To improve the experience of continuity and quality of care for patients:**
   a) Note this report, including the experiences and voices of patients and carers, and reflect on potential to improve services in light of this insight.

b) The report has highlighted some gaps in joined-up care. Our recommendation is to use this report to identify gaps and inform the development of further service design and action plans to address them.
c) Identify scope for providing more person-centred care and support to both patients and unpaid carers at each step of the discharge process. For example, patients have told us about problems with timing of home care visits.
d) Build on the Health and Social Care Connections programme, to ensure that patients and unpaid carers continue to be involved in the co-design and future development of services.

2. Clear communication with patients and carers

This report indicates where improvements to communication with patients and carers could be made. We would like to recommend the following:

a) Improve communication about all aspects of the discharge pathway to ensure that patients and unpaid carers are fully informed about every step. For example, patients have told us that a leaflet and a single point of contact would be helpful.
b) Ensure that communication and information about discharge is accessible to all patients and unpaid carers, in line with the Accessible Information Standard.

3. Improve support for and identification of unpaid carers

Based on what we heard from unpaid carers, we make the following recommendations, noting OCC's Unpaid Carers Strategy:

a) Improve recognition and understanding of unpaid carers' role and capacity to provide care, including proactive identification of unpaid carers, for example flagging unpaid carers on medical records.
b) Improve holistic support to unpaid carers, including signposting to Carers Oxfordshire and other support.
c) We heard that unpaid carers were not always involved in decision-making about discharge. Ensure that, where appropriate, unpaid carers are involved in decisions about discharge.

4. To continue to develop joined-up working across the system

We saw that good progress has been made in services working together around discharge from hospital. The report identifies the following areas for continued improvement:

a) We heard that health and social care professionals are not always clear about discharge pathways, including the D2A offer and follow-on healthcare. We recommend exploring ways to improve communication with staff to ensure consistency of approach.

b) Work together to improve communication and understanding between services, e.g. interface between secondary care, GPs and district nursing teams when a patient is discharged, multi-disciplinary team handovers and discharge letters.
c) Explore potential to build in better support for patients through greater involvement of other relevant partners, for example home care providers and extra care housing providers.

Background

Moving care closer to home in Oxfordshire

In recent years, national government policy has encouraged a shift towards more community-based care. Local health and care providers have developed ways to make health and social care services available to people near to their homes and communities, rather than in large hospitals.[1] In Oxfordshire, for example, this has included the development of 'hospital at home' services to enable people to be treated at home where possible[2], rather than having to stay in hospital, and recent initiation of integrated neighbourhood teams within Primary Care, focused on community level support to help people stay well.[3]

There has also been development of a new approach to supporting adults who need support, rehabilitation and care immediately after leaving hospital. In the past, people often waited in hospital beds while their care needs were assessed, leaving hospital only when this assessment had taken place, and the care put in place. This could lead to longer waits in hospital while care was being arranged, sometimes with significant negative effect on people's health and ability to recover.[4] Under the new system, people are now discharged to return home as soon as they are clinically ready – that is, they no longer need to be in an acute hospital bed to have their medical care needs met. Whatever care they need is

[1] https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance
[2] https://www.bucksoxonberksw.icb.nhs.uk/news/posts/bob-icb-news/september-2024/thousands-effectively-treated-by-hospital-at-home-services-according-to-new-evaluation/
[3] https://www.bucksoxonberksw.icb.nhs.uk/media/4312/primary-care-strategy-final-21_05_24.pdf
[4] https://www.nuffieldtrust.org.uk/news-item/understanding-delays-in-hospital-discharge

provided at home, and the care assessment is carried out in their home once they are settled.

This new approach, called **Discharge to Assess (D2A)** not only reduces the length of time people stay in an acute hospital, but is proven to reduce the negative impacts of a long hospital stay on people's physical and mental health, as well as making more beds available for other people. People often feel happier in their own home, can return to independence and recover more quickly. Assessment of need done in a person's own home can support health and social care professionals to make more accurate decisions about the person's long-term care needs. D2A, first introduced as best practice by NHS England in 2016, was piloted in Oxfordshire from July 2023[5], and rolled out across the county from November 2023-January 2024[6]. Timescales for care that were introduced early on – people were told they would have an assessment within 72 hours of getting home and would get free care at home for up to six weeks – were later changed to be more flexible according to people's needs.

In Oxfordshire, there are four pathways through which people are discharged from hospital (see diagram below).[7] Our report focuses on listening to experiences of adults leaving acute hospitals on what is known as 'Pathway 0 and Pathway 1 or 'Discharge to Assess' (D2A)'.

- **Pathway 0**: about half of people leaving an acute hospital are able to go home without any social care – this is known as Pathway 0.
- **Discharge to Assess – Pathway 1:** Around 45% go home with D2A, also known as Pathway 1. A small number of people leaving an acute hospital may need more social care or support than can be provided in their home and may move to a bed in a community hospital or care home for rehabilitation before going home (in which case, this temporary bed might be referred to as a 'step-down' or 'short stay hub' bed), or for long-term care.

[5] https://news.oxfordshire.gov.uk/new-programme-launches-in-oxfordshire-to-help-patients-leave-hospital-on-time/

[6] https://news.oxfordshire.gov.uk/update-more-oxfordshire-patients-being-supported-to-recover-from-hospital-stay-in-the-comfort-of-their-own-home/

[7] Note: People leaving other hospital settings, such as inpatient mental health wards, children leaving hospital, people with some health conditions and people with some life circumstances (such as experiencing homelessness) may have a different journey out of hospital. These journeys are not covered in this report.

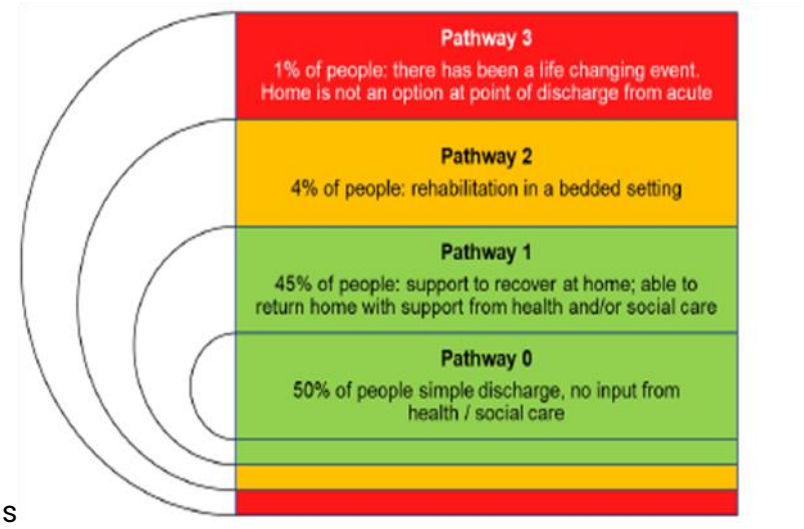

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Figure 1: Discharge pathways in Oxfordshire. Source: Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

Pathways 0 and 1 may involve patient contact with and coordination of care across a number of different health and care services, including:

- **secondary care acute hospitals** – in Oxfordshire, most people go to hospitals run by Oxfordshire University Hospitals (OUH) or hospitals in neighbouring counties, including Royal Berkshire Hospital (RBH) in Reading and Great Western Hospital in Swindon.
- **patient transport services** – provided by SCAS, EMAS and others
- **social services** – part of Oxfordshire County Council (OCC)
- **home care providers** – private domiciliary and reablement care providers contracted by OCC, including the four main 'strategic providers' offering reablement in Oxfordshire: AllCare, Agincare, Care Outlook and Eleanor Healthcare Group.[8]
- **primary care services** – e.g. GPs, community pharmacies
- **community care services** e.g. Occupational Therapy, District Nursing, – mostly provided by Oxford Health NHS Foundation Trust (OH)
- **voluntary sector organisations**, including commissioned support for people leaving hospital, provided by Age UK Oxfordshire, commissioned support for unpaid carers provided by Carers Oxfordshire, and organisations providing support for different communities and for specific health conditions and impairments.

[8] https://www.oxfordshire.gov.uk/residents/social-and-health-care/adult-social-care/adult-social-care-services/living-home/home-first-oxfordshire/reablement

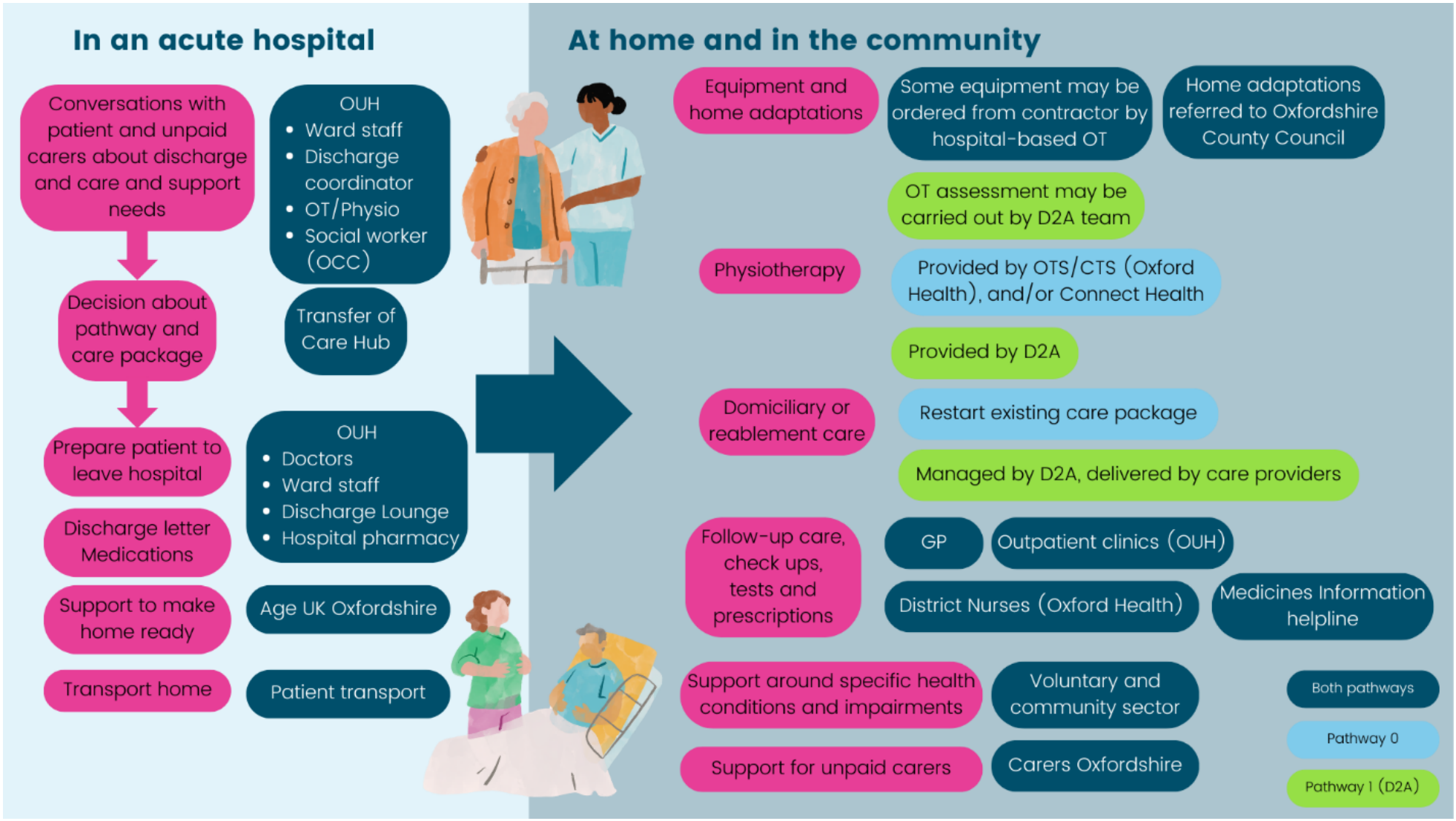

Figure 2 The Journey Home – Pathway 0 and Pathway 1 (D2A) in Oxfordshire

National government guidance on what people can expect from hospital discharge includes:

- Making sure unpaid carers and family members are included in decisions about discharge, where appropriate.
- Planning for discharge as soon as someone is admitted to hospital (or sooner if for a planned procedure).
- People should be discharged '*to the right place, at the right time, and with the right support*' to help the person recover as well and be as independent as they can in the long term.
- Discharge teams should make sure that people have transport to get home – usually this is with a friend or unpaid carer.
- People leaving hospital should be given information about who to contact if there are any issues with their care after leaving hospital.[9]
- Information should be shared 'across relevant health and care teams and organisations across the system in a secure and timely way to support best outcomes'.
- People should be given as much choice and control about their discharge as possible within what is appropriate and available to them, and their choice should be respected.

However, findings from the most recent Care Quality Commission (CQC) hospital inpatient survey suggests that people's experience of discharge has worsened since before the COVID-19 pandemic, including in areas such as being involved in conversations about discharge.[10]

Joined up working around the patient

A report by The Kings Fund in 2024 called for commitment to making care closer to home a reality, rather than a narrow focus, for example on hospital targets. It highlighted the importance of multi-disciplinary working to provide holistic care to patients, and the risk of overlooking the importance of primary and community health and care services.[11] In Oxfordshire, local health and social care providers have been working together to deliver hospital discharge in a joined-up way that is centred around the needs and strengths of each person leaving hospital. This has been demonstrated for example in the close partnership work between

[9] https://www.healthwatch.co.uk/blog/2023-11-20/nhs-urged-do-more-help-patients-leave-hospital-safely

[10] https://www.cqc.org.uk/press-release/more-people-report-poor-discharge-experiences-and-deterioration-health-while-waiting

[11] https://www.kingsfund.org.uk/insight-and-analysis/reports/making-care-closer-home-reality

health and social care to plan and allocate funding for integrated working, through the Better Care Fund.[12]

Development of the D2A approach has similarly involved significant partnership work across secondary, primary and social care, and has brought clear improvements in Oxfordshire's delays in discharge. This new way of supporting people represents a shift in the way services are provided. It also represents a cultural shift on the part of patients and families, and has been met with some reservations, as well as concerns over potential gaps in care, for example for rural areas, and for those at the end of life. Over the summer of 2024, health and care commissioners have carried out listening exercises, and conversations with the public to support better understanding and communication of these changes among the public, including taking part in Healthwatch Oxfordshire patient webinars.[13]

New developments in Oxfordshire's health and care system to promote joined-up working include the Transfer of Care Hub (TOC) and the Trusted Assessors scheme. The TOC brings together people from acute hospitals, community hospitals, care homes and social services and voluntary sector for meetings three times a day, to make real time decisions about where patients will be discharged to and identify the support they need. Trusted Assessors liaise between acute hospitals, social services and care providers, carrying out assessments of patients in acute hospitals on behalf of care providers.[14]

As well as health and care services, **unpaid carers** – people who informally provide care for other in their lives, often friends, relatives or neighbours – play a key role in the supporting people leaving hospital. Carers' rights are protected in law – including the right for an adult to choose whether or not to be a carer for another adult, and the right to choose what caring tasks they are willing to do. The Oxfordshire Unpaid Carers Strategy 2023-26 sets out priorities for supporting unpaid carers over the next three years.[15] In Oxfordshire, the main sources of planned support for adult unpaid carers are via Carers Oxfordshire, Dementia Oxfordshire and Oxfordshire County Council. The wider voluntary and community sector also plays an important role in supporting patients and unpaid carers.

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[12] https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/better-care-fund/
[13] https://healthwatchoxfordshire.co.uk/news-and-events/patient-webinars/ https://www.bucksoxonberksw.icb.nhs.uk/health-and-social-care-connections/
[14] https://www.oacp.org.uk/trusted-assessors-in-oxfordshire
[15] https://www.oxfordshire.gov.uk/sites/default/files/file/plans-performance-policy/OCCUnpaidCarersStrategy.pdf

Healthwatch Oxfordshire wanted to understand how changes in discharge and support were being experienced by people leaving hospital in Oxfordshire. We have researched and written this report to bring to the fore the voices of patients and unpaid carers about what it is like leaving hospital on Pathways 0 and 1 in Oxfordshire – what is working well and what could be better.

What did we do?

We used a mixed methods approach to hear from a range of people across Oxfordshire, including people who have recently left hospital and unpaid carers of people who have left hospital. We heard from people between March and September 2024. Our methods included:

- An **online survey**, developed with input from unpaid carers and representatives of system partners including Age UK Oxfordshire, Carers Oxfordshire, Oxford University Hospitals and Oxfordshire County Council. The survey ran from May-September 2024 and was shared widely using our networks and social media. It was advertised in local newsletters, such as Age UK Oxfordshire's *Engage magazine*, and *Round & About*. We shared posters with GP practices, community noticeboards and libraries. We provided print versions of this survey to people who requested them
- During face-to-face outreach, we used a simplified **outreach survey** to record responses. This included speaking to people during our ongoing schedule of outreach and engagement events across Oxfordshire, including Witney Pride, play days and visits to patient participation groups. We also carried out targeted outreach to hear from groups most likely to have experienced health inequalities, including Action for Deafness and an OX4 BAME elders' group, or to have recent experiences of leaving hospital, including older people's groups, Banbury Royal Voluntary Service, a Carers Oxfordshire support group, and extra care housing schemes
- Outreach surveys were also given directly to patients and unpaid carers by Age UK Oxfordshire's hospital team, social workers from Oxfordshire County Council, and staff in the discharge lounge at the John Radcliffe hospital.
- **In-depth conversations** with people who were put in touch with us (with their consent) by the Discharge to Assess team and Carers Oxfordshire, who shared their contact details in the survey, or who contacted us directly
- An **online survey for health and social care professionals** – staff working to support patients through the discharge process, circulated widely including through staff networks at OUH, Oxford Health and OCC, and via

Oxfordshire Community and Voluntary Action and the Oxfordshire Association of Care Providers
- **Observation of Transfer of Care meetings** – a member of the Healthwatch Oxfordshire staff team observed two meetings of the Transfer of Care Hub, which take place on Microsoft Teams three times a day
- An **Enter and View visit** to the Discharge Lounge at the John Radcliffe Hospital in August 2024.[16]

Once collected, we compiled the data and carried out a thematic analysis of the qualitative responses.

Who did we hear from?

We heard from a total of **293 people**:

- 122 people through our full online survey for patients and unpaid carers[17]
- 27 people through our simplified outreach survey for patients and unpaid carers
- In depth conversations with 6 D2A patients and 7 unpaid carers – the stories collected have been published on our website.
- Around 30 people through outreach visits to community groups
- 14 people via phone through our signposting service
- 87 health and social care professionals through our staff survey, including follow-up interviews with 6 respondents.

Of those who responded to our surveys:

Who are you?					
Patient			**Unpaid carer**		
127			22		
When did you leave hospital?					
Before April 2023	**April-June 2023**	**July-September 2023**	**October – December 2023**	**January-March 2024**	**Since April 2024**
2 (14%)	15 (10%)	15 (10%)	24 (16%)	33 (22%)	59 (40%)

[16] Our Enter and View report on the Discharge Lounge at the John Radcliffe has been published separately on our website.

[17] We heard from another 6 people about experiences of being discharged from mental health inpatient settings, which is outside the scope of this report and which we will report on separately.

Which hospital did you stay in?					
John Radcliffe (JR)	**Churchill**	**Nuffield Orthopaedic (NOC)**	**Horton**	**Royal Berkshire (RBH)**	**Other**
74 (50%)	19 (13%)	10 (7%)	23 (15%)	12 (8%)	11 (7%)
Pathways home from hospital (inferred from responses)					
Pathway 0 (home without additional care and support)		Pathway 1 / Discharge to Assess D2A (home with additional care and support)		Pathway 2 (rehab in bedded setting e.g. care home or community hospital)	
115 (80%)		26 (18%)		3 (2%)	

Of the **patients and unpaid carers** we heard from, who told us about their gender, ethnicity, age and location:

- Most (77%, 96 out of 124 people) were women
- Most were White British (86%, 105 out of 122 people) or said they were from any other White background (8%, 10 out of 122 people). We heard from small numbers of people who are Arab, Chinese, Indian, Pakistani, another Asian ethnicity, or have a mixed ethnic background
- The biggest age groups were ages 65-79 (52 people, 43%), 80 or over (31 people, 26%, of whom two were unpaid carers, and at least 6 were aged 85 or over), and 50-64 (25 people, 20%). We heard from 12 people aged 25-49 (10%)
- People were fairly evenly distributed across Oxfordshire's five districts. The most common postcodes we heard from were in Banbury, Oxford, Wantage and Henley.

In the **survey for health and social care professionals**, we heard from a younger set of people: over half (48 people, 59%) of those who told us their age were 25-49. We still predominantly heard from White British people (62 people, 82%) but had responses from several people with Chinese, Indian, Pakistani, and Black African backgrounds. We heard from people working across the sector, including acute care, community care, primary care, social care, and home care providers. Community care (predominantly Oxford Health) was best represented, accounting for 68% of responses.

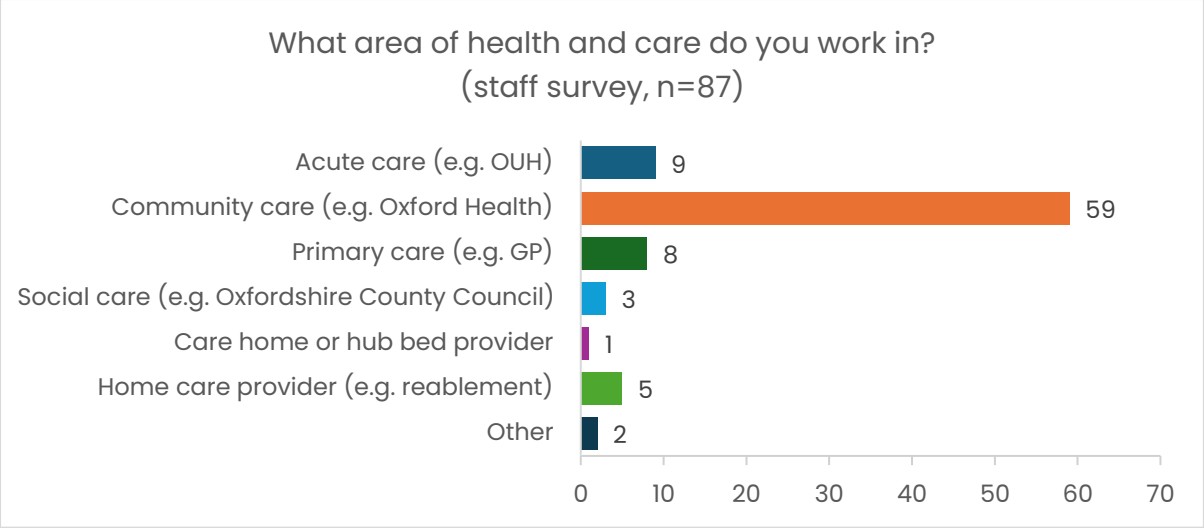

Figure 3. Graph showing breakdown of respondents to our survey for health and care professionals by area – including acute care, community care, primary care, social care and home care providers.

What's working well?

We heard that many people had positive experiences of part or all of the process of leaving hospital, particularly around:

- Good communication, being kept informed and up to date, and being given helpful advice
- Being listened to and involving unpaid carers
- Proactive and high-quality follow-up care and aftercare
- Support from charities and voluntary organisations
- Care and support at home for D2A patients, especially the friendliness and professionalism of carers and the coordination of care provision
- Being happy to be home.

Figure 4: What's working well?

Good communication and information

People told us they valued good communication from health and social care professionals about when they were going to leave hospital and what would happen next with their health and social care.

> *"Everything explained very well to me and my husband."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

We heard that people appreciated it when they were given relevant information and advice, especially when this was explained in person, and in an accessible, practical way.

> *"The Physio was the best explainer. She talked through not being able to drive for 6 weeks (that's so hard) and also talked through all the different physical challenges and how to solve them."* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

> *"I knew when I was due to leave, given useful advice about what to do and how to do it e.g. physio & medications."* (Pathway 0 patient, online survey, NOC, Jan-Mar 2024)

> *"A lady from the company the hospital arranged came to see me at home and was v helpful."* (D2A patient, online survey, NOC, Jan-Mar 2024)

> *"Following a total hip replacement, I was a little concerned about mobility - was greatly reassured by promise of physio and by clear instructions about exercise regime."* (Pathway 0 patient, online survey, NOC, since Apr 2024)

People also said it was helpful to be given information in different formats – like a letter as well as a conversation – and to be given contact information in case they had any questions or concerns after leaving hospital.

> *"I was given a lot of info about my condition, treatment, medication, what next. It was too much to remember. The letter of discharge was a great help, when I received it 2 weeks later."* (Pathway 0 patient, online survey, JR, since Apr 2024)

> *"I was given contact numbers in case I had any concerns."* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

Being listened to and involving unpaid carers
Several people told us they felt listened to and that their preferences around leaving hospital were heard and respected.

> *"My discharge from the John Radcliffe was excellent and all questions I had or worries were answered."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

> *"After one night in hospital I wanted to get home as my husband and I are unpaid carers for my [son]. A lady whose role I can't remember was very helpful in arranging all tests and scans I had to have before discharge very quickly."* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

We also heard positive comments about how health and social care professionals worked to make sure that unpaid carers were involved in decision-making and kept informed.

> *"My wife was kept informed at all stages."* (D2A patient, online survey, Oct-Dec 2023)

> *"There was the discharge coordinator on the ward most of the time who I could always talk to."* (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

Follow-up care and aftercare
People told us about good experiences of follow-up care from the hospital or their GP and highlighted how much they appreciated being contacted proactively by health and social care professionals.

> *"GP rang me after a day or so (when she had had the hospital letter) to check how I was and how it was going."* (Pathway 0 patient, online survey, Churchill, Oct-Dec 2023)

> *"My doctor returned my call quickly when I had concerns at home. Sorted me out!"* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

> *"I knew I could phone the ward with any problems or concerns. After a week I could phone my GP or 111."* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

"The Churchill Hospital have been superb in fixing problems post leaving the hospital." (Pathway 0 patient, online survey, JR and Churchill, since Apr 2024)

"Community physio and all absolutely amazing - all phoned every couple of days to ask me." (Pathway 0 patient, outreach survey, JR, before Apr 2023)

Support from charities

One person told us about the support they had had from a charity around managing a specific health condition:

"A terrific example of what I'm talking about is Headway. Where they have time. And my wife even said afterwards, Wasn't that a terrific experience? You can't buy that, you know, that's priceless. It's a woman who is a skilled practitioner, who knows what she's about, but has got time. And she's communicating and she looks optimistic as well. And that matters, believe you me, in all this, optimism." (Unpaid carer of D2A patient, interview, RBH, Jan-Mar 2024)

Care and support at home

People shared positive experiences of different aspects of their care, including the coordination of the care, the promptness with which the care started after getting home, the friendliness and professionalism of carers and the quality of the care itself.

"The social worker who arranged my care was excellent. She was based at the JR. The social worker made sure that I had adequate care and that it continued until I could manage independently." (D2A patient, online survey, NOC, Jan-Mar 2024)

"I had to wait for care to be arranged because I live on my own. Because of this, I was in hospital longer than was necessary and there was a weekend in between. But once the care was arranged, it was brilliant. I had hospital transport home, and the care agency lady came to see me about two hours after I'd returned home, and she informed me about the care package." (D2A patient, interview, NOC, Jan-Mar 2024)

"Excellent care from a care agency." (D2A patient, online survey, JR, Jul-Sept 2023)

"The care providers were all extremely caring and professional." (D2A patient, online survey, JR, Oct-Dec 2023)

"I was pleased to have the care package, and even more so when I was able to tell the social worker that I no longer needed them!" (D2A patient, online survey, NOC, Jan-Mar 2024)

"The carers first time around [March 2024] different carers and times very variable, which older people find difficult to deal with. The second time [May 2024] much improved continuity of carers and timing very good. Overall very impressed with overall care and support given." (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

"I was supposed to go to a community hospital - but wanted to go home even though they wanted me to go to Bicester to continue rehab - but none of my family drive and I would be isolated up there so that made me say no and go home. OT assessment (OCC) and now have physio and have request for walk in shower alterations. Normally 3 week wait but had assessment very quickly. Everything worked well, it was non-stop care, didn't have to wait at all, happened all at once." (D2A patient, outreach survey, JR, since Apr 2024)

"Very good carers - reliable and trustworthy." (D2A patient, outreach survey, JR, since Apr 2024)

"All the girls that come to see me are all nice, friendly girls, so I'm quite happy with those." (D2A patient, interview, JR, since Apr 2024)

One person also noted how health and social care professionals had worked together to help her achieve her goals, reflecting a good example of person-centred care:

"The community people found out what was happening and brought me a wheelchair and a mattress – I'd never had a mattress like that before, I didn't sleep very well the first night but it's lovely now. They asked me what I'd like to do, and I said I'd like to get out, because I hadn't been out for six months, so they got me a wheelchair and I go out once a week, I go to the market, and it's been lovely." (D2A patient, interview, JR, since Apr 2024)

Happy to be home

People overwhelmingly said that they felt safe and happy to be home. 16 people, 84% of respondents to the online survey who got additional care and support at

home, said they agreed or strongly agreed to the statement 'I felt happy to be home'. People told us about the difference being home made to their recovery.

> *"I felt better with my home comforts, my daughters helped with my meals and showers."* (Pathway 0 patient, online survey, RBH, Apr-Jun 2023)

> *"Pleased to recover and be back at home with my family."* (Pathway 0 patient, online survey, Churchill, Jul-Sept 2023)

What could be better?

We also heard about things that were not working so well or could be better at each stage of going home from hospital. These included:

- Room for improvement in people's experience of **discharge planning**, such as people not feeling involved in decisions about their discharge, not being kept informed, and delays to being discharged
- Problems experienced on the **day of discharge**, including people being discharged before they felt ready, delays with medication, paperwork or transport on the day of discharge, a lack of information about what would happen next or where to get help, problems with medication and with patient transport, and being discharged late in the evening or at times that did not work for patients or unpaid carers
- Gaps around **follow-up care**, including people not knowing who to contact or who would provide aftercare, challenges accessing aftercare from acute hospitals, GPs or District Nurses, a lack of follow-up from health services, difficulty accessing support from charities, delays to getting physiotherapy and equipment, and people not being offered or getting additional care and support at home despite feeling they need it.
- Gaps and challenges around **home care for people on the D2A pathway**, including delays in receiving care, problems with routine and timings of care visits, problems with the quality of care received, care not being tailored to patients' needs, a lack of information about social care provision, delays and confusion around getting physiotherapy and occupational therapy assessments.

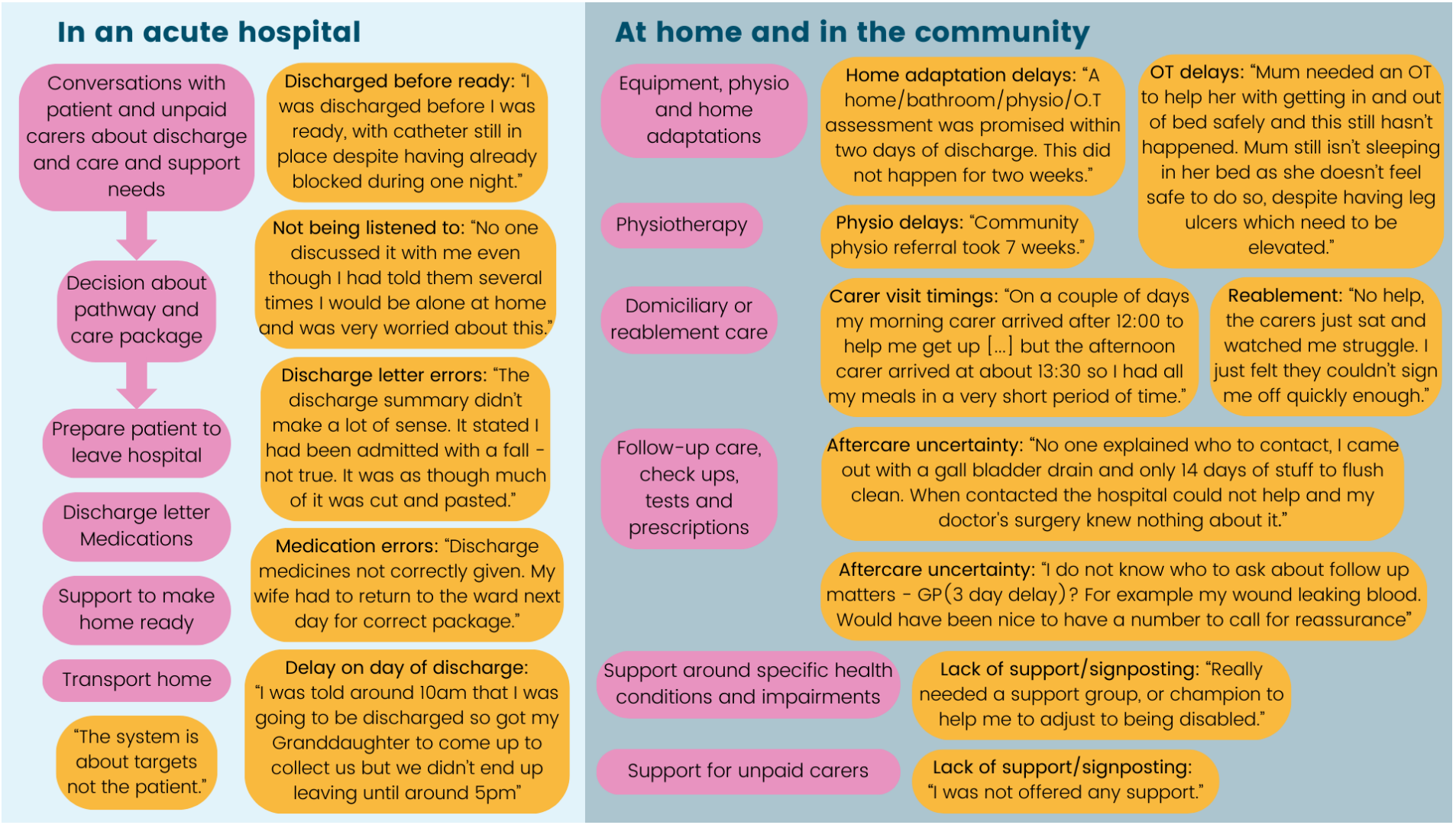

Figure 5: What could be better?

What we heard suggests that there is a **lack of consistency** in people's experiences of discharge and D2A – when everything comes together it works well, but gaps in communication and care provision mean that not everyone is having a good experience.

Preparing to leave hospital

Conversations about discharge

We asked people to tell us about the conversations they had with health or social care professionals about leaving hospital. Most people (17 out of 24, 71%) who responded to our outreach survey said they agreed or strongly agreed that staff had involved them and their carers in decision-making about leaving hospital and getting care and support afterwards.

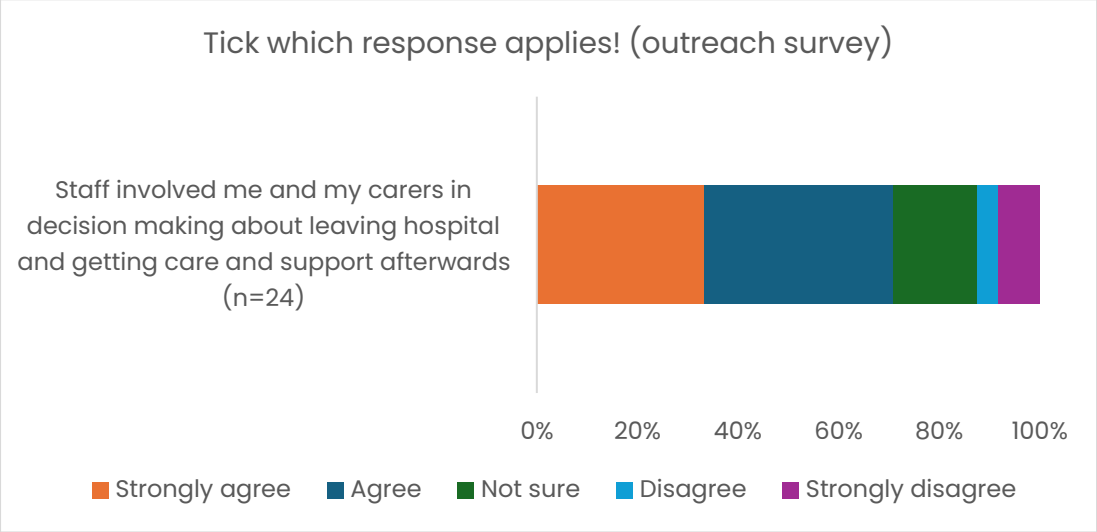

Figure 6: Graph showing responses to our outreach survey question about whether staff involved the patient and their carers in decision-making about leaving hospital and getting care and support afterwards.

In our online survey, a narrow majority of people gave positive responses (agree or strongly agree) to statements about conversations with health professionals about leaving hospital, but there was also a significant proportion who gave negative responses – particularly to statements about involving family or carers in decisions (47 people out of 102, 46% said 'disagree or strongly disagree'), whether health or social care professionals had explained what would happen after the person left hospital (46 people out of 108, 43%), and who to contact if they had any problems after leaving hospital (41 people out of 118, 35%).

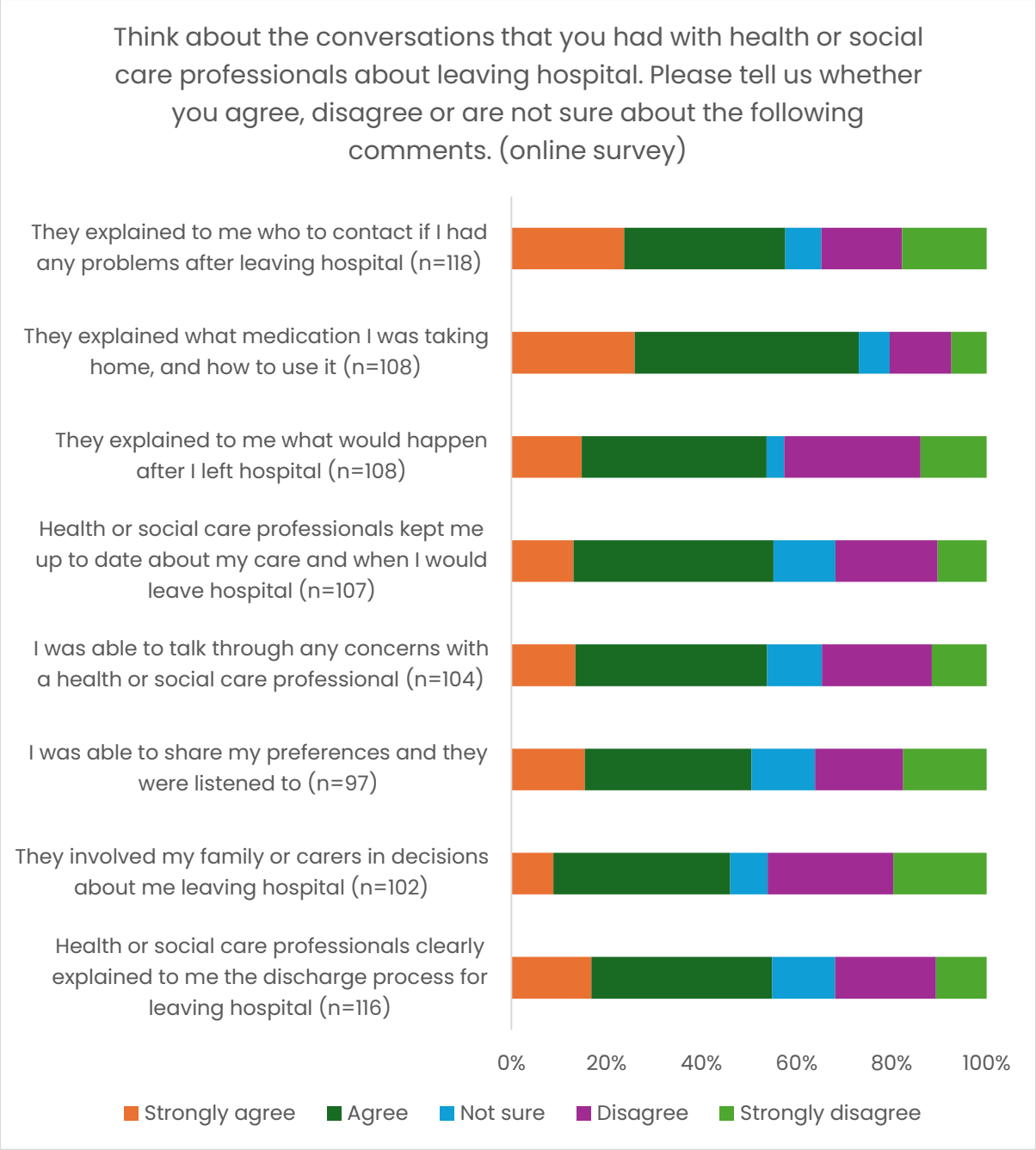

Figure 7: Graph showing responses to online survey questions about conversations with health and social care professionals after leaving hospital.

Things that made conversations about discharge unsatisfactory ranged from a lack of suitable spaces to have these conversations, **to people not feeling listened to** or feeling their circumstances or preferences were ignored.

> *"Discharge discussions took place in a very busy corridor."* (Pathway 0 patient, online survey, RBH, since Apr 2024)

"None whatsoever. Was told the hospital was full." (Patient discharged from emergency department, online survey, JR, since Apr 24)

"It was never fully explained to me what help could be made available." (Pathway 0 patient, online survey, NOC, Oct-Dec 2023)

"[Staff] don't bother to read written instructions from other departments; I kept on telling them I was supposed to see certain people to be checked out before discharge, but they don't listen to patients. As a consequence, it must have cost a lot of money to have to send a car to bring me back in the next day." (Signposting email about discharge from the JR, May 2024)

"The pre-op nurse has told me that I will need a person to drive me home after the surgery and someone to supervise me for 24 hours after the surgery at home. When I told her my neighbour is going to do it, she said it cannot be my neighbour. This was before asking me if my neighbour was a close friend or if she was going to stay in my house or hers. She said if I do not find someone else, they could cancel the surgery." (Signposting call about the JR, April 2024)

One person also told us they were concerned that discharge **decisions were made without a proper assessment of their home situation**.

"There was no, or seemingly no assessment of me, my capability, our home for safety and so on. Nobody ever mentioned any of those things. So [my wife] could have been exiting to a very unsafe house." (Unpaid carer of D2A patient, interview, RBH, Jan-Mar 2024)

We heard from several people who said they felt they were **not listened to when they expressed concerns about going home without any additional care** and support.

"No one discussed it with me even though I had told them several times I would be alone at home and was very worried about this. No one cared once they had discharged you." (Patient, online survey, JR, Jan-Mar 2024) – this person said they paid for a private post-operative care bed because they could not be looked after at home.

"I am frail [and] vulnerable. No one listened or was concerned about not being able to look after myself. I was in a great deal of pain still got discharged. No care until ambulance called via my alarm two days later

cos I couldn't breathe, diagnosed with pneumonia." (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

"My partner was having cancer care and he shouldn't have been looking after me, and I told the hospital this but no one listened and no one cared!" (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

We heard that **unpaid carers were not always included**, or did not always feel listened to, in conversations about leaving hospital and care and support afterwards, including in situations where the patient was very elderly, or unable to retain information, or was struggling to make those decisions themselves – so involving unpaid carers would better support the patient.

"My mother is elderly and a little confused, I asked several times to be involved and informed instead she was the only person involved and also signed a DNR she didn't understand and has since ripped up still not understanding it's on a computer now! I specifically asked her nurse for 24 hours to find another home [nearer family], but hospital went ahead and discharged her anyway." (Unpaid carer of Pathway 2 patient, online survey, JR, Oct-Dec 2023)

"Only my mother was involved in discussions - and she was still in a poor mental state following a serious, and unexpected, operation." (Unpaid carer of D2A patient, online survey, JR, Oct-Dec 2023)

"Carers should be allowed in with their partner, especially if partner is non verbal, so that they can explain things to the nurses and provide reassurance to their partner and make sure they are comfortable. Nurses should discuss patient's needs with family carer as they are best placed to give them the information they need re positioning, continence, diet, comfort generally. Carers should be kept informed and updated re discharge as they need to be sure they have adequate supplies of essentials (pads, medication) and because they have responsibilities at home. They shouldn't just be abandoned." (Unpaid carer of Pathway 0 patient, online survey Horton, since April 2024)

"I was not listened to about discharge risks and was in fact told 'if you're so worried you can stay with her overnight'. No one had asked if that was even possible. It was a highly stressful few days chasing up referrals and trying to ensure Mum took her medication. I missed work and had to get childcare." (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

One person told us that health and social care professionals had **not made reasonable adjustments** to ensure good communication with unpaid carers (this is discussed in more detail under Communication below).

> *"There wasn't always a consideration for the issues of whom they were speaking to be that the patient or the carer. Even the carer has issues with hearing and mobility so the whole picture needs to be considered. […] It's difficult combination of the patient not having good recall due to cognition issues, a mother that cares for him that has hearing issues and uses an aid and a sister that can only be there as soon as work and family allow to pick through the details from the other two and then realise that not all the facts were heard or understood and so to gather a nurse or doctor again to get some sense of the full picture, which from the health care professional's point of view believe they have already communicated to the patient a their carer!"* (Unpaid carer of Pathway 0 patient, RBH, Jan-Mar 2024)

Contradictions and differences between expectations and reality

We heard that sometimes **people were told they could expect one thing, but then something different actually happened**. This could cause uncertainty and dissatisfaction. Sometimes this highlighted inconsistencies in communication between professionals or departments, as well as in communication with patients.

> *"I had a major operation and expected to stay in hospital for at least 2/3 days. I was asked to give up my bed, which I was happy to do, and went home less than 24 hrs after the surgery. I literally went from morphine to paracetamol."* (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

> *"Dr said happy to discharge me but I was able to stay another night if I was happier doing that - I agreed. Nurses discharged me that day anyway."* (Pathway 0 patient, online survey, JR, since Apr 2024)

> *"Theoretically, someone did explain most steps to me, but the reality was very different. I kept on being told what should happen, but had no way of checking up on what was happening."* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

> *"I felt communication was poor between nursing staff and patient. Doctor was clear as to when I could leave but then followed many hours of no communication between patient and nursing staff."* (Pathway 0 patient, online survey, Churchill, since April 24)

Delays to discharge

We heard from several D2A patients that after they were medically ready to go home, there were **delays while a package of care was put together**.

> *"I stayed in hospital longer than I needed to because they wouldn't let me go home without a carer. I was ready to go home after about 5 days but I was in there about 9."* (D2A patient, interview, JR, since Apr 2024)

The day of discharge

Being discharged before being ready

We heard from several people who felt they had been **discharged before they were ready**. Readiness meant different things to different people, including feeling like they did not get enough notice that they or the person they look after were going to be discharged, or feeling they were rushed out of the ward without time to pack their belongings or get themselves ready.

> *"My wife had little time to get my bed ready as she had an appointment that day."* (D2A patient, online survey, JR, Oct-Dec 2023)

Three others told us they had been **discharged despite feeling that they still required acute hospital care**, meaning that they had to return to hospital.

> *"I was discharged before I was ready, with catheter still in place despite having already blocked during one night."* (Patient, online survey, JR, Oct-Dec 2023)

> *"I had an infection which wasn't picked up and had another 3 1/2 weeks back in hospital."* (D2A patient, online survey, NOC, Jan-March 2024)

> *"I was sent home without seeing a certain doctor, although it was written in my notes. I was then phoned and told I would have to return to the JR at 7.30am the next morning."* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

Delays on the day

People told us about delays on the day they were discharged, between being told they would be leaving (and often being asked to leave the ward) and actually leaving the hospital. For most people, this was due to waiting for paperwork, medications, transport, or a combination.

> *"The discharge process took a long time. I was told mid-morning that I would be going home but didn't go to the "departure lounge" till late afternoon and was there for two hours waiting for my medication."* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

> *"Was taken from the ward around lunch time and taken to a discharge bay - where we had to sit and wait for hours for everything to be sorted. I was told around 10am that I was going to be discharged so got my Granddaughter to come up to collect us, but we didn't end up leaving until around 5pm."* (Pathway 0 patient, online survey, JR, April-June 2023)

> *"Having to wait until 8-9pm for medication when I'm due to be discharged at 12pm after the ward round!"* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

We heard that people would have liked **more communication about what was happening** while they were waiting.

> *"Nurses could have been more communicative. E.g. 'we now have your meds but are still waiting for blood test results.' Had we not asked at 7pm and requested an update, not sure what would have happened. As it was, I got home after 10pm."* (Pathway 0 patient, online survey, Churchill, since Apr 2024)

> *"We were misinformed and led to believe that we were going home in the early hours when this could not have been the case as patient transport do not operate in the early hours. […] There seemed to be no contact between the doctor who assessed my partner and the nurses arranging patient transport. We were left for hours not knowing what was happening and if we would get home that night. It was very distressing."* (Unpaid carer of Pathway 0 patient, online survey, Horton, since Apr 2024)

We also heard that for some people, a lack of hospital capacity and focus on clearing beds made them feel like **care was less centred around patients**. One person also noted the impact of industrial action on hospital capacity.

> *"I felt that the left hand did not know what the right hand was doing and the staff just wanted to get rid of me."* (Pathway 0 patient, online survey, RBH, since Apr 2024)

> *"The system is about targets not the patient."* (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

"In short stay ward, they were desperately short of staff and extremely busy. Their mission was to discharge patients as quickly as possible which was not compatible with my operation." (Pathway 0 patient, online survey, NOC, Oct-Dec 2023)

Information about what would happen next

People told us they would have liked to have **more information about what would happen next** with their healthcare, how to manage their condition or medical appliances, and where they should go for support.

[What could have been better?] "Given care plan and conversation explaining what to expect re: Hemovac [drain]. I had to google it to find out what it was." (D2A patient, Churchill, Jul-Sept 2023)

[What could have been better?] "Someone taking the trouble to explain what would happen with future appointments and what would happen." (Pathway 0 patient, online survey, RBH, since Apr 2024)

[What could have been better?] "Provision of central phone no. to ring if any problems or queries would have given me more confidence when at home." (Pathway 0 patient, online survey, JR, since Apr 2024)

"Until I asked, I was not provided with a sling for my arm. I had no advice about pain relief, and none was provided [which was OK, I had some at home]. The nurse gave me no advice about what to do when I got home, and what to expect. I was not given any advice about how to get in touch if I had a problem. I was surprised not to be given a leaflet with some basic information about self-care after my operation - for example what to do about showering/bathing with my arm in a full bandage." (Pathway 0 patient, online survey, JR, since Apr 2024)

"I wasn't informed of services I was entitled to (PIP, volunteer drivers, blue badge etc)." (Pathway 0 patient, online survey, Churchill, Jul-Sept 2023)

Medications

We heard about **problems with getting medications to take home** from hospital, including errors.

"Discharge medicines not correctly given. My wife had to return to the ward next day for correct package." (Pathway 0 patient, online survey, RBH, Jan-Mar 2024)

> *"My medications were a mess. I was taking 8 paracetamol a day but discharged without any. I weaned off [medication] but was given a full box of 60 and only used about 10. It was really unclear what I was meant to be taking as some medications were missing. My daughter managed to figure it out and write me a chart."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

What people told us about problems and delays with medication echoed what Healthwatch Oxfordshire heard in a previous project, Leaving hospitals with medicine, in January 2023.

Transport

People also told us about problems with **patient transport**, including delays.

> *"The transport arrived with the wrong equipment, so I had to wait (up to 48 hours!) to get the correct transport."* (D2A patient, online survey, Horton, since Apr 2024)

> *"The actual discharge from the John Radcliffe to Abingdon Hospital was a nightmare. Waiting for transport from mid-morning eventually left in the evening. Wintertime, it was dark. This completely disorientated my Mum on arrival to Abingdon hospital and took her nearly a week to settle again."* (Unpaid carer of Pathway 2 patient, online survey, JR, Jan-Mar 2024)

> *"I waited a long time for transport with was stressful for me."* (Pathway 0 patient, outreach survey, Horton, since Apr 2024).

We also heard from staff working in acute care that a lack of patient transport availability is contributing to delays in people leaving hospital.

Timing of discharge

We heard from several people who had been **discharged at night**, which affected their access to medications or was a source of stress.

> *"Meds were not available as late discharge."* (Pathway 0 patient, online survey, Horton, Jan-Mar 2024)

> *"I was discharged from A&E at 3am, they sent me up to the main entrance to book a taxi. I got home and couldn't wake my husband and I had no cash on me, fortunately I had a back door key so I was able to get in and*

find money to pay the taxi that way." (Comment from Carers Oxfordshire coffee morning, August 2024)

People told us they found the **information in discharge letters confusing, and sometimes inaccurate and incomplete**, with implications for joined-up care, including between secondary and primary care.

> *"Discharge letters don't tell the story or connect the dots. From reading discharge letters my GP was completely unaware that one surgeon had started surgery and then had to call a different surgeon as the thought of my issue was not the case. What actually happened made a difference due to the length of time I was left. There needs to be some narrative around what actually occurred."* (Pathway 0 patient, online survey, JR, since Apr 2024)

> *"The discharge summary didn't make a lot of sense. It stated I had been admitted with a fall - not true. It was as though much of it was cut and pasted. I had a very large brain tumour removed, but the discharge summary stated I could return to work in 6 weeks and fly! Whereas I was told I would take 6-12 months to recover."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

> *"The operation was carried out Feb 23. They noticed a brain tumour and did not tell me. [This year] another scan was done I was notified that I had a brain tumour for the past two years."* (Pathway 0 patient, outreach survey, Churchill, Jan-Mar 2024)

> *"There is a lot of information from a stay in hospital. It would have been great to have a summary of what happened and the follow up action and signposts for information to take away with us, not to be emailed later or for two or three different teams to contact us at random, unexpected times on a landline and then a mobile and then email. Having someone with long term health issues is difficult enough without having to manage all the different inputs from different parts of the NHS and hospital."* (Unpaid carer of Pathway 0 patient, online survey, RBH, Jan-Mar 2024)

Follow-up care

For Pathway 0 patients who shared their experiences with us, one of the most common issues was around **a lack of follow-up care or aftercare** from primary care, community services or hospital outpatient care, after leaving hospital. This is likely a reflection of the fact that people are being discharged from hospital into a stretched system, where there are already capacity challenges for example, long

waits for appointments with GPs and for referrals. It some cases, it also seems to be linked to barriers to communication and joined-up working, discussed in more detail in Joined up working below.

Who to contact

People told us they were not always sure about who to contact after leaving hospital, if they had any questions or concerns.

> *"I do not know who to ask about follow up matters – GP (3 day delay)? For example my wound leaking blood. Would have been nice to have a number to call for reassurance."* (Patient, online survey, RBH, since Apr 2024)

We heard that people were **not always sure about would provide aftercare**, for example changing wound dressings, catheters). In some cases people just did not know, or in others they got **mixed messages from health and social care professionals or were signposted to or fell between multiple services**. This meant that some people felt unsupported and uncertain in after care.

> *"[I] came out with a temporary catheter that needed to be removed at a specialist clinic called Trial Without Catheter Clinic (TWOC). However the TWOC is run by Urology, and since their staff did not put the catheter in, they were not going to be responsible for removing it at a TWOC Clinic. Alternative arrangement was that the District Nurses would remove the catheter, but they were unable to remove it on time, or even tell me when they could come to remove it. Leaving a catheter in the bladder longer than necessary increases clinical risk considerably. The outcome was that I removed it myself."* (Patient, online survey, Churchill, since Apr 24)

> *"My husband had a serious pressure sore on his heel and who would provide aftercare and treatment was very unclear. […] We were bandied around between GP practice, district nurses, diabetic clinic and podiatry department."* (Unpaid carer of Pathway 0 patient, online survey, NOC, since Apr 24)

> *"No one explained who to contact, I came out with a gall bladder drain and only 14 days of stuff to flush clean. When contacted the hospital could not help and my doctor's surgery knew nothing about it."* (Patient, online survey, RBH, since Apr 2024)

Difficulty accessing aftercare from acute hospitals

People told us about challenges getting aftercare from outpatient care services – including **not being given care, transport issues** and **long waits** for appointments.

> *"Was told to go back and get blood thinning injections and be shown how to use them. Rude nurse refused to do so."* (Patient, online survey, Churchill, Oct-Dec 2023)

> *"When teams expect you to come back every other day for continued tests but now have to pay for public transport and have no one accompanying you due to short notice - poor planning."* (Patient, online survey, JR, Jan-Mar 2024)

> *"Very little help!! I was told to go home and book an appointment. I got an appointment six weeks after I was discharged."* (Pathway 0 patient, outreach survey, JR, Oct-Dec 2023)

> *"I had a bilateral mastectomy [last year]. The actual surgery went well, but there was zero aftercare. Oh, I had multiple hospital appointments, which were never on time. I had to travel a relatively short distance, 25 miles each way, but the traffic and parking meant 1.5 hours travel time, so effectively half a day each time. All I ever got told was 'it's normal' or 'everyone is different'. No constructive help with seroma, iron bra syndrome, or scar management. Every bit of help I got was paid for by me or from charities."* (Signposting call, April 2023)

Coordination of **cross boundary support** was also noted. We heard from one person from out of county who had trouble getting outpatient support from their local hospital due to communication issues with OUH.

> *"Was discharged and told to contact [my local hospital] if I had any issues - when I did contact them they hadn't received any of my notes nor had my GP. Then had to spend time co-ordinating with JR and GP and [local hospital]."* (Pathway 0 patient, online survey, JR, Apr-Jun 2023)

Difficulty accessing aftercare from GPs

People told us about problems **contacting and making appointments with their GP practice** after they left hospital. Examples included for wound dressing, as well as transport issues getting to the GP.

"I needed to change my bandage, called the doctor's surgery. The nurse was not available, when I needed the dressings changed. Called the hospital, they told me that they could not change my dressing. I then tried and tried my surgery, eventually, they accepted me, but the nurse was not dealing with me appropriately." (Patient, online survey, NOC, Jan-Mar 2024)

"Getting to see my GP is impossible and they are my medical link when at home." (Patient, online survey, JR, Jan-Mar 2024)

"I needed to use taxis for the first couple of weeks, to get to the GP and pharmacy. I can afford this but the cost could be difficult for less fortunate people." (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

Difficulty accessing aftercare from District Nurses

We also heard about challenges getting aftercare – mostly with wound dressings – from the District Nursing teams (part of community care services provided by Oxford Health[18]). This highlighted some of the system communication pressures between secondary and primary care. Again, some people were given **contradictory information** about who could treat them and where.

"Very hard to get a district nurse which I was told had been organised so called 111 to get the district nurse to attend." (D2A patient, online survey, Horton, since Apr 24)

"Initially a lady came to dress pressure sore, dressing was not large enough so left uncovered, she said as dad was mobile in wheelchair he needs to attend clinic at GP for further dressings, Dad explained they change his catheter at home as he can't use their trolleys. She insisted, two days later he attends and they are unable to treat him there and a DN referral is requested. He then has to wait till they're able to visit." (Unpaid carer of D2A patient, online survey, Horton, since Apr 24)

"Was told district nurse would come but didn't. 1st time was told 'you are mobile so come to the surgery'. I wasn't and had to borrow a wheel chair so daughter could bring me. 2nd time district nurse came 2 days after I was told to expect her. Needed dressing changed every day but my surgery couldn't fit me in for 12 days. Had to do it myself which was v difficult as I couldn't see what I was doing and the wound in my thighs was v big." (D2A patient, online survey, NOC, Jan-Mar 2024)

[18] https://www.oxfordhealth.nhs.uk/wp-content/uploads/2020/03/OH-147.20-District-Nurse.pdf

Lack of follow-up

People told us about **a lack of follow-up** from health and care services – both in terms of appointments or calls they had been told to expect, and in terms of a courtesy check-in from health and care services for reassurance, particularly when no other follow-up or support had been arranged.

> *"They said I would have follow up in 6 months and may be physio but I never heard anything at all ever."* (Patient, online survey, JR, July-Sept 2023)

> *"No contact was made from either the hospital or the GP. I was in shock from the surgery and could have done with some support even if by phone. I had lost a kidney but had no aftercare on diet and GP finally referred me to a dietician which has not yet taken place."* (Patient, online survey, Churchill, Jan-Mar 2024)

> *"Although discharging nurse very helpful, no support offered or received from hospital or GP once at home. Left feeling "exposed" if any problems."* (Patient, online survey, JR, since April 2024)

Difficulty accessing support from charities and support groups

People also told us about **gaps in terms of support from charities and support groups** – which may reflect a lack of information and signposting as well as limited capacity.

> *"No after care or support other than being able to contact Macmillan if needed. That involved leaving a message and waiting for call back which didn't always happen."* (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

> *"Really needed a support group, or champion to help me to adjust to being disabled."* (Pathway 0 patient, online survey, Churchill, Jul-Sept 2023)

Physiotherapy and equipment for Pathway 0 patients

People who went home on Pathway 0 told us about **waiting days or weeks to receive physiotherapy, equipment and home adaptations**, or both.

> *"I asked my GP to refer me to OT, but it took them almost two months to contact me."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

> *"Community physio referral took seven weeks. I didn't have any rails, or all appropriate equipment that I needed as a newly disabled person."* (Pathway 0 patient, online survey, Churchill, Jul-Sept 2023)

In some cases, this led to **additional pressures on unpaid carers**, including children, to ensure that the person could safely move around their home.

> *"The only help I had was my 10-year-old daughter. I had no equipment, no help and no care. I was non weight bearing with a broken leg. I was unable to get upstairs. Was discharged home with no commode or frame to help. My daughter had to get me a saucepan to use as a toilet. The hospital should have checked who I was living with and help with basic equipment such as a commode. I eventually referred myself to the community therapy team in Oxford Health, who after 5 days at home, came with a commode and a frame."* (Pathway 0 patient, online survey, Horton, since Apr 2024)

> *"My wife has MS and balance problems. They wouldn't let her out [of hospital] until they knew what she had at home. I had two calls from the physios and she was grilled in hospital. I'm a practical person, so I put up rails and parallel bars and so on around the house. The community therapy service visited today and there'll be a follow up visit with the manager in a week. Two and a half weeks had gone by and I said to my wife "we won't hear anything now", and then we had a call from them."* (Comment from Carers Oxfordshire coffee morning, August 2024)

Not getting care and support at home

We heard from at least nine patients who were discharged on Pathway 0 but **felt they would have benefited from additional care** and support at home.

> *"I was fine about leaving hospital, but care once home was non-existent and I had to phone ambulance and two trips to A&E after which was horrendous after an operation to sit and wait for hours to be seen. Very little support and it was scary."* (Pathway 0 patient, online survey, RBH, Apr-Jun 2023)

> *"What I was promised as going to happen "when you get home" hardly happened. I was left with very limited eyesight, after picking up a hospital acquired infection. I am still unable to cook a meal, and haven't been able to afford a carer come in - so haven't had a hot meal for the past 10 months. As for help in getting mobility back - forget it."* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

"My husband was at home and has mobility issues. I was not offered any other care but friends and family kept in touch with me." (Pathway 0 patient, outreach survey, Horton, Oct-Dec 2023)

"I have very limited mobility and the hospital could have offered me help. They just don't care! When you are old it is really hard when no one cares for you." (Pathway 0 patient, outreach survey, Cherwell Hospital, Oct-Dec 2023)

"I am 74 years old and live alone. I could not even sit up in bed. My son was at the house overnight and helped me climb the stairs. I've not had any home care offered and physio was just once." (Signposting call about discharge from Cherwell Hospital, July 2024)

"The pre-op team said I could stay in for a few days after my hysterectomy because I had no help at home. The post-op surgical team sent me home the day after my operation even though they knew I had no help. Pre and post op should have a joined-up plan. Vulnerable patients should not be discharged." (Feedback received by Healthwatch Oxfordshire at Didcot Play Day on 22nd June 2024)

"There's such a difference between discharge for day surgery and staying in hospital as a trauma patient. After day surgery I had no help at all, and I mismanaged my medication and ended up back in hospital again. Recovering means you have to look after yourself but I couldn't look after myself because I was running round caring for people. Then I broke my hip and I got such amazing care afterwards, carers twice a day and physio at the end." (Comment from Carers Oxfordshire coffee morning, August 2024)

"I would not have recovered so well if I had not paid for care, if I had gone home and something had gone wrong I would not have been able to access help. I would also have gone hungry as I did not have the energy to care for myself." (Pathway 0 patient who paid for a private rehab bed, online survey, JR, Jan-Mar 2024)

Care and support at home – D2A pathway

Many of the people we heard from who went home under D2A, or are the unpaid carer of someone who did, were generally positive about the care and support they got within this pathway. However, there were several recurring areas for improvement, mostly around the timing of when they got care and support, and communication about it.

Delays in receiving care

People told us about **delays in receiving care** after getting home. This included **differences between what they had been told to expect and what actually happened**.

> *"Initially the carer only did an assessment and the caring started 36 hours later. I had been informed that the carer would have been at my home three hours after leaving hospital."* (D2A patient, online survey, Horton, since Apr 2024)

> *"None, relied on family to help. After a week care was offered but it was too late and family had a plan in place."* (D2A patient, outreach survey, Horton, since Apr 2023)

One person also told us about a **gap between reablement care and long-term care** while a care plan was put in place.

> *"Hospital staff were very keen to free up the bed. They did their best. Lack of resources at the end of the post-op care meant the gap in care was six-eight weeks. The burden fell on my husband. The delay in obtaining a care plan in place was extremely stressful."* (D2A patient, outreach survey, Horton, Apr-Jun 2023)

Routine and timings

One of the most common negative comments about care was around the **timing of visits from carers** from home care providers. Patients are usually allocated a **four-hour time window** for each visit. This can make care **unpredictable, disrupt people's routines, is not always patient centred**, and can **increase pressure on unpaid carers**, including them taking on more of a caring role in order to maintain the person's routine.

> *"I was initially given home care twice a day, they were lovely, but they tried to put me to bed at 3pm. The second time I was discharged I opted to go without home care and accept friends and family support."* (D2A patient, online survey, Churchill, Jul-Sept 2023)

> *"They were v helpful but I never knew when they would arrive."* (D2A patient, online survey, NOC, Jan-Mar 2024)

"When carers did come you could not choose a time. So I had to get up at 10am and back in bed at 7pm." (D2A patient, outreach survey, Horton, since Apr 2024)

"I was told by the agency my care was erratic because I was not paying for it, so carers came at very different times. Sometimes 7am and sometimes 11am to get me up. The same thing happened in the evening 5 pm to go to bed or maybe 10pm or any time in between. A more regular time frame would have been better." (D2A patient, online survey, JR and NOC, Jan-Mar 2024)

"On a couple of days my morning carer arrived after 12:00 to help me get up, have a cup of tea and breakfast but the afternoon carer arrived at about 13:30 so I had all my meals in a very short period of time." (D2A patient, online survey, JR, Oct-Dec 2023)

"It would be good if the carer could ring the person they're coming to and let them know they're on their way, so you're not waiting around. That would be a sensible thing. Because not knowing when someone's going to come through your door, it's just…" (D2A patient, interview, JR, since Apr 2024)

"Timing of visits did not work well. [My mother] would have benefited from less visits if she had been given a smaller window of when to expect carers." (Unpaid carer of Pathway 2 patient, online survey, JR, Oct-Dec 2023)

Experience and quality of care

We also heard comments about people's experience of care. As well as the positive comments included in What's working well? above, people told us that care visits were sometimes **rushed or too short** to help the person reach their reablement goals. They also told us about challenges around **carers' lack of experience, cultural and language barriers,** and **perceived rudeness** or inappropriate behaviour.

"The carers were lovely but rushed and some were inexperienced with British food which made getting my lunch and dinner a bit hit and miss depending on who it was." (D2A patient, online survey, JR and NOC, Jan-Mar 2024)

"There wasn't much conversation with the carers but they may have had limited English and were pushed for time." (D2A patient, online survey, NOC, Jan-Mar 2024)

"My mother found it hard to understand some of the carers and thinks they probably felt the same of her." (Unpaid carer of Pathway 2 and D2A patient, online survey, JR, Oct-Dec 2023)

"Nothing really worked well and I had been told they couldn't cook for me without a microwave. Made me feel I had done something wrong because they couldn't help me - stressful." (D2A patient, outreach survey, JR and Churchill, Apr-Jun 2023)

"I've seen people coming out of hospital and there are these young people coming in to help them who have no experience and no manners." (Comment from BAME elders' group)

"We didn't get any say about the care provider and I see that they have a CQC rating of 'needs improvement'. We have had carers playing explicit songs and wearing outside coats while they are helping my mum, and not noticing that she has wee on her nightie." (Signposting call, April 2024)

"I think the biggest difficulties I had with the care company was that I never really knew who was coming. I also never really knew exactly when they were coming. For a few of them, English was at best their second language, might even have been the third language. I didn't have any problems with them personally, but the level of basic care was just that, basic, but the communication was a considerable problem. It was difficult to communicate quite a lot of the time and led to misunderstandings." (D2A patient, interview, JR, Oct-Dec 2023)

We heard from a health and social care professional about a patient who was **readmitted to hospital** because he did not seem to be getting the care he needed.

"Poor quality [package of care], we had a [patient] who was readmitted after falling when trying to get out of the chair he had been sat in for several days after going home." (Acute staff, online survey)

We heard from someone who found **having carers in their home** difficult, and from an unpaid carer who noted the impact of a **lack of continuity of carers** on their own wellbeing as well as the person they look after.

"Not easy - support in home where usually in charge." (D2A patient, online survey, Churchill, Jul-Sept 2023)

"We had – I counted in my head – for a period of three weeks, 22 different carers. Every time somebody new came round, I got a knot in my stomach, because I had to show them how the microwave worked, and I'd have to show them where everything was and explain M's situation. What would happen would be, some of them would be really good and they really engaged with M, but they were meeting him for the first, second or third time. The others were just disengaged." (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

Care tailored to patient's needs

We heard about delays and challenges around getting **carers who could meet specific patients' needs**, including having female carers to assist women with personal hygiene.

"I could have left hospital earlier if a care provider who could do my neck brace was available." (D2A patient, outreach survey, JR, since Apr 2024)

"My elderly mother would have appreciated female carers to help with her hygiene needs. She saw females on a very few visits so did not get the appropriate help and support she needed. Timing of visits did not work well. She would have benefited from less visits if she had been given a smaller window of when to expect carers." (Unpaid carer of Pathway 2 and D2A patient, online survey, JR, Oct-Dec 2023)

"I, in exasperation, phoned [the care provider] and said, 'Enough is enough, just out of ten days of care, six days have been with a lady and was satisfactory, three days were men who I had turned away and the last day was a no show.' And quite honestly, I didn't know where I was, and my wife certainly didn't know where she was. So that was that, end of the care, we're now on our own." (Unpaid carer of D2A patient, RBH, interview, Jan-Mar 2024)

We heard from an unpaid carer and a community care professional about concerns about whether some D2A care providers are able to offer **adequate support for people with dementia**.

"I realised in retrospect that although [the night carer] was very experienced, she had absolutely no idea how to handle somebody with

dementia. I think the "care" was harmful. Now we've got [private] carers that we've selected that have experience of dementia or who are doing courses in it, M's nights are very much better. They're not problem-free, they're still problematic, but he's treated in a humane way." (Unpaid carer of D2A patient, interview, JR, since Apr 2024).

"Patients being discharged from hospital without adequate care provision on the D2A pathway. Vulnerable patients that have dementia for example that need 24hr care and not safe to be living alone and sent home with [four times a day] care package. Very stressful for patients, family and also health care professionals. I am not a social worker and been out to patients that do not have a therapy needs, but it is social. Having to phone D2A social worker to sort care out for patients." (Community care professional, online survey)

We heard from some health and social care professionals and patients a concern that rehabilitation support at home is limited, and that carers do not always have the training, experience or time to support patients with reablement.

"Care providers are quick to discharge people stating they are independent - when in fact they are not. They often decline care as the carers are very late for visits. Carers are meant to be reablement carers and more often than not, people are not given time for their exercises, nor do carers or care providers take the time to find out what exercises are prescribed if any." (Social care professional, online survey)

"The carers used do not appear to be trained or confident in delivering a reablement model of care that is required. Therefore, patients do not have access to the rehab needed to improve their function." (Community care professional, online survey)

"No help, the carers just sat and watched me struggle. The time before the pandemic the carers were great showed me how to help myself i.e. use the grab stick to put my pants on, things I still do. The last time I just felt they couldn't sign me off quickly enough." (D2A patient, online survey, JR Apr-Jun 2023)

Lack of information about social care provision

People told us that they were **not clear about what social care would be provided** when they or the person they look after got home. There was uncertainty about **time frames for assessments**, **if and when they would have to pay for care**, and **how long care would last**.

"No pamphlets for social care on what is the process when getting home." (D2A patient, online survey, Horton, Oct-Dec 2023)

"A very simple thing that would have helped would have been just two sheets of A4 about what Home First is, what you can actually expect – because I expected an evaluation after three days of being at home. Because it's going to take a long time for the new government to get the health service turned around again. I think that sheet of paper has to be really realistic about: your social worker, your care worker that's going to look after you, might not be able to talk to you for two or three weeks. It has to be realistic – I kept thinking, I'm going to get a call from somebody soon." (Unpaid carer of D2A patient, interview, JR, since April 2024)

"Families are not given enough information about live in carers. What are families needing to provide – bed? bed linen? food? They only meet the live in carer who is going to live with their loved one on day of discharge." (Care home staff, online survey)

This contributed to some people experiencing **the end of D2A care as abrupt and sometimes upsetting**, or **feeling anxious about having to pay for care**.

"Abruptly care ceased so employed private care through sterling help of family who were not able to give practical help." (D2A patient, online survey, Churchill, Jan-Mar 2024)

"I was abruptly notified that my six weeks were nearly up and that was on a Friday which left us in a bit of a pickle. Basically, my six weeks were up in effect and my wife had to be shown very quickly what to do in order to help me out of the bed and into the bed etc… This meant it was left to my wife helping me morning and evening. We then had to get my own carer back on board to give me bed baths. It didn't really upset me but it very much upset my wife more because it was so, so abrupt." (D2A patient, interview, JR, Oct-Dec 2023)

"A carer came every day at 10.30 and then they just stopped coming. I've still got the forms. I was supposed to have night time care too, two visits a day, but that never happened. Suddenly there was nobody." (D2A patient, interview, JR, since Apr 2024)

"I think the worry about money on top of everything else was the thing that almost finished me. Because if we hadn't got Continuing Health Care

(CHC), I knew that I could only pay the carers for nine months, and then all our savings would have been gone, it would have got M's savings down to £23,000. After that, I was told, we would be eligible for social service care but they couldn't provide a night carer and they could only provide visits during the day, they couldn't provide live-in. I worried about that constantly, 'How are we going to do it? I don't want to sell the house to pay for this care.' Those financial issues are important." (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

We also heard from one person who was (seemingly incorrectly) told they were **not eligible for any care and support** at home.

"I was in hospital over Christmas and New Year. Three days before I was discharged the nurse came round and said "sorry but you're not entitled to anything", because I'm not on pension credit. My son and my family helped me." (comment from outreach with BAME elders group)

Physiotherapy, Occupational Therapy and equipment for D2A patients
People told us about **delays in getting support** from physiotherapists and Occupational Therapists, and **confusion about who would provide support** with physiotherapy.

"A home/bathroom/physio/O.T. assessment was promised within two days of discharge. This did not happen for two weeks. Adaptions needed to be made to enable my mother to access the shower." (Unpaid carer of Pathway 2/D2A patient, JR and NOC, Oct-Dec 2023)

"Mum needed an OT to help her with getting in and out of bed safely and this still hasn't happened. […] Mum still isn't sleeping in her bed as she doesn't feel safe to do so, despite having leg ulcers which need to be elevated. Without a family member leaving work and sleeping on her floor for days she may well have fallen at home or been unable to take her medication, and this is still an ongoing risk." (Unpaid carer of D2A patient, JR, since Apr 2024)

"Was discharged and told I would have physiotherapy at home, as happened when I had same condition and discharged from another hospital, but this turned into being told carers would do this - they refused of course." (Feedback Centre review of Abingdon Community Hospital, August 2024)

We heard about delays in people being provided with the equipment they needed, and in one case, a refusal to provide equipment the person requested.

> *"I was refused aids [such as a walker frame], so I had to buy my own from Amazon!"* (D2A patient, online survey, Horton, since Apr 2024)

We also heard from one person about extremely long waits to get a grant for longer term home adaptations.

> *"We are constantly fighting to get help, firstly it was equipment so could access upstairs so could shower. We were told it would take 18 months to get a grant and I simply couldn't have my [partner] going without a shower for 18 months so a friend very kindly crowd-funded so we could get a lift and wet room."* (Signposting, April 2023)

Mixed experiences

Of the people who got additional care and support at home, many gave positive responses to questions about the care and support they got. Responding to our outreach survey, 19 out of 25 people (76%) said they agreed or strongly agreed that they were happy with the quality of care and support they got, and 15 out of 22 people (68%) said they felt safe.

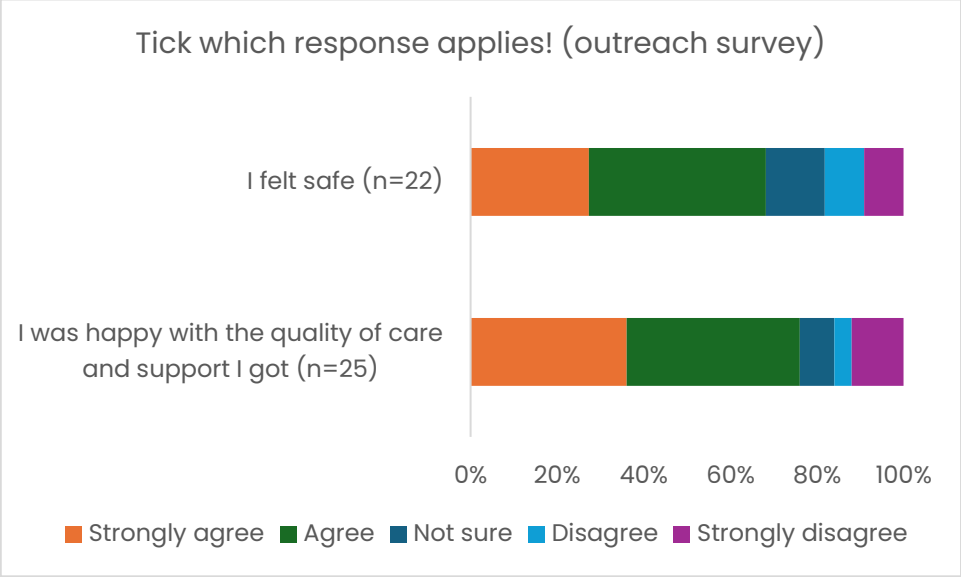

Figure 8: Graph showing responses to outreach survey questions about how people felt about the quality of care and support they got at home, and whether they felt safe.

Similarly, most people who responded to our online survey agreed or strongly agreed that they were happy to be home (16 out of 19, 84%). However, only half of

respondents said they were happy with the quality of care and support they go and how health and social care professionals communicated with them about their care. Less than half said they felt safe (7 out of 15 people, 47%).

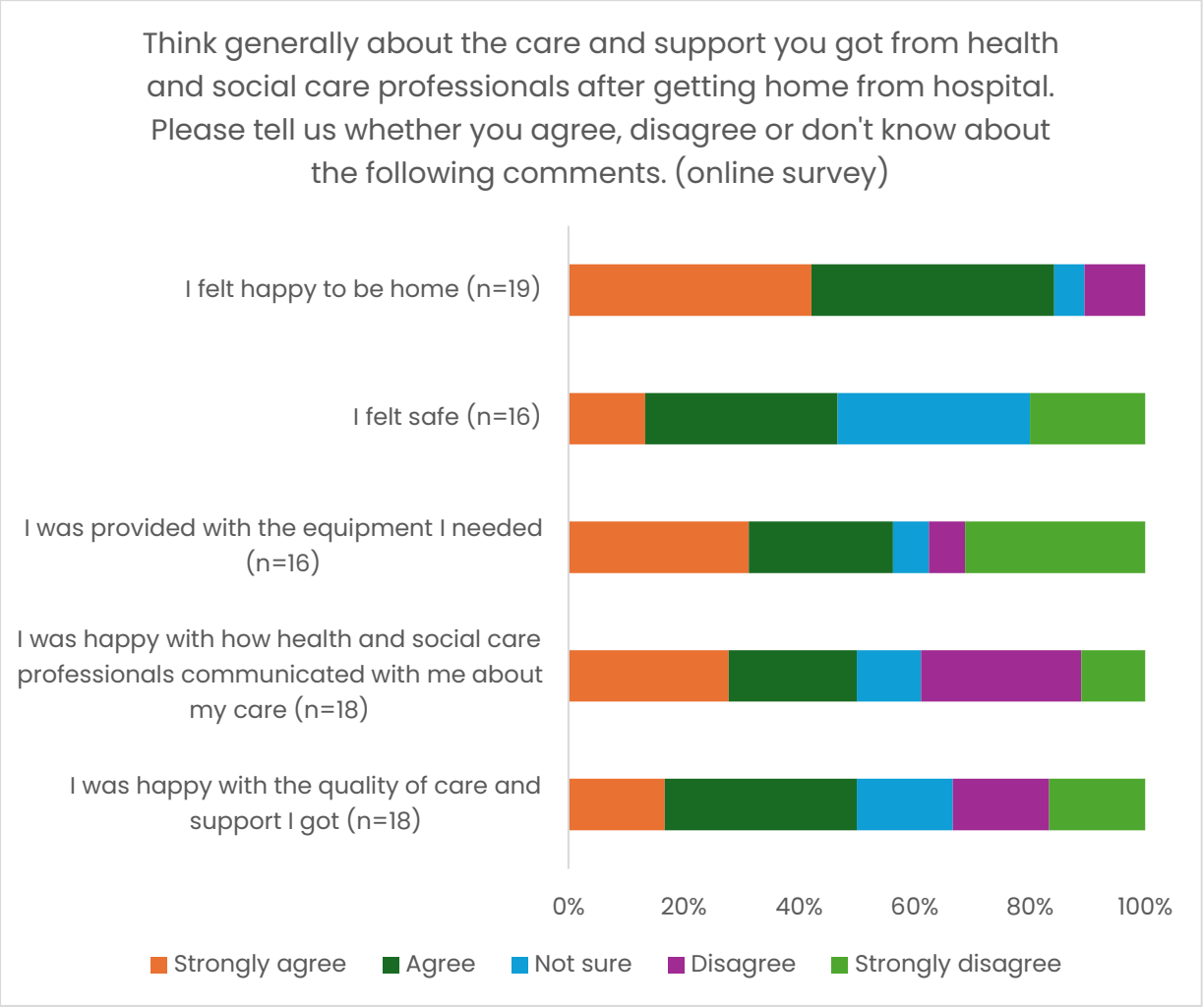

Figure 9: Graph showing responses to online survey questions about how people felt about the care and support they got from health and social care professionals after getting home from hospital.

Outcomes for patients following discharge

We asked people responding to our online survey about what their situation is now at the time of response. Most of them told us that they are now living independently at home (55, 49%) or with support from an unpaid carer (42, 38%). A small number are living at home and getting support from paid carers (10, 9%), have passed away or are now living in a family member's home.

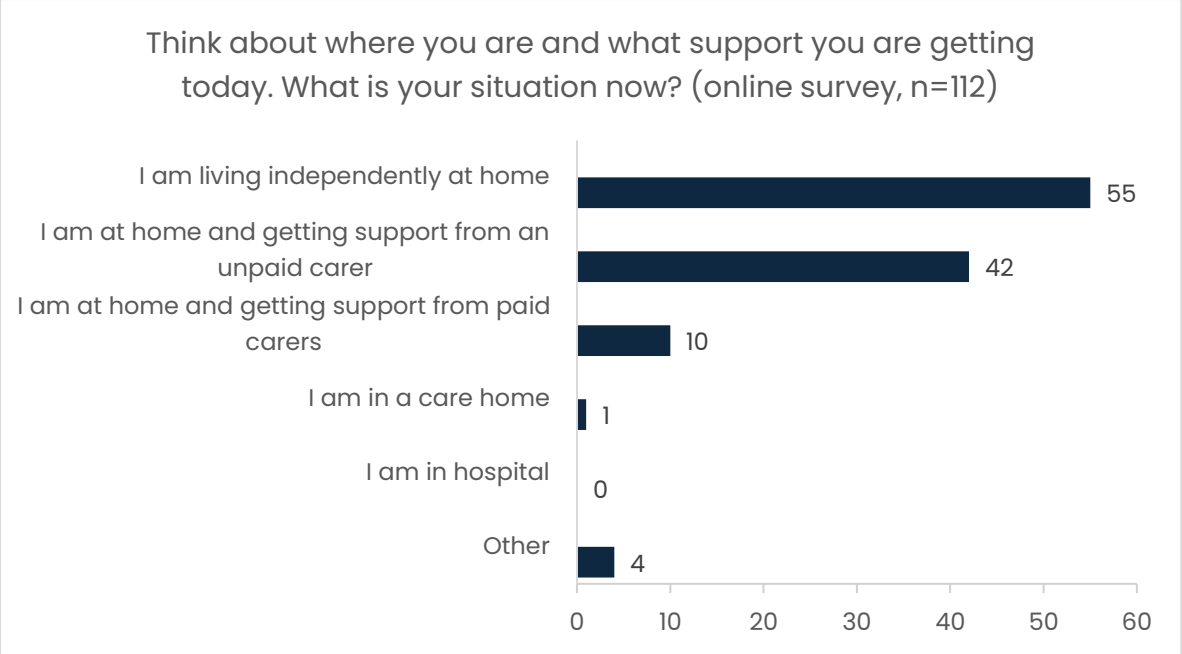

Figure 10: Graph showing responses to online survey question about where patients are now and what support they are getting now.

Four people we heard from had had to go back to hospital soon after being discharged. We also heard from the unpaid carer of someone for whom home was not the right place for them long-term.

> *"Mum is now in a care home permanently after a monumental battle to get her there and further falls at home."* (Unpaid carer of D2A patient, online survey, Horton, Oct-Dec 2023)

Cross cutting themes

Across all the responses from all sources, key cross cutting themes were clear:

- Communication
- Support for unpaid carers
- Health inequalities
- Continuity of care and joined-up working across the health and care system.

Communication

A theme that weaves through people's experiences was communication. Where there was clear, consistent and accessible communication with patients and unpaid carers, and between services, people had a better experience. When there were problems with communication, people were more likely to have a negative experience and face gaps or challenges in getting the care and support they needed.

The main areas where there were communication issues were:

- Conversations around discharge planning
- Information about social care provision
- Information about follow-up care and aftercare – who, when and where
- Keeping patients and carers informed and up to date about what was happening
- Discharge letters and referrals into other services
- Accessibility and reasonable adjustments.

Accessibility and reasonable adjustments

We heard concerning feedback from members of the d/Deaf and hard of hearing community about a lack of accessible communication and access to interpreters in their experiences of hospital discharge and home care.

> *"I was in hospital for seven days I asked daily for an interpreter but there was no interpreter available. […] I was discharged with medication but I had no instructions so I went to my GP two weeks later but there was no record of my hospital admission. My GP had to ring the hospital and I found out from my GP the reason I was so unwell."* (Comment from Action for Deafness coffee morning)

> *"I was discharged from hospital, and I had some care professionals coming to help me to dispense my medication and had the key box fitted. They couldn't really sign only just a bit so communication was really difficult but the service was good."* (Comment from Action for Deafness coffee morning)

> *"My worries are about home care - a lot of people who are home carers English is not their first language and it makes it difficult to communicate home carers should have some training in BSL when needed."* (Comment from Action for Deafness coffee morning)

> *"You could improve discharge by making sure information is translated by an interpreter and use simpler language not jargon and lots of long words.*

Medication should be fully explained by an interpreter." (Comment from Action for Deafness coffee morning)

Suggestions

Ideas for improving communication around discharge included a leaving pack with signposting information, and a follow up call or visit after discharge.

"Having a leaving pack from hospital with key agencies that can help you." (Patient, outreach survey, Horton, since Apr 2024)

[What would make a difference?] *"Even one good visit after you've been in hospital to talk through what to do and what to take, instead of coming out of hospital slightly woozy and trying to understand it all."* (Comment at Carers Oxfordshire coffee morning, August 2024)

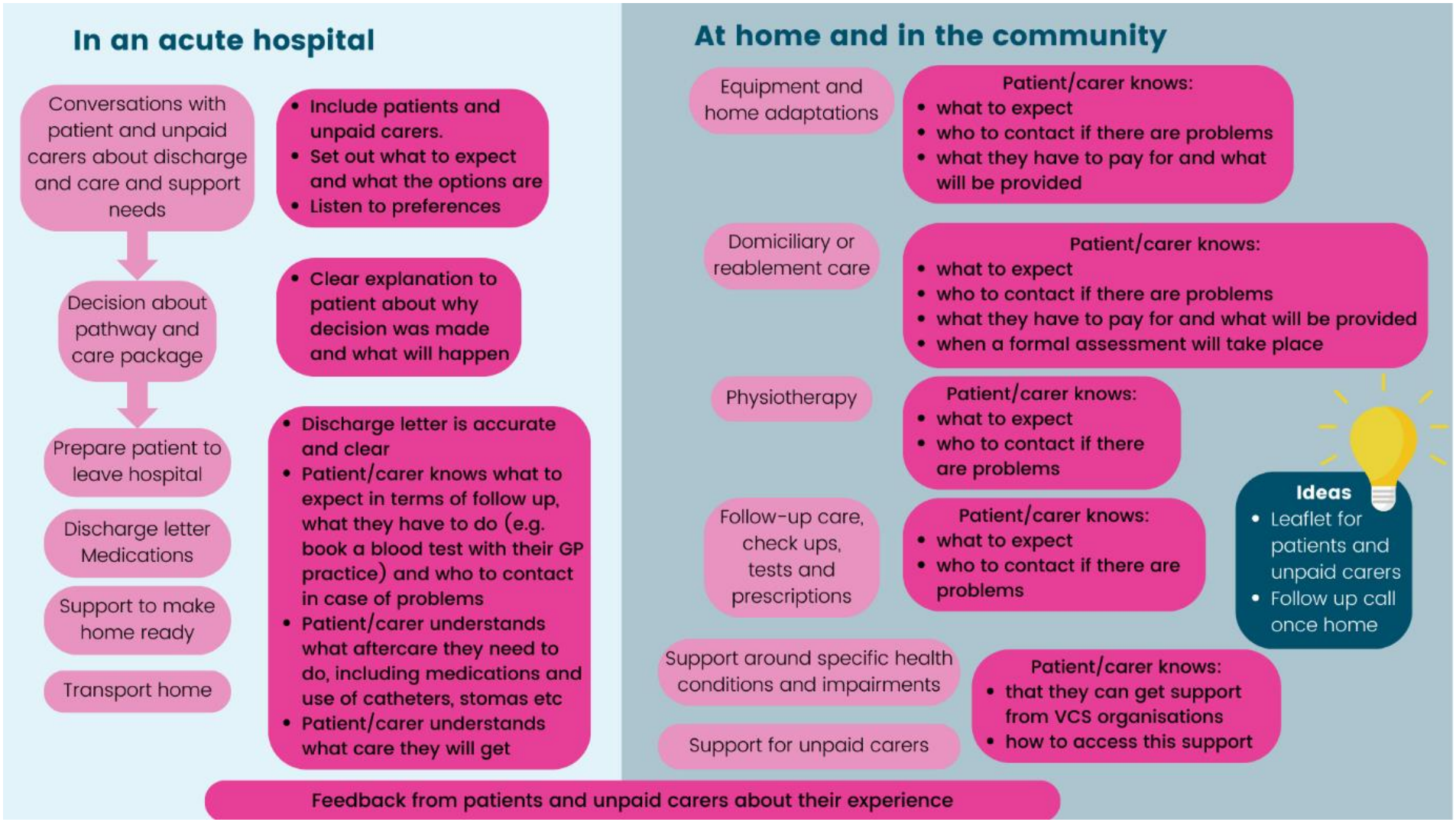

Figure 11: What would good communication look like at each stage of leaving hospital?

Unpaid carers

Another recurring theme in what people told us was about gaps and challenges facing unpaid carers, who can play a crucial role in supporting someone through the process of leaving hospital and making a recovery. What we heard included:

- Unpaid carers are not always included or listened to in decision-making about care for the person they look after
- Some people felt decisions about their care placed an unfair burden on their unpaid carers – this included both people going home on Pathway 0 and with D2A
- Sometimes assumptions seemed to be made that a patient had someone who could provide unpaid care at home, which was not always the case
- Unpaid carers were not always offered support with their caring responsibilities
- Caring had a significant impact on unpaid carers' own health and wellbeing, and unpaid carers were not always offered support to look after themselves – although when they were, it made a real difference.

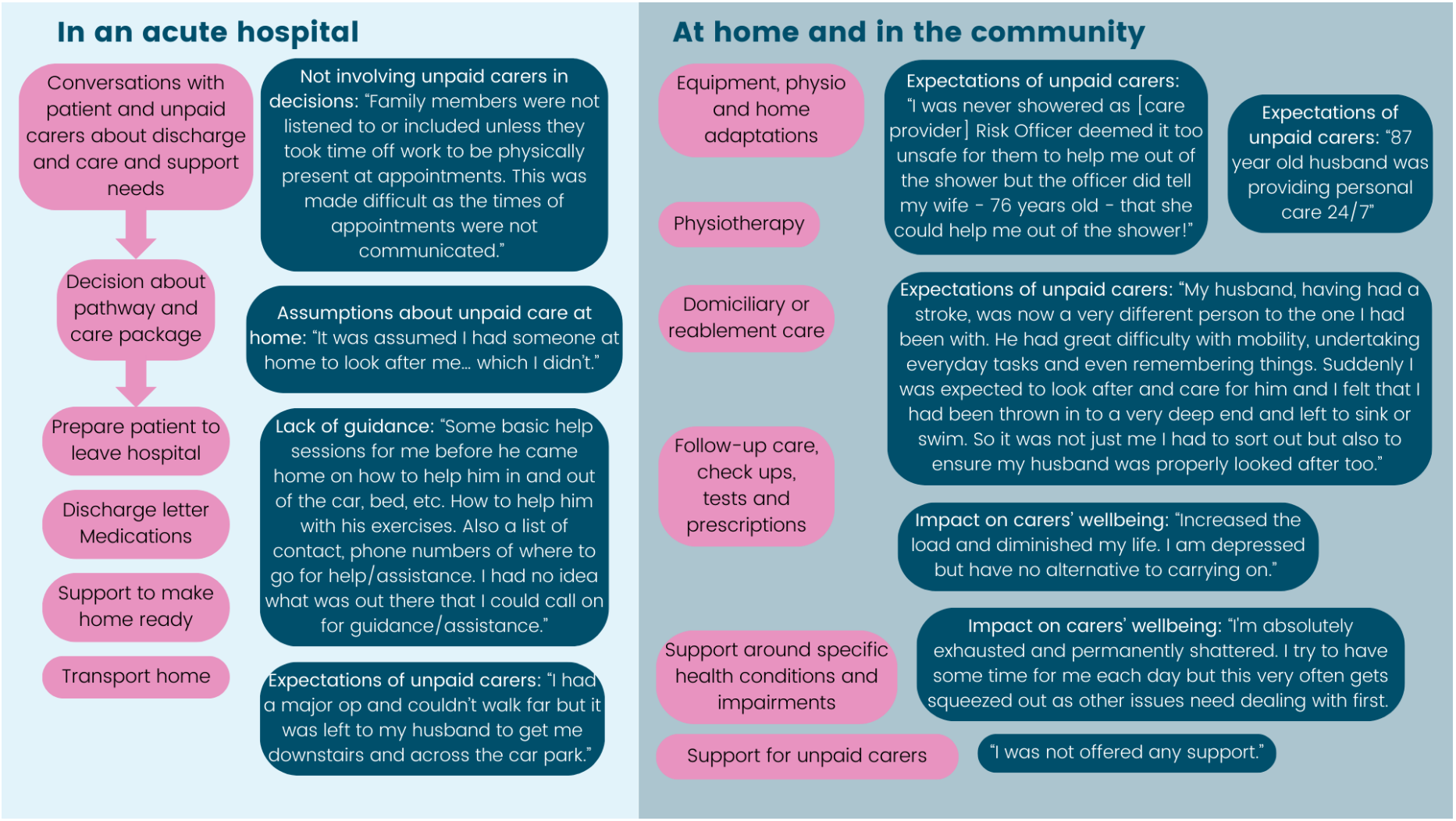

Figure 12: What are the challenges for unpaid carers supporting someone leaving hospital?

Involving unpaid carers in decision-making

Although as noted in What's working well? above, people told us about examples of good practice in involving unpaid carers in decision-making, we also heard that it could be challenging for unpaid carers to take part in decision-making about care for the person they help look after.

> *"Family members were not listened to or included unless they took time off work to be physically present at appointments. This was made difficult as the times of appointments were not communicated."* (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

When unpaid carers were able to share their preferences, these were not always listened to.

> *"We expressed concerns about my mum falling and having difficulties taking her medicines and taking care of herself. These were totally ignored and only the paramedics engaged with us, telling me to call 999 if there were any problems."* (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

> *"They kept us updated and messaged us to say she's doing well, she's progressing, but she can't go upstairs so she will need to have carers and we've got to put bed in. Okay, it sounded promising so I asked when they would be sending her home. They told us it would probably be next week sometime - we pointed out to them that I [and my brother-in-law] were due into hospital [that week], so we said whatever you do, leave it. We actually ended up with a phone call on the Wednesday, just before the Thursday morning that I'm going into hospital saying we're discharging her today. Can you have someone there?!"* (Unpaid carer of D2A patient, interview, since April 2024)

We also heard that involving unpaid carers in decision-making can be a difficult balance – patients did not always want their relatives to be consulted or agree with unpaid carers.

> *"I told staff that I would be ok on leaving hospital if a care worker would visit soon after I got home. Instead someone phoned my son telling him I would be home alone and needing care. I DID NOT NEED CARE as the care worker was visiting. My son was greatly inconvenienced by being called to care for me. That was totally unnecessary."* (D2A patient, online survey, JR, Jul-Sept 2023)

"We need to educate the public and families regarding capacity and what that legally is. Also we need to educate the wider public re. unwise decisions and that they cannot stop these if their relative has capacity."
(Acute care professional, online survey)

People who responded to our online survey suggested that while some unpaid carers are involved in decisions about the care of the person they look after, this was not always the case. Half of respondents (7 out of 14) said they disagreed or strongly disagreed that unpaid carers were involved in decisions about their care.

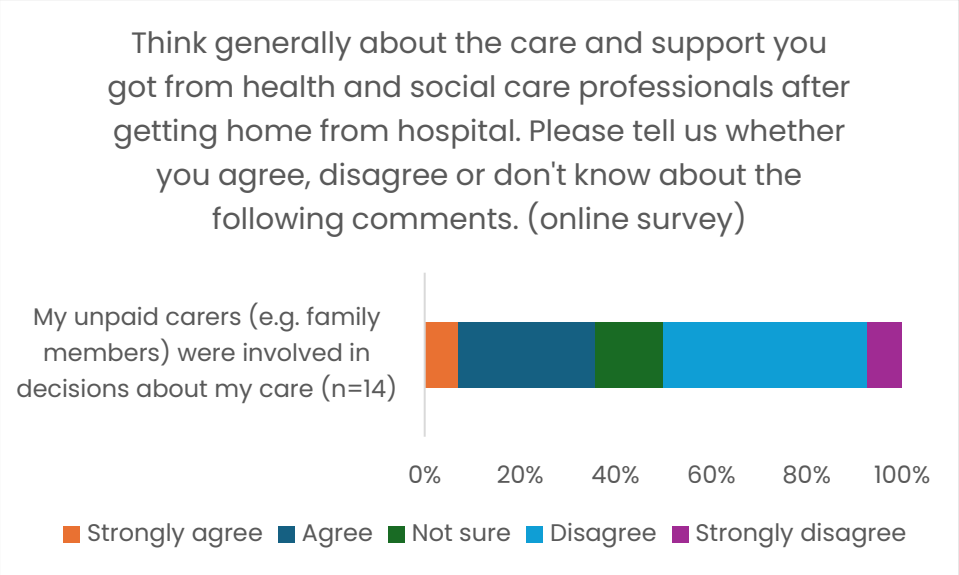

Figure 13: Graph showing responses to online survey question about whether or not unpaid carers were involved in decisions about people's care in the time after they got home from hospital.

Expectations of unpaid carers
We heard from some people that they felt that decisions about care and support leaving hospital put the **burden onto their unpaid carers**.

"I had a major op and couldn't walk far but it was left to my husband to get me downstairs and across the car park." (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

"My daughter had to care for me which was very stressful for her."
(Pathway 0 patient, online survey, JR, Jul-Sept 2023)

This was the case in several instances **even where there was a package of care** in place, with **unpaid carers filling in the gaps around short carer visits**.

"In [four weeks of care] I was never showered as their Risk Officer deemed it too unsafe for them to help me out of the shower but the officer did tell my wife - 76 years old - that she could help me out of the shower!" (D2A patient, online survey, OSRU, Apr-Jun 2023)

"I can't see how within half an hour you can get someone who is elderly washed and dressed. I was getting my mother dressed." (Unpaid carer of D2A patient, online survey, since Apr 2024)

"87 year old husband was providing personal care 24/7." (Unpaid carer of D2A patient, online survey, Horton, Oct-Dec 2023)

"Without my neighbours I would have been struggling to cope." (D2A patient, online survey, Horton, since Apr 2024)

"I was given 24 hours notice that my husband would be bought home by ambulance. During his eight week stay in hospital I had to make sure the downstairs room was turned into his bedroom as he would not be able to get upstairs. […] No-one actually checked either verbally or in person that the home was suitable for him to return to. My husband, having had a stroke, was now a very different person to the one I had been with. He had great difficulty with mobility, undertaking everyday tasks and even remembering things. Suddenly I was expected to look after and care for him and I felt that I had been thrown in to a very deep end and left to sink or swim. So it was not just me I had to sort out but also to ensure my husband was properly looked after too." (Unpaid carer of D2A patient, online survey, OSRU, Apr-Jun 2023).

Assumptions about unpaid care at home

People also told us about assumptions made by health and social care professionals about the support that they had at home.

"It was assumed I had someone at home to look after me… which I didn't." (Patient, online survey, JR, Jan-Mar 2024 – this patient paid for a private post operative care bed)

"They knew that I had no one to support me, but it seemed that there were no communication between departments. So, at first, they placed me in a day case ward. Then I insisted that I did not have support at home. I forced myself in hospital stay for a few days. It felt as though, I was just making excuses to stay for no good reason. Eventually, as soon as I was given equipment to become a little more mobile, I have decided that in the

interest of the facilities being available for other patients, I would leave. So, my stay after the operation was not longer than four days. So, my relations had to come to Oxford to take me to London (with no facilities to attend health professionals) to care for me. There were no community care homes in Oxford. I have tried to find a reasonable care home, but they were extortionate in price. I could not afford it with just a state pension. I would have preferred to stay on in Oxford." (Pathway 0 patient, online survey, NOC, Jan-Mar 2024)

Supporting unpaid carers with their caring responsibilities

We heard that unpaid carers would have liked more support, training or guidance from health and care services in what they should be doing to help.

[What could be better?] *"Some basic help sessions for me before he came home on how to help him in and out of the car, bed, etc. How to help him with his exercises. Also, a list of contact, phone numbers of where to go for help/assistance. I had no idea what was out there that I could call on for guidance/assistance."* (Unpaid carer of D2A patient, online survey, OSRU Abingdon, Apr-Jun 2023)

"I felt extremely alone and frightened. I felt abandoned and my husband wasn't sure what he should be doing to help." (Pathway 0 patient, online survey, Churchill, Jan-Mary 2024)

Impact on carers' wellbeing

We heard about the significant impact that being an unpaid carer could have on people's mental and physical health and wellbeing.

"Now I have a lot of friends. [But] even I have low moments where you feel a bit overwhelmed. And it's an unbelievable feeling that who do you actually go to? Who do you turn to? I mean everybody, I'll say will do the shopping for you or fetch this. But it's the emotional support that you need." (Unpaid carer, interview, RBH, Jan-Mar 2024)

"Increased the load and diminished my life. I am depressed but have no alternative to carrying on." (Unpaid carer, online survey, Horton, since Apr 2024)

"I am now caring for a disabled person who has great mobility issues and could easily become housebound soon as I will be unable to get him out of the house to get him into the car/wheelchair. As for my health, I'm absolutely exhausted and permanently shattered. I try to have some time

for me each day but this very often gets squeezed out as other issues need dealing with first." (Unpaid carer of D2A patient, online survey, OSRU, Apr-Jun 2023)

Supporting unpaid carers with their own wellbeing.

Of the 23 unpaid carers who responded to our full survey, 12 told us they had not been offered any support. Several of those who had been offered help mentioned Carers Oxfordshire. Other barriers to getting support included not being able to attend support sessions due to work. However, we heard that when people did get support from Carers Oxfordshire and other organisations, they found it extremely helpful.

"None until I became aware of Carers Oxfordshire last year and are now on their lists and do know that there is somewhere I can go for advice/help." (Unpaid carer of D2A patient, online survey, OSRU, Apr-Jun 2023)

"Age Concern [Age UK Oxfordshire] always responded to me immediately, they were so helpful. A person from Age Concern came to see me on the ward a couple of times and helped as much as she could, and tried to get a social worker to talk to me and things like that." (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

"Once you get on the first rung of the ladder and get known a bit, things start to open up. I found [carer] through South Oxfordshire Carers, she told me about the blue badge, personal allowance, Carers Oxfordshire." (Comment from Carers Oxfordshire coffee morning, August 2024)

"I sent the [Carers Oxfordshire] questionnaire in [and] I got an almost immediate response, regular phone calls, and then a lovely interview with lots of ideas about reduction of council tax, lots of resources, cheaper holidays. And then I got a gift from the council, this beautiful box of toiletries to use in the bathroom to relax. I suddenly felt that there was somebody that I could contact. I don't anymore, but it was just feeling that there was somebody there for you, and understanding the importance of respite. I've just had four nights away for the first time. That support from the council – it must be difficult for them, because I know they're cash strapped, but it's really important that there's somebody there for you. Because actually very few care workers, when I took M to see them, would say, "And how are you?" There was only one other person who did that, and that was the physiotherapist who first helped me. But the council were saying 'How are you?' and 'We recognise how difficult it is, and also what

you're doing is really important.'" (Unpaid carer of D2A patient, interview, JR, since Apr 2024).

Health inequalities

There were no clear differences in people's experiences between different hospitals or when they were discharged. However, we did hear how **health inequalities could be exacerbated** by issues around **accessible communication** and the **cost of transport** (for example to attend follow-up appointments). We also heard several instances where people **felt they had to pay for care** – a rehab bed, physiotherapy, or carers – to get the level of support they needed.

Joined-up working

Effective collaboration between different departments and services is fundamental to providing a good patient experience of a process like leaving hospital, which involves multiple organisations. We heard from patients who received additional care and support at home after leaving hospital that, from their perspective, joined-up working and communication was not always happening.

> *"Communication was terrible and appeared to be no interdepartmental cooperation - dreadful!"* (D2A patient, online survey, Horton, since Apr 2024)

Half of online survey respondents who received care at home said they disagreed or strongly disagreed that health and social care professionals communicated effectively with each other about their care, and more than half (10 out of 17, 59%) disagreed or strongly disagreed with the statement 'I felt that health and social care professionals worked together to support me in a joined up way.'

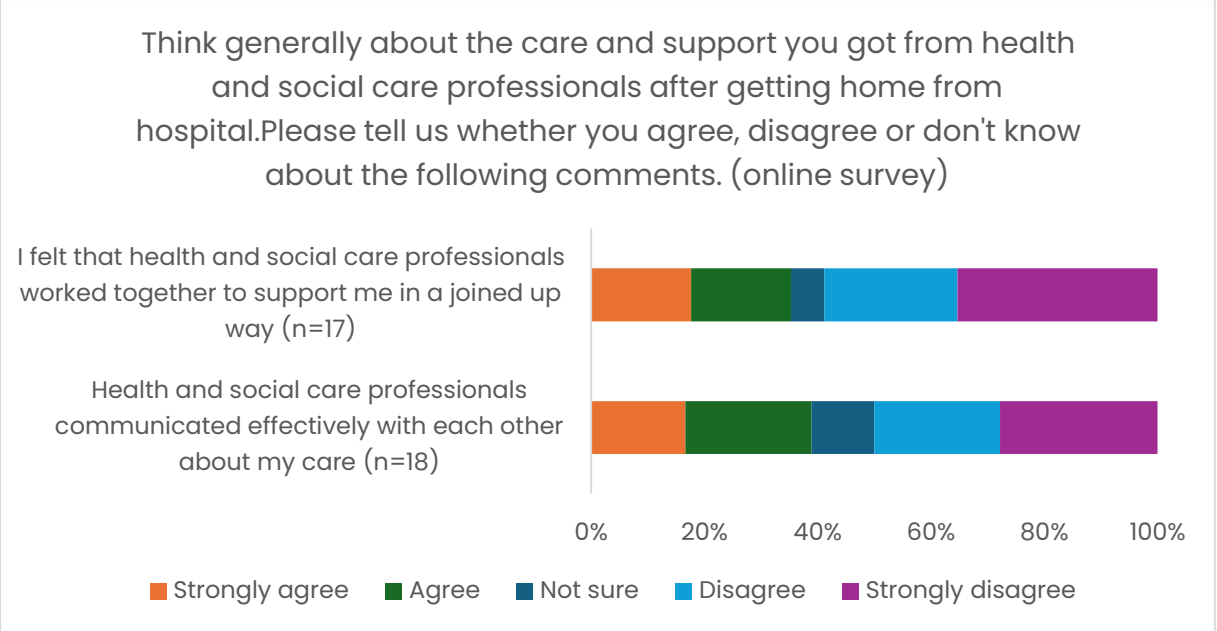

Figure 14: Graph showing responses to online survey question about patient and carers' perceptions of how well health and social care professionals communicated and worked together to support the patient in a joined up way.

Health and social care professionals' views on joined up working

In our survey for health and social care professionals, we heard from 87 people about what is enabling joined-up working and what makes it challenging, as well as suggestions for how things could be improved.

What is working well?

Health and social care professionals told us that multidisciplinary teams and the Transfer of Care Hub are working well, and expressed appreciation for colleagues doing good work across the system.

> *"Think that MDTs within OUH are effective and that TOC has sped things up. Lots of excellent staff."* (Acute care professional, online survey)

> *"The TOC process is generally working well and has reduced some inappropriate referrals to community hospitals."* (Community care professional, online survey)

Healthwatch Oxfordshire attended two Transfer of Care 'huddle' meetings as an observer, and saw in action the positive communication and teamwork that is possible when different services are able to come together. These vital meetings enable the different services to share insights and work together to best develop joined-up support around an individual's care.

Staff also praised the Trusted Assessor scheme (a collaboration between the Oxfordshire Association of Care Providers, OUH and OCC[19]), and the 'out of hospital' support provided by Age UK Oxfordshire.

> *"Age UK support on the ward has been critical for patients who do not have family/friends support for discharge planning."* (Community care professional, online survey)

People told us they valued being able to have verbal handovers with colleagues about a patient's care, especially for complex cases. A GP told us they appreciated being emailed a discharge summary, reducing the potential for delays.

> *"Recently I received a phone call from a junior doctor on a hospital team about a specific patient's discharge which was very helpful, but a one-off."* (Primary care professional, online survey)

Barriers and challenges

Things that people told us got in the way of joined-up working and providing a good discharge experience for patients included difficulty contacting and liaising with other services, which people attributed to staff pressures, high staff turnover or rotation, and a lack of understanding about when different services operate.

> *"It can be hard to get hold of care providers, social workers, GPs etc."* (Acute care professional, online survey)

> *"It is often challenging to get in touch with the wards for further clarification on things."* (Community care professional, online survey)

Linked to this were barriers to sharing notes between services and the fragmentation of patient records between multiple data systems.

> *"Lacking a shared notes system does not help. We are having to waste time sharing lots of basic information with the social workers and community teams because they are not able to access the hospital notes."* (Acute care professional, online survey)

> *"Huge barriers, we use different systems so have no access to hospital records. Communication is hugely challenging as we are often not copied*

[19] https://www.oacp.org.uk/trusted-assessors-in-oxfordshire

in to planned procedures or post discharge recommendations and follow up." (Community care professional, online survey)

We heard that social workers and care providers are not always given key information about a person's mobility, home situation or healthcare needs – which may be linked to this fragmentation or be due to care providers not being involved in discharge planning.

> *"People are often not sent home with the right equipment. We get told people are fit and mobile and find this is not the case. They rarely know the home set up and are often surprised when told the situation. It needs proper assessments or conversations with care providers before discharge is planned."* (Home care professional, online survey)

We also heard from home care providers and extra care housing providers who would like to be kept informed about when people they care for come home – there is currently no system for this. This can mean that residents in these settings are not as supported as well as they could be had the housing support been informed.

Health and social care professionals told us about a lack of clarity among staff and patients about the D2A process, and gaps in understanding of the support in place.

> *"Unsure what to advise patients as to when they will be assessed at home. Previously told 72 hours but feedback is this isn't happening. It would be helpful to be able to provide patients with a leaflet or documentation about D2A and contact details in case of issues."* (Community care professional, online survey)

There can also be a lack of understanding about how other services work and what services are available, particularly in new or developing areas such as the D2A therapy service – in some cases leading to duplication of referrals into D2A and community services.

> *"We don't know what services are available or who the relevant people/teams are to talk to."* (Acute care professional, online survey)

> *"Promises made to patients on our behalf which we cannot meet. Lack of preparation for discharge i.e. teaching patient or families to give injections or medication."* (Community care professional, online survey)

> *"Patients seem to get passed around, communication between teams could be better. For example, D2A referral is made. The patient is needing therapy input but there is no space on the form for this so we have to send a separate referral. Community Therapy Services (CTS) won't take a referral for a patient if they are on the D2A pathway but often seem to see them anyway as they get passed across. This feels very bitty. I think either D2A need a better resourced therapy team that can promptly follow up and be part of the assessment process or it should be scrapped and CTS be involved as needed from discharge."* (Community care professional, online survey)

We heard that people are frustrated by delays in other services picking up referrals.

> *"Community services to respond to referrals in a timely manner to minimise risk of failed discharges."* (Acute care professional, online survey)

We also heard that there are problems with the quality and timing of referrals to community services, particularly around District Nursing.

> *"Poor referrals to District Nurses. Minimal information shared. This delays us seeing the patient."* (Community care professional, online survey)

> *"We get poor referrals and the majority of DTAs [Decision to Administer forms] for medications from the hospital are incorrect. It is then very difficult to contact the ward to get a doctor to amend it so it is useable. This is especially difficult as hospitals often discharge patients before we have accepted their referral so patients are sent home without us being able to do their care."* (Community care professional, online survey)

> *"There is a huge gap between ALL hospitals and the district nursing service. The DN's are receiving referrals when the patient has already left hospital for same day/next day appointments. It's impossible to allocate all patients these appointments, meaning patients are often calling distressed/emergency appointments (aka syringe drivers/urgent medications) are then needing to be outsourced to Hospital at Home or similar - which wastes resource. Hospitals need to be requesting visits ahead of discharge."* (Community care professional, online survey)

People also told us about problems with quality of discharge letters (although we also heard from one primary care professional that this has recently improved) and delays in discharge letters reaching GPs.

> *"Discharge letters are not clear enough, especially if the patient is being discharged from a Same Day Emergency Care unit, it can be very difficult and time consuming trying to work out in what order and what date the info relates to. Not enough information for the GP regarding next steps."* (Primary care professional, online survey)

> *"Poor/late/missing discharge summaries (often never receive one) and no contact when there's important/urgent info to pass on."* (Primary care professional, online survey)

> *"Relevant information is usually buried in a multiple page document, often towards the end. This makes it longer to process them, and increases risk of information being missed. [Priority information is] scattered across 3-10 pages, often buried in text formatted in a way that makes it hard to read (multiple short lines, apparently random formatting and spacing)."* *(Primary care professional, online survey)*

The bigger picture is one of significant pressures on the system. People told us that low staff morale and lack of consultation when implementing changes was affecting capacity for joined-up working. We also heard that there is sometimes a lack of trust and goodwill between services – linked to a lack of capacity and sense that work and responsibility is being 'dumped' on one service by another. This may be contributing to the lack of clarity for patients over who will provide follow-up care and aftercare.

> *"Workload dumping on primary care - i.e. secondary care asking primary care to complete the episode by chasing results, prescribing medicines urgently, making onward referrals. Urgent meds requests that should be provided by secondary care."* (Primary care professional, online survey)

Suggested improvements

Ideas that health and social care professionals shared for improving joined-up working and the discharge process included:

- Clear, up-to-date information about the D2A process – both for staff across the system and to share with patients and families
- Amend the D2A referral form to include therapy needs
- Opportunities for handovers between teams, e.g. therapy handover between community hospital and community therapy services or D2A team

- Ensure medication changes are clearly documented and communicated to patients and unpaid carers, and continue to fund and signpost to the Medicines Information helpline for queries
- Using flag or alert systems to ensure community and acute teams liaise to support discharge of patients with specific medication and equipment needs (e.g. home oxygen, insulin, catheters)
- Continue to improve the relationship between community care services and social services – for example to make homes safe for people who are already known to social services
- A framework for primary care professionals to escalate discharge discrepancies
- Ensure all relevant staff are able to feed into discharge decisions – including those spending time with patients on the ward, and where appropriate, specialist services such as the Tobacco Dependency service
- Addressing staffing and capacity pressures.

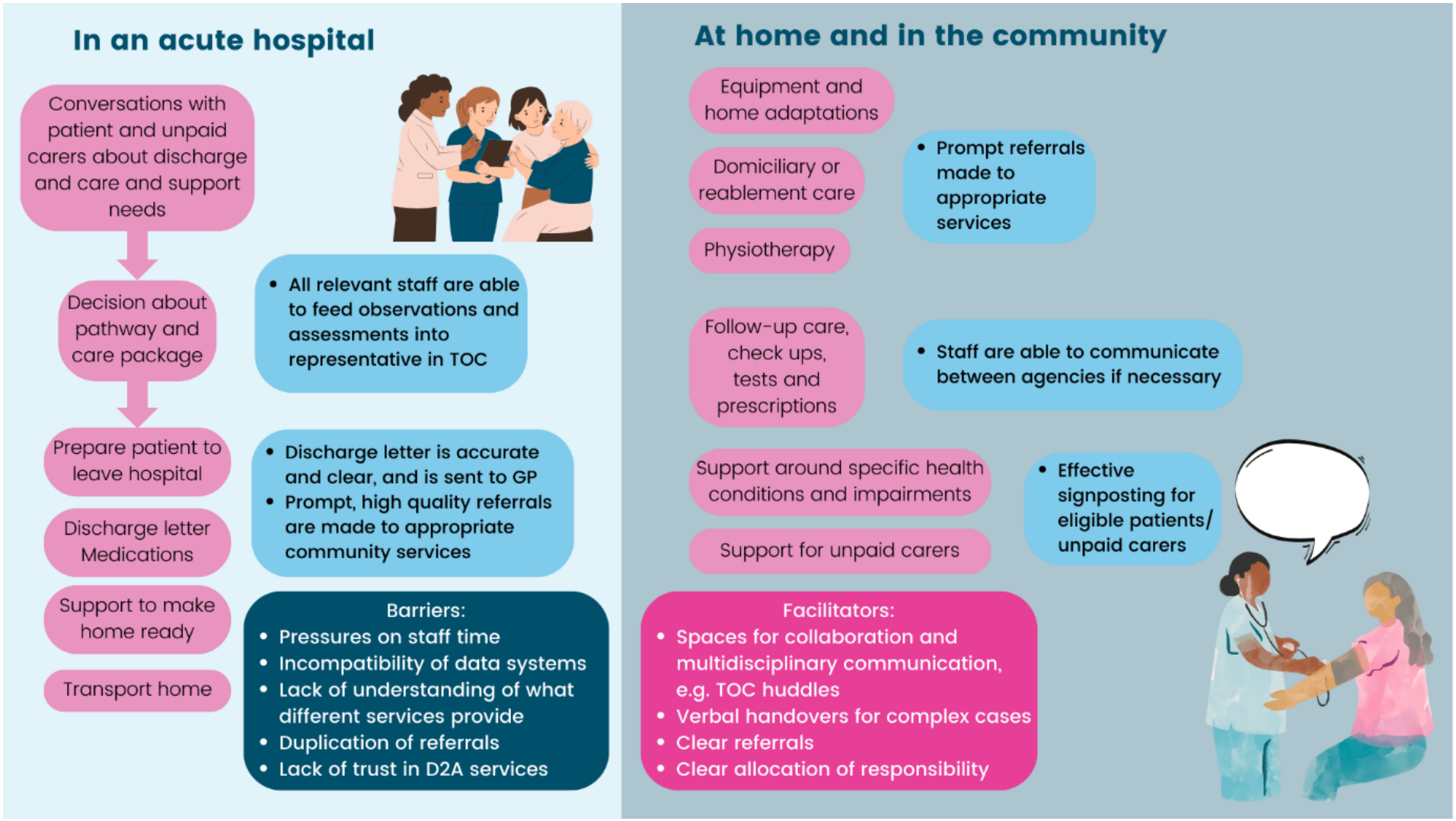

Figure 15: What would good joined-up working look like? What are the barriers and facilitators to joined-up working?

Acknowledgements

Many thanks to everyone who shared their experiences and supported us with this project.

Useful links

- Carers Oxfordshire website
- Age UK Oxfordshire website
- Be Free Young Carers
- Accessible Information Standard
- National guidance on hospital discharge and community support guidance
- LiveWell Oxfordshire – directory of groups and organisations

Appendix 1 – Previous research

Leaving hospitals with medicine, January 2023
In 2022 we were asked to help OUH gain insight into patient experience of its Patient Medicines Helpline. The Helpline provides support – via email and phone – from a pharmacist to patients leaving hospital with medicines.

We heard from 113 people about this. Nine people kindly came forward to share their stories in depth**,** illustrating the journeys people took. Some of these stories are included at the end of the main report and on our website here.

A key finding was that few respondents had heard of the Helpline. We also identified other themes around clear and timely communication about medicines and discharge waiting times. Based on what we heard, we made a series of recommendations to OUH, including to:

- Review communication and promotion of the Helpline

- Seek patient input into the written communication and instructions for patients about medicines taken home
- Review and improve discharge process within hospital
- Review and ensure patients have clear communication about follow up prescriptions and where to turn once left hospital

Read the full report on our website.

How people experienced joined-up care in Oxfordshire, October 2023

In May 2023 we conducted a survey to ask about local people's ideas and experiences of 'joined up' care.

A central theme of the NHS Long Term Plan is to develop joined up care between health and social care services. This will help patients get timely, appropriate, and holistic care based on their needs, and avoid being passed to multiple services, or having to repeat their story several times. The 2022 Health and Care Act aims to make this easier in England through the creation of Integrated Care Systems (ICSs).

This report summarises the responses of 38 completed questionnaires and follow-up interviews with five people. It captures the range of views and experiences we heard about, including people's perceptions of what joined up care looks like as well as their experiences of it.

We will share this report with health and social care providers, the Oxfordshire Health and Wellbeing Board and Oxfordshire Place Based Partnership. We hope it helps to complement and support more integrated ways of working in Oxfordshire between health, social care, and others, including voluntary sector partners, which have been emerging in the past few years. Read the report on our website.

Healthwatch England report: leaving hospital, November 2023

A Healthwatch England study, published in November 2023, heard that while some patients said they had an excellent hospital discharge, others had negative experiences including not being asked about whether they had transport, not being given contact information, feeling unprepared and waiting over 12 hours from being told they were ready to leave to being discharged. Read a blog about the findings on the Healthwatch England website.

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Your voice on health and care services

healthwatch Oxfordshire

Your voice on health and care services

People's experiences of leaving hospital in Oxfordshire

Executive summary, recommendations and responses from providers and commissioners

November 2024

Executive Summary

"So the good care, it's not just about healthcare, it's about the quality of life and the relationship and everything – it's just priceless."
(Unpaid carer comment)

Over the past year, informed by national guidance, the Oxfordshire health and social care 'system' has been working to develop new pathways to care and support for people when they leave hospital. This has included a shift towards rehabilitation and care for people in their own homes or usual place of residence, as a way of supporting speedier recovery and independence. This in turn helps to relieve the pressure on acute hospital beds, by reducing hospital stays and associated negative impact on recovery. There is focus on providing 'joined-up care', with support services planning and working closely together around the patient.

Between May and September 2024, Healthwatch Oxfordshire reached out to hear from people in the county about their experiences of this care and support. We heard from people via a combination of online and paper surveys, face to face outreach, and interviews. We focused on patients returning home via two pathways – Pathway 0 (going home without additional social care) and Pathway 1 or Discharge to Assess (D2A) (going home with additional social care before being assessed for longer-term social care needs).

In all, we heard from a total of 293 people:

- **206 members of the public** about their experiences of leaving hospital and any follow-on care and support they received after their stay
- This included the views of **22 unpaid carers**
- We also heard from **87 health and social care professionals** from primary and secondary care and social care.

What people told us:

What's working well?

- Parts of the process are working well for some patients. People valued the support and care from health and care professionals. What was clear was that good, consistent communication, being involved in decision-making about their care, effective follow-up care and aftercare, and high-quality care all made their experience of care positive. Most people told us they were happy to be back in their own home.

- Health and care professionals are finding effective ways of working together around patients' needs. Central to this is the coordinated approach taken in the Transfer of Care Hub and in multidisciplinary teams, to help get more people home with the support they need.

What could be better?

- Some parts of the discharge process are not working well for everyone. There are challenges around consistent and clear communication, listening to people and involving their unpaid carers in decision making, delays in leaving hospital and getting care, and accessing follow-up care and aftercare from different services. There are also challenges around the quality and continuity of care provided.
- Some areas of joined-up communication across primary and secondary care can still be improved following discharge of a patient from hospital, including handing over care to GPs and district nursing teams.
- We heard that unpaid carers were not always included or did not feel listened to, and were not being offered support.
- Overall communication and information about the discharge support offer and expectations could be more accessible, both for patients and carers but also for the health and care professionals within the system.

Recommendations

We would like to make the following recommendations based on what we have heard. They focus on building on existing good practice to improve the experience of patients and unpaid carers as well as system working.

- Recommendations are for response for all system partners – including BOB ICB with Oxfordshire Place-Based Partnership, OUH, Oxford Health, Oxfordshire County Council and home care providers – as to how they will address them.
- For noting by Oxfordshire GP Network, Age UK Oxfordshire and Carers Oxfordshire.

1. **To improve the experience of continuity and quality of care for patients:**
   a) Note this report, including the experiences and voices of patients and carers, and reflect on potential to improve services in light of this insight.

b) The report has highlighted some gaps in joined-up care. Our recommendation is to use this report to identify gaps and inform the development of further service design and action plans to address them.
c) Identify scope for providing more person-centred care and support to both patients and unpaid carers at each step of the discharge process. For example, patients have told us about problems with timing of home care visits.
d) Build on the Health and Social Care Connections programme, to ensure that patients and unpaid carers continue to be involved in the co-design and future development of services.

2. Clear communication with patients and carers

This report indicates where improvements to communication with patients and carers could be made. We would like to recommend the following:

a) Improve communication about all aspects of the discharge pathway to ensure that patients and unpaid carers are fully informed about every step. For example, patients have told us that a leaflet and a single point of contact would be helpful.
b) Ensure that communication and information about discharge is accessible to all patients and unpaid carers, in line with the Accessible Information Standard.

3. Improve support for and identification of unpaid carers

Based on what we heard from unpaid carers, we make the following recommendations, noting OCC's Unpaid Carers Strategy:

a) Improve recognition and understanding of unpaid carers' role and capacity to provide care, including proactive identification of unpaid carers, for example flagging unpaid carers on medical records.
b) Improve holistic support to unpaid carers, including signposting to Carers Oxfordshire and other support.
c) We heard that unpaid carers were not always involved in decision-making about discharge. Ensure that, where appropriate, unpaid carers are involved in decisions about discharge.

4. To continue to develop joined-up working across the system

We saw that good progress has been made in services working together around discharge from hospital. The report identifies the following areas for continued improvement:

a) We heard that health and social care professionals are not always clear about discharge pathways, including the D2A offer and follow-on healthcare. We recommend exploring ways to improve communication with staff to ensure consistency of approach.

b) Work together to improve communication and understanding between services, e.g. interface between secondary care, GPs and district nursing teams when a patient is discharged, multi-disciplinary team handovers and discharge letters.
c) Explore potential to build in better support for patients through greater involvement of other relevant partners, for example home care providers and extra care housing providers.

The following responses from health and care providers and commissioners reflect how the support for people leaving hospital involves services working together.

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People's experiences of leaving hospital

Edited excerpts of stories collected in phone interviews

November 2024

Story 1: D2A patient, JR, since April 2024

Well, it was annoying because I wanted to get home, but they said I needed a carer and they were trying to find a carer for me. I kept saying, I can manage on my own! I may be 87 but I can manage without a carer! I would have liked to go home and get on with things.

When I went home I had to wait until 7pm. I was told that someone would be there but there wasn't, so I arrived to my dark little cottage. It wasn't funny and there was no one there, and all the lights weren't on. A person came about half an hour later, but it was just the assessor, not a carer, asking questions about what I wanted. I said what I wanted was help to unpack my bag, and to be fair to her, she did help me with that. She said I'd have a carer the next day, but no-one came so I got up and washed myself. The carer came at about 10.30 and there wasn't much for them to do, so I asked them to help with the dishwasher, but they put dirty plates in with the clean ones. A carer came every day at 10.30 and then they just stopped coming. I've still got the forms. I was supposed to have night time care too, two visits a day, but that never happened. Suddenly there was nobody. But I was quite pleased because now I can lock up properly at night and draw the curtain across the door and everything. Before, I couldn't do that in case the carer came at 7.30, though they never did.

The girls who came were lovely, they were so kind and some of them were quite fun! They were very chatty and polite. Sometimes I didn't have anything for them to do, so they just watched television. They wouldn't look for work. I've sorted private care since then and that's absolutely fantastic, it's very different.

The community people found out what was happening and brought me a wheelchair and a mattress – I'd never had a mattress like that before, I didn't sleep very well the first night but it's lovely now. They asked me what I'd like to do, and I said I'd like to get out, because I hadn't been out for six months, so they got me a wheelchair and I go out once a week, I go to the market, and it's been lovely.

The carers only came for half an hour. I asked for two days together so that I could have a shower. They said it was a good idea but it didn't happen. One day I had an appointment at Specsavers and I rang to tell them I wouldn't be in but she came anyway and had to do her forms. So next time I was going out I didn't bother to tell them. Sometimes nobody turned up.

It would be good if the carer could ring the person they're coming to and let them know they're on their way, so you're not waiting around. That would be a sensible thing. Because not knowing when someone's going to come through your door, it's just...

I had a marvellous surgeon and I only had to wait two weeks. It was wonderful, that even though I am 87, the surgeon thought it was worth operating on me for three hours! But I stayed in hospital longer than I needed to because they wouldn't let me go home without a carer. I was ready to go home after about five days but I was in there about nine. But they were all very kind and treated me with the utmost respect.

Story 2: D2A patient, JR, Oct-Dec 2023

It was literally just before Christmas and as you can imagine, I wanted to be home. I knew I was weak and dependent, but I still wanted to be home. At the time, it was very unclear to me whether I was going to be able to be discharged or not. The nurses, I think, were making plans for it but it was the junior doctors strike, and the nurses were being run ragged because they were trying to do too many jobs at once, even more than usual and care assistance with it, fitting in where they could. Finally, the doctors were saying, well, yes, you can go home as the blood test results are fine and you're medically stable. The only thing was, the afternoon I was due to be discharged, I had to have an iron injection to take up my iron levels, which were very low.

I was told, and my son and daughter were told, that I would be ready to be discharged at 4pm, that was the plan. My daughter took time off work so that the two of them could come in together for 4pm to collect me and take me home. However, at 4pm, I was still in bed. Not dressed, not ready, not anything. I think there was a problem or delay with getting the medication up from the hospital pharmacy. And eventually I think it was about 5.30pm and we were left hanging about with nobody knowing quite what was going on. It probably happens quite a lot of the time, it wasn't desperately surprising, but with two fairly tired and fraught family members, it was a bit much.

Eventually, they did get me home safely and sat me into bed. Now that's the other thing that sort of made the discharge fairly iffy as normally they can't discharge you unless you've got a care package set up. But nobody wants to start a care package on the 23rd of December. So, they agreed that I could be trusted to the care of my family until the 27th of December when the care package was to start. The first day's visit was a man who came in who sort of talked through everything, i.e. what was going to happen. Most of which I think went over my head if I'm honest. As I said, I really don't remember, but he was there for a long time talking, I think, in considerable detail.

From then on, I had a week of carers coming in to help me. They came four times a day and did most things for me, but occasionally they would see if I could do some things for myself. And then when they finished, the care company took over. I continued having visits four times a day; however, timings were distinctly haphazard. I'd have a midday/lunchtime carer may be coming in at 11am. And I have a bedtime carer coming in about 7pm wanting to get me ready for bed, which didn't go down terribly well I have to admit!

So that's for six weeks of care from the NHS social care providers and I think it is what you get. It gradually dropped from four times a day to three times a day.... and then I think towards the end they gave up on the first, early morning, getting up visit because they decided I could cope for myself.

I mean I could, I guess (well most of the time). I was sort of quite glad because I could do it at my own pace instead of being rushed and washed at speed, had my clothes pulled on and then put in a chair. It took longer without help but I had control. I was, I think, more ill than I probably realised and I was very weak, and I wasn't capable of doing anything much for any length of time.

My daughter-in-law had worked out with me that it was possible to hold a small bowl of water balanced in the well of the Zimmer frame, so that I could take that through to the bedroom and wash myself. This allowed me to give myself an acceptable wash once the morning care visits stopped. And there was somebody to set out my clothes where I could reach them and then each day, I was able to dress myself. So, I wasn't sitting there in my night dress and dressing gown all the time!

I am also very lucky having my daughter and grandchildren were able to pop in and check on me and they helped me look after my dog. My dog is a great companion, but I couldn't have coped on my own at home with him. I would have needed much more care - but dog care rather than person care!

I think the biggest difficulties I had with the care company was that. I never really knew who was coming. I also never really knew exactly when they were coming. For a few of them, English was at best their second language or may have even been their third language, I didn't have any problems with them personally, the level of basic care was just that, basic, but the communication was a considerable problem. It was difficult to communicate quite a lot of the time and led to misunderstandings. I suspect that that's increasingly common, but it could be difficult.

I'm doing much better now; well, I think so. I'm very much more mobile and I use the frame if I have to get up in the night, which I do most nights and first thing in the morning when I'm at my least steady. And then I don't use it around the house during the day. Going outside, I can cope with a walking stick, one stick and I can manage short distances down the road, but I've got to build up my stamina, which is very low at the moment. And I am longing to be able to be confident enough to move my bed back upstairs instead of having it downstairs.

Looking back at the whole journey, I don't know how much difference it would have made but had there been more information available to me, i.e. had I known a bit more about how the discharge was going to pan out would have been useful. But it seems as though it wasn't practical to give me a plan as maybe it wouldn't have been possible to say they were going to stick to it. I think until the last few days that I was there, one of the consultants was saying that she thought a period in respite care might be a good idea. And I said, I thought that would be a seriously bad idea, and fortunately she listened to me and accepted what I was saying.

Story 3: D2A patient, JR, Oct-Dec 2023

I was admitted to the trauma unit for 13 days and I was given some indication of what would happen next, but I can't remember when, or which day it was, and I can't remember exactly what, or who it was who told me but I could be transferred to the enablement sector or I could be sent home to survive and recuperate. So basically, get myself back to square one at home or I could be sent to somewhere else. I can't quite remember. No, nowhere else was specifically mentioned to the best of my knowledge, other than somewhere else.

On the day of my discharge, I was not given any prior indication about my leaving hospital until 6:00am in the morning. I was already awake and was then told to get up and to get yourself ready because someone's coming home. So, I think to myself that I haven't actually been told before this, which meant that the

discharge was all coming about rather quickly. So anyway, I was discharged - picked up at 9:00am and brought home and told that someone on the care side of things would be coming to see me in the afternoon. As explained, later on that day, a lady came to see me and assessed my care needs. It was decided that I would have six weeks maximum care. One in the morning and one in the evening. And sure enough, someone came the first evening at 6:00pm and to put me to bed etc. It was really quite difficult because I had to do a transfer onto my own bed which I haven't had the luxury of having. See, having been in hospital, it was quite a bit easier than at home because the hospital beds were so soft, even though they changed my bed to what they called was a hard mattress, but it wasn't terribly hard, right? So, for weeks, I had care at 8am in the morning, to help me wash, to do the dressings, to get me up and to wash etc...

And I'd asked once or twice in hospital have they got any idea how long I'd have the leg in plaster? And they said for as long as it takes, basically. And so, I was discharged with a long leg cast and that was, the carers coming morning and evening for five weeks and four days, five days, right? And then I was abruptly notified that my six weeks were nearly up and that was on a Friday which left us in a bit of a pickle. Basically, my six weeks were up in effect and my wife had to be shown very quickly what to do in order to help me out of the bed and into the bed etc... This meant it was left to my wife helping me morning and evening. We then had to get my own career back on board to give me bed baths, but she doesn't help me into bed, and I deal with my incontinence.

Story 4: D2A patient, Nuffield Orthopaedic, Jan-Mar 2024

Okay, so at the time of discharge, I had to wait for care to be arranged because I live on my own. Because of this, I was in hospital longer than was necessary and there was a weekend in between. But once the care was arranged, it was brilliant. I had hospital transport home, and the care agency lady came to see me about two hours after I'd returned home, and she informed me about the care package.

The carers were very good. I was able to attend to my own personal care washing, etcetera. I'm not sure I would have liked the young men to wash me if it had been necessary. But then I would have asked the agency lady for a female carer. They came twice a day, mornings and evenings, but eventually I became more independent. After about two to three weeks and I just needed one carer a day. All in all, I thought it was very good.

The only thing I would say, was there was one blip at the Nuffield, which I feel I should tell you about in case it happens to anybody else. They were obviously

very short staffed in their defence, which I can understand and the day after my operation they tried to discharge me. The discharge nurse came round and said this at 3pm and said you can go home at 6. I said, well, I have no one to take me home and I have no care package in place. This would have been on the Friday after my operation on the Thursday.

She became rather insistent, and she said if you stay here, you'll have to be moved to the infection ward which I felt was rather intimidating. I stood up for myself and I said because during the pre-op it has been arranged that I would have transport home and carers because I live on my own and it wouldn't have been possible to manage immediately after the operation. So I said to her, I'm not leaving until I've got hospital transport and the care package. At which point she went awa and the OTs came after about 5 minutes and apologise to me because I was very upset. But apart from that, that was the only negative thing I have to say about my stay in hospital and my aftercare. That was the only negative thing as I understand the discharge nurse was under pressure to release me.

But as it happened, I didn't go on the infection ward, and I was just moved to another part of the short stay ward. The following week, the lady came round once it had been arranged (my discharge) and she said that somebody will be here to collect me from 8:30am onwards and that a care agency lady will come and visit at 12:30pm. So yes, I felt they were confident in the plan and communicated this with me effectively.

Six months on and I'm doing well. I've been away on a short break and feel more like I used to. It's a miracle operation, it really is. As I say, the treatment and care at the Nuffield is second to none, you know. They all treated me very well, apart from that wallet. And I haven't got a toilet upstairs, so the main reason I needed a carer was to deal with the commode for me. Also, I couldn't stand to wash up all. So for two to three weeks, I was quite dependant.

Story 5: Unpaid carer of D2A patient, JR, since April 2024

M, my husband, has advanced Parkinson's and Parkinson's dementia. The thing about the discharge process is first of all, there are things that are absolutely fantastic. There was the discharge coordinator on the ward most of the time who I could always talk to. The OT people were really good, and the nurses and the healthcare assistants were really good, and they were used to people with dementia. I was keen to get M home, because I've worked in hospitals nearly all my life, and I know that they're dangerous places. I kept being told, "maybe in another week". We had [financial challenges] and I wanted to talk to a social

worker. People didn't actually laugh, but you felt that they were laughing. They said "a social worker will be in touch in due course." The OT workers were very, very good with M but they didn't test him on the stairs, and that actually became a really big issue. They said the OT would be around when you get home. Actually, it took hours.

Eventually we got a discharge date, and I was told that M would have a carer available for when he came home. The consultant and the OT people said to me he has to sleep downstairs. That was a really big thing because we've got an open plan house and I had to get screens from Ikea, we had to get the hospital bed, and we had to put his clothes downstairs and all the rest of it. It was a huge upheaval.

M got back home in the ambulance sometime just after 10. He was really confused. He was wandering around the house and he was unstable, he could fall really easily. He was doubly incontinent and there I was with M, who I was so excited about getting home, I couldn't make a cup of coffee. I couldn't do anything. And there was no sign of the agency. Eventually I phoned them and I spoke to the manager and he said, "oh no, we have to do an assessment before we can send a carer around." The manager came and he was clearly very experienced, and he did an assessment and all the rest of it.

I had asked for three visits a day, and all the time I kept reining back what my needs actually were, because I kept getting messages from social services who would talk to me, the staff on the ward, the discharge coordinator: "They won't be able to do that." And actually I knew what I needed, I needed 24 hour care, but I didn't like to ask for it. So I asked for a waking night carer and two visits a day. One of the visits was going to be in the evening, so I was expecting a carer to come at 5 o'clock.

So, this was the day of discharge, the manager had been, he'd assessed M, he could see how disabled he was, the carer was meant to be coming at 5, I'd called my son to be with us just in case. The carer didn't arrive until 6.15, and M had been doubly incontinent, and he was still confused, he was still wandering, he was still having terrible hallucinations. Anyway, when the carer arrived, I was in the middle of changing M and we'd given him his dinner, and a carer arrived halfway through changing M and he said: "I'll take over." Eventually I said: "I think we'll manage now." He left and I saw afterwards that he'd written in his notes that we didn't need any help or something like that, which was actually untrue.

Then we were expecting a night carer, and the night carer phoned me from [the other side of Oxford] saying she couldn't find our house. She was about an hour

and a half, an hour and a quarter late. And when she arrived, she started to tell me about all her personal problems, almost immediately. But she seemed really experienced and I slept all night, she managed to keep M in bed or got him back to bed, because his nights are terrible. This first day was a terrible experience when it should have been happy.

We had the agency I think for about three weeks. The whole of this discharge process was marked by not knowing what was going to happen. I thought that we had a three-day evaluation period, and then we would know what was happening. On the one hand, I was grateful, because the agency, within their limits, did what they could. Secondly, I had significant help at home for the first time and I was pleased that M was able to come home. But we had – I counted in my head – for a period of three weeks, 22 different carers. We ended up with a night-time carer who came from 10 o'clock at night until 10 o'clock in the morning, and I would meet the carer, hand over to her, I'd go to bed. But I began to realise, I realised in retrospect that although she was very experienced, she had absolutely no idea how to handle somebody with dementia. I think the "care" was harmful. We had one person from that agency who was really experienced at night, and M had a wonderful night with him. The night carer I think made M very much worse.

Now we've got carers [with CHC funding] that we've selected that have experience of dementia or who are doing courses in it, M's nights are very much better. They're not problem-free, they're still problematic, but he's treated in a humane way.

I think that the staff are really doing their best in a really threadbare system, beyond capacity. Staff were often really pessimistic. When I talked to people about having 24-hour care for M, they said: "well that's just not possible". I always had this feeling that I was asking too much, in a service that couldn't manage it. And then eventually, I thought, actually, I can't look after M, and he won't recover, and we need to rehabilitate him. But actually he is very much better now than he was. He has lucid moments, he has moments where he actually says he feels quite well, we're normalising his life, and the carers have got to know him, and they really enjoy him as a person.

What happened when I got the 24-hour care with [specialist] carers I could trust, was that my empathy for M returned. Before that I was getting more and more irritated, and I couldn't look after him properly, I couldn't see him as a person. And it was really wonderful, as he started then to have more lucid moments. There was one point at which he stopped me, and he said: "I've just really got to talk to you." And I didn't know what was going to happen. I sat down and he looked at

me and he said, “I really love you.” So, the good care, it’s not just about healthcare, it’s about quality of life and the relationship and everything – it’s just priceless.

Story 6: Unpaid carer of D2A patient, RBH, Jan-Mar 2024

So J's admitted to hospital on that Saturday night in the early hours and 18 hours later, she goes to a bed in the acute medical ward, so it’s an 18 hour wait. I come in on the Sunday and generally it's like a battle zone and you can't believe how busy it is. On the Monday I became involved with the occupational therapist, a nice person and all that but obviously limited in what she could do. She said to me – it’s not obvious I’m 80, I’m fit and do a lot and so on – “but you do need some support, don’t you?” I said, “that'd be very good, yeah.” We were getting warm Monday, Tuesday, and then it starts to cool, till we get to the Friday when it was officially stated that J could come out, assuming there was some care. It became obvious that the care would be non-existent and generally there wouldn't be any because she couldn't lay it on. So here we are. I'm at home on the Friday, one wife who's still confused. What do you do? Well, you have to be resilient and what that means is turning to the doctor, making an appointment for the following Monday, and you've got the weekend to contend with.

On the Saturday I got a call from Oxfordshire Care about lunchtime and said, “Generally are you coping?” or “How are you? How's the patient?” And I said, “Well, you know, we’re coping, but I'm an 80 year old man. What do you do?” And she says, “I'll see what I can do.” I got phoned on the Thursday by Bridges Home Care, who came in to do an evaluation and said, “I will send somebody on for you on Saturday.”

[The care started with] a lovely lady from Czechia. Then the next day we got a new person, who’s Sri Lankan, and so on. And we're doing all right, I mean you know, it's satisfactory, it's getting J out of bed and establishing a routine and so on. I also went to Headway. And Headway are very good. They’re a brain charity. I'd raised money for them [in the past] and I thought instantly, let's have a go with Headway. They were very good, we met a counsellor who gave us some extremely good advice. Because when you're in this sort of predicament, you need good quality advice. You know, dos and don'ts. She said you’ve got to get into a routine so that the patient is starting to feel orientated and it will probably take six months. The carers were allowing us to get into that mode of a routine. OK, they were not the same time every day, but they were close.

Then we have a problem. On the Tuesday I think it was, they send a man. And we never discussed this and it was somewhat a shock to be confronted by a male.

My wife didn't like the concept, so I said to the guy, “You're probably very good,” and he seemed a very decent bloke, but really in an intimate domestic setting of the bedroom... I think it's different in a hospital situation from a domestic situation and regretfully had to turn him away. I talked to the care company, Bridges, and they said, fine, tomorrow will be different. Well, it wasn't because they sent another man. A second man. It was the same story, of saying, “Well, I really do think it's not appropriate for a 77 year old woman, you know, she would feel uncomfortable.” So we got over that. Then the next day was a lady and in fact it was the manager, which I thought was quite strange that the manager should be coming out. The next day, Saturday, they sent another man. And then on Monday by 11:00 we’d had a no show. I, in exasperation, phoned them and said enough is enough, out of 10 days of care, six days have been with a lady and was satisfactory, 3 days were men who I had turned away and the last day was a no show. Quite honestly, I didn't know where I was, and my wife certainly didn't know where she was.

Story 7: Unpaid carer of D2A patient, RBH, before April 2023

I started with the OT as to, what is the process for discharge I said and how long is it going to be because we need to get planned. I said “there's no way my mother can get upstairs.” We have got a downstairs toilet, thankfully. So then she started to ask me for photographs. So I said, “do you come out?” “No, we don't come out,” she said, “just take a photograph of her bedroom, tell us the height of her bed, tell us the height of her toilet. And where could you put a hospital bed?” So I said “Well, the obvious place is to where I could move furniture would be the bottom lounge.” Lots of photographs sent and all the rest of it. And then this OT who I kept ringing, she kept muttering about Home First, and I said, “What are you talking about, Home First?” And she said, “Well, you know” - I got no explanation. So I did some Internet searching about Home First and discovered who they were and phoned them.

It was very difficult to get through but I got through, explained that my mother had been 10 days in hospital, she was 96. “What do you provide?” I said because I'm not getting any sense from RBH on this. They had all this NHS language, like, “we're an MDT.” I said, “You’re just talking in riddles, what is it you're going to provide?” Well, you know, “There is this provision for up to four weeks support, delivered through All Care” and I said, “who are All Care when they're at home?”

So slowly I started to find out what the scenario was and in the meanwhile my mother was getting very upset about being stuck, and she said, “I'm just sitting here, I'm not doing anything, so I'd much rather be at home.”

RBH rang up and they said they could get a bed, a commode and a walker and a perching stool to me, so that came that following weekend. That was two weeks then. So that arrived and we did put it in the bottom lounge and move furniture around and they were really good. Then all of a sudden we get this phone call to say “Your mother's coming.” And they kept emphasising it's up to four weeks, up to four weeks, up to four weeks. The occupational health in Royal Berks said she needed four visits a day.

So Home First rang me and said that somebody would come, not the coordinator, but somebody would come that day just to introduce themselves. So anyway, mum did come home. They did turn up, the office manager came just to get us to sign the forms and she looked around and she saw the bed down the bottom and she went and had a look at the toilet, and I mean, the only way for washing would have to be come up three stairs, walk through the kitchen and go into the utility room, to be honest. But she looked at all that and she said, “Oh, well, we're going to reduce this immediately to two visits a day. You're not having four.” She said, “We'll have one in the morning, half an hour. And we'll come and get you to bed.” She said, “It will start tonight with getting you to bed with this firm called All Care.” And that was that. She said, “Oh, a coordinator will come and see you at some point.”

Somebody from the care firm came, but they came about half past 5. Bearing in mind this is the first day mum was home. She said, “Where's your nightie, where's your dressing gown?” And Mum went and I went, “No way.” I said, “I'm sorry, I'll struggle myself. We'll get mum down there somehow. But she's not going to bed at 5:30. This is ridiculous. We haven't had dinner yet.” So it was reduced immediately to half an hour a day. And so that's what happened. A succession of people used to come anytime between 7.30 and 11, it was hopeless. They were individually OK. I was emptying the commode, sorting all her clothes out, making the bed. Literally they were helping my mother walk up the stairs and helping her have a strip wash and helping her dress and most of them were gone within 25 minutes. There was no way they could have done you know the things that were on the list, it was supposedly empty the commode, make the bed, sort her out. There was no way they could have done that.

But what used to frustrate Mum was absolutely not knowing, you know, sitting there. Luckily, I was there, so I was giving her breakfast and sorting her out and

getting her to the toilet in the morning, because she'd use the commode in the night but she didn't like to use it in the day. But you'd never know. By the time they came they were exhausted, they were fed up, they were being sent all around the country. A couple of times they didn't turn up at all, so I was often ringing the office about it. Individually there were some nice people. We eventually got somebody called [name], but she was always stressed. Young girl. Very stressed.

I can't remember how many times I rang Home First, probably five times over three weeks to say, "When is this assessment happening? When is the coordinator coming?" And all I got was, "We're very busy, we're overstretched, there isn't anybody. There's no duty social worker." But we hadn't seen the coordinator, so I kept ringing. It must have been nearly three weeks after Mum had exited when this guy arrived, me having created a massive fuss. He arrived, very nice. He said he'd transferred from somewhere and he said "You've only got this visit because you've been basically creating a fuss." He was very nice. He went round the house, he looked at Mum's bed and he looked at the toilet and he looked at where we needed a handrail. He watched Mum walk and I think he ordered something else. He said, "I'll come once a week for a few week, but just remember," he kept saying, "This care is up to four weeks. You're not entitled to four weeks. It's *up to* four weeks." So by this time, you know, she'd had probably over 2 weeks, nearly three weeks. I kept on about the physio, so he said yes, you will get a visit. It must have been the end of that week, a very nice chap in a gym outfit came and got Mum stood up and stood down and blah blah blah, very good. He said to me, "What's your e-mail address? I'll send you some leaflets." I said, "When do you come again?" And he said, "Oh, no, that's it. You're entitled to half an hour. So your mother's had your half an hour." So that was that.

Story 8: Unpaid carer of D2A patient, JR, Oct-Dec 2023

She'd been in hospital four days when I heard a rumour that they were about to discharge her. I didn't really know what was going on and no one had contacted me directly. I tried to explain to them on several occasions that my mom doesn't have an enduring health cover and that I'm responsible for looking after her. She was also very confused the whole time that she was in the hospital, I think mainly because of the drugs that she was on.

During the time that she was there, they got her to sign an NDA, which she still swears she never signed up the minute she got home, and I tried to explain to her that that's on a computer somewhere now. So that's tough. They then had a conversation with her about moving her to another home, offered her a home in Bicester, she refused that, saying my daughter couldn't get to me. The next thing

they then offered her another home in Chipping Norton, and they told her because she'd already refused one, then she would have to accept this one.

I then found out what was going on, even though I'd asked several times that if she had to be discharged in a hurry, can you please let me know? Because I'm happy to ring around and try and get her somewhere closer to home. She's obviously going to be there for some weeks because of this broken knee. Anyway, that didn't happen. The next thing I had a call from the lady who discharges people to say that that she was on the transport to Chipping Norton. So it was too late to do anything about anything about that and I just felt a little annoyed that nobody had written anywhere, even though I'd actually had a word for the nurse and said, please, can you just give me 24 hours to try? It was just before Christmas, so as you can imagine it's very difficult anyway to try and pin anything down. And I said to her just put in a message in her notes not to talk to her and to talk to me and please could I have 24 hours to find somewhere else for her? They didn't give me that. They just discharged her. So that that was my experience.

The home that she went into was not good. I mean, I don't have a huge amount of experience of what these homes are like, but she was in a bed with a torn mattress. There was very little in her room, she had no physio while she was there. The food was pretty appalling, and she needed feeding up because she was very weak having been so poorly. When we arrived Saturday evening, they were giving her two slices of white bread with pâté on it. That was supposed to constitute as her evening meal!

She’s back at home now and she's recovered quite well. She's managing to do most things. We've now got her a stairlift fitted, finally. We’ve also had some wonderful help from the occupational therapy people, finally. Again, I say finally, because I made three calls over the last two or three years and registered a request for this to happen and it never did because of COVID. I think we just, everybody just let these things go and I suspect that might be part of the reason, but they didn't actually contact me until somebody from the hospital who was a physio there had actually seen her and recommended that the occupational therapist contact her. I mean maybe there's something wrong with the website, I don't know. But anyway, when they did eventually contact, they've been absolutely marvellous. They've given her lots of aids to help her while she's at home. She's as safe as possible.

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HOSC Meeting: 21st November 2024

Introduction

This report provides an update on Maternity Services at Oxford University Hospitals NHS Foundation Trust (OUH). It highlights key updates and offers a comprehensive overview of the current state and future for maternity services at OUH. At the request of the Health Overview and Scrutiny Committee a narrative overview of the trends in birth injuries, perinatal and maternal mortality, birth trauma, and the implementation of various action plans and initiatives are included alongside an update on the CQC action plan and the Keep the Horton General Campaign Group (KTHG) Birth Trauma Dossier.

Please note that in this document, the terms "mothers" and "women" also encompass all other birthing individuals.

1. Trends in Birth Injuries, Deaths, and Birth Trauma

1.1 Birth Injuries

OUH routinely collects and analyses outcomes for women and babies who give birth within its service. These outcomes are reviewed within the maternity directorate, as well as at divisional and board levels. This systematic approach helps identify patterns and implement targeted interventions aimed at reducing risks and improving patient outcomes. In terms of birth injuries there two indicators for women and two for babies that are reported locally and nationally.

Please note that OUH Maternity Services offers care to the local community and is a tertiary referral centre for women at high risk of complications. These women are referred to OUH from Buckinghamshire, Berkshire, Northamptonshire, Wiltshire, and parts of Warwickshire. The service also receives referrals for women with severe medical conditions (such as major cardiac disease) and those who may face complicated caesarean births.

Birth Injuries - Women

The standard reported birth injuries in women are postpartum haemorrhage (PPH) of more than 1500mls and 3rd or 4th-degree anal sphincter tears. Table 1 below provides a summary of the number and percentage of PPH of more than 1500mls and 3rd or 4th-degree anal sphincter tears at OUH over the past six years.

Table 1 Number and Percentage of PPH >1500ml and 3rd or 4th-degree Tear at OUH

Year	Total Births	PPH >1500ml	3rd or 4th-degree Tear

2018	7199	2.81% (202)	2.72% (196)
2019	7146	2.39% (171)	2.64% (189)
2020	6768	2.25% (152)	2.25% (152)
2021	7343	2.02% (148)	1.78% (131)
2022	7396	2.35% (168)	1.71% (122)
2023	6789	2.74% (186)	2.08% (141)
Published UK Rates / Target		**3.3% (3.1%-3.5%)**	**2.9% (0-8%)**

As indicated in the table above the rates of these injuries have remained consistently below the published UK rates and targets. The Trust is committed to reducing these injuries to the lowest possible levels, and in 2024/25, identified this area as a focus for a quality priority. As part of this initiative, the Trust has implemented new training programmes and revised its induction of labour care pathways. These improvements aim to reduce delays, as improving the induction of labour processes is linked to better outcomes and reduced rates of PPH above 1500mls and third- or fourth-degree tears.

Birth Injuries - Babies

The standard reported birth injuries in babies relate to an NHS England initiative aimed at reducing the number of full-term babies (born at or after 37 weeks) admitted to neonatal units. This programme is referred to as a ATAIN (Avoiding Term Admissions into Neonatal Units). The second reporting measure related to birth injuries in babies relates to the babies requiring therapeutic cooling, which is a treatment for babies born affected by low oxygen level and at risk of potential brain injury (also called hypoxic ischemic encephalopathy or HIE) after 37 weeks.

Table 2 below provides a summary of OUH percentage and number of babies who were admitted to the neonatal unit after 37 weeks and the number and percentage of babies who required therapeutic cooling after 37 weeks.

Table 2 Number and Percentage of babies admitted to NNU after 37 weeks and cooled after 37 weeks

Year	**Total Births**	**NNU at >= 37weeks (ATAIN)**	**Cooled >= 37weeks**
2018	7199	4.50% (324)	0.19% (14)
2019	7146	4.04% (289)	0.14% (10)
2020	6768	4.64% (314)	0.21% (14)
2021	7343	4.58% (336)	0.25% (18)
2022	7396	4.06% (290)	0.10% (7)
2023	6789	3.86% (262)	0.07% (5)
Published UK Rates / Target		**National Target 6%**	**National Target 0.1 – 0.35%**

As indicate in the table there has been a significant improvement in the most serious outcome reported (cooled >= 37 weeks therapeutic cooling). Since implementing a

foetal physiology-based CTG interpretation in February 2022, risk assessment has improved, leading to better neonatal outcomes. This approach helps clinicians recognise and manage CTG patterns by educating them on foetal adaptations to hypoxia during labour. Consequently, there has been a notable reduction in Hypoxic Ischemic Encephalopathy (HIE)—where babies require cooling for potential brain injury—and fewer unplanned term admissions to the neonatal unit, highlighting the initiative's success.

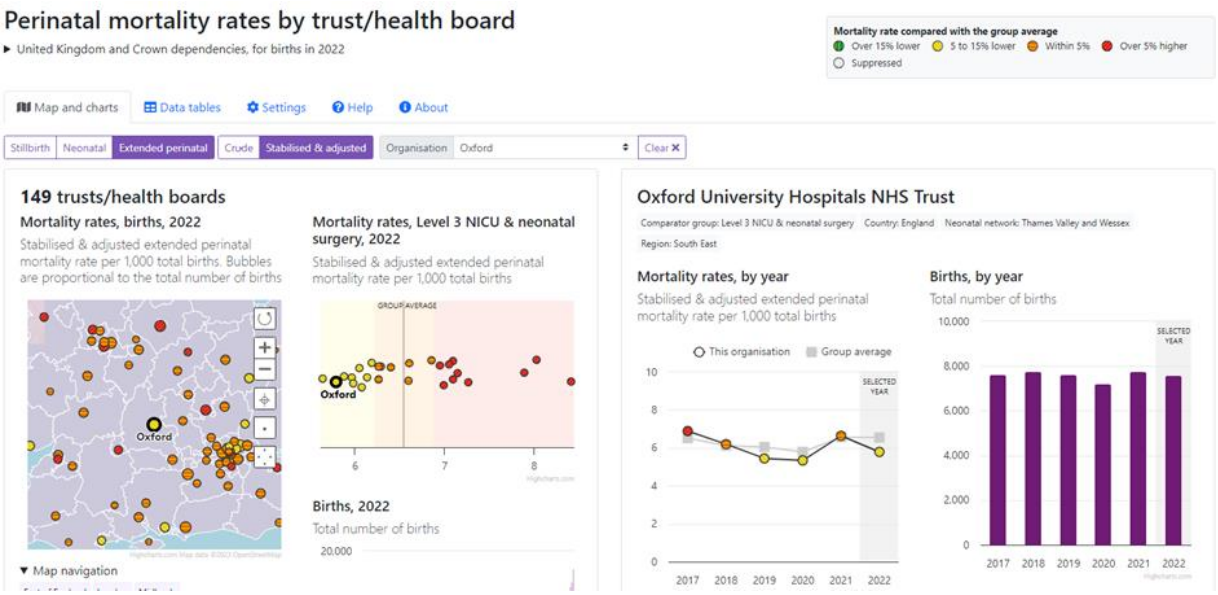
In addition, work is underway to create a unified reporting system and harm level for the birth injuries described within the BOB Integrated Care System (ICS) and to establish consistent benchmarks for all providers. The Trust's quality priority is to reduce maternal and neonatal morbidity by tracking harm metrics for women undergoing induction of labour. Additionally, the service is monitoring the impact of reducing delays in IOLs and performing thematic analyses in accordance with the Patient Safety Incident Response Framework (PSIRF) to identify trends and inform necessary interventions and improvements.

1.2 Perinatal Mortality

Perinatal and maternal mortality data is reported to the MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) programme at the National Perinatal Epidemiology Unit. MBRRACE-UK is a national initiative to improve health outcomes for mothers, newborns, and infants. The programme provides detailed data on perinatal mortality rates for individual Trusts, including rates for stillbirths, neonatal deaths, and extended perinatal mortality. These rates are adjusted for maternal age, socio-economic status, and ethnicity to ensure fair comparisons.

Trusts are categorised into groups based on their level of service provision, allowing for more accurate comparisons by considering variations in case mix. OUH is a tertiary-level unit with neonatal surgery (the highest risk category), complex pregnancies from other units are referred to OUH for care. MBRRACE UK considers this and compares OUH with similar-level units. In July 2024, MBRRACE UK published the Perinatal Mortality Surveillance Report for UK perinatal deaths in 2022.

As illustrated in figure 1 below the MBRRACE data from 2022 (the latest to be analysed) shows that the OUH perinatal mortality rate to be 5.79 per 1000 births. This rate is the 2nd best out of 26 similar units that OUH were compared against and is 5-15% lower than the average of the comparator group.



To access the specific perinatal mortality rates for Oxford, you can visit the MBRRACE-UK section on the National Perinatal Epidemiology Unit (NPEU) website. This will provide you with detailed statistics and analysis.

1.3 Maternal Mortality

Maternal mortality data is also reported to MBRRACE-UK annually. For OUH, this includes the deaths of mothers who either gave birth or passed away in Oxford. Maternal deaths are defined as deaths occurring during pregnancy or within six weeks following the end of the pregnancy.

As a tertiary referral centre, OUH receives referrals for and provides care to women with complex medical issues from other Trusts for high-risk maternal medicine. While maternal mortality has increased nationally, OUH has not experienced the same trend. Including referred pregnancies, there were two reported deaths in both 2020 and 2021, two in 2022, and one in 2023. All cases of maternal death undergo a national review and are rigorously investigated by the Trust and external partners to continuously enhance maternal healthcare services.

The Trust has implemented a new pre-eclampsia screening process, based on the Tommy's app in November 2024. This new screening process aims to improve prevention through aspirin, reducing complications such as perinatal and rarely maternal mortality. The Trust are also increasing growth scans for foetal growth restriction, the primary precursor of stillbirth, and enhance access to specialist care for women at the Horton by expanding outreach clinics. OUH is also developing an integrated screening program for perinatal mortality, with a new phase launching in January 2025. These efforts will specifically support women from ethnic minorities and those facing disadvantage.

1.4 Birth Trauma and Birth Reflections Service

The definition of birth trauma can vary, but it generally includes both the psychological impact of a difficult birth and any physical complications that may arise. According to the Birth Trauma Association, up to one in three women in the UK experience a traumatic birth.

In 2022, OUH collaborated with Oxford Health to develop a Birth Trauma Pathway. This service offers direct access to the Birth Reflections service. The service is designed to assist individuals in processing their birth experiences and managing any emotional challenges they may face. In addition to self-referrals, general practitioners (GPs) can direct people to this service. Typically, the service caters to individuals up to one year postpartum, but it also considers referrals after a longer period on a case-by-case basis.

The table below outlines the rates of accessing the Birth Reflections service between 2021 until 1st November 2024.

Rate of Attendance at the Birth Reflections Service	
Year	**Total**
2021	207
2022	205
2023	237
2024 (to 01/11/2024)	260 (projected 334)

The Trust also has in place a designated birth trauma midwife and the clinical lead consultant in Postnatal Care provide additional targeted support for women after childbirth. They also collaborate with specialised mental health midwives to identify and address mental health concerns that may require different referrals. The Trust are currently conducting a gap analysis on the recent parliamentary reports on birth trauma and are mapping Birth Reflections capacity to ensure demand is met.

2. CQC Action Plan for Midwifery-led Unit (MLU) at the Horton General, the Keep the Horton General Campaign Group (KTHG) Birth Trauma Dossier and Independent Review Panel

2.1 CQC Action Plan for Midwifery-led Unit (MLU) at the Horton General

In October 2023, the Care Quality Commission (CQC) inspected the Midwifery-led Unit (MLU) at Horton General. Following the inspection, the CQC rated the service as "Requires Improvement" in both the Safe and Well-led domains. The report outlined six must-do actions. A summary of progress against each action is summarised below:

- **Must Do Action 1:** The Trust must ensure thorough checks of emergency equipment and consumables to identify outdated items for replacement. The Trust has implemented 'MyKitCheck,' a digital system that replaces paper checklists and provides real-time updates on medical equipment. This system streamlines the management of equipment and safety checks, ensuring they are current and compliant.

- **Must Do Action 2:** The Trust must ensure staff complete risk assessments for women, birthing individuals, and babies, addressing any identified risks. The Trust has now digitalised these risk assessments, which form part of the electronic patient record in maternity. A monthly audit programme is in place and is reported and shared with the Maternity Clinical Governance Committee (MCGC) and the Trust Clinical Governance Committee (CGC).

- **Must Do Action 3**: The Trust must that all medicines are in date and stored within the correct temperature range. The Trust has put in place a cold chain room temperature monitoring form and room temperature monitoring action log. All areas within Maternity Services have completed the Trust's Safe and Secure Storage of Medicines audit. Weekly leadership care assurance visits have been implemented a core component of which is a thorough review of medicines safety and storage. Recent audits showing a 98% compliance rate in medication storage standards.

- **Must-Do Action 4:** The Trust must ensure that staff adhere to the established policies, procedures, and guidelines, including the decontamination of the birthing pool. The cleaning and decontamination instructions for the birthing pool have been updated and are now posted in the area where the pool is used. Additionally, funding has been secured for a new birthing pool, which is set to be installed at the Horton MLU in November 2024.

- **Must-Do Action 5:** The Trust must conduct regular audits to ensure patient safety. A schedule for routine maternity audits for 2024-25 has been established, along with additional audits to assess the activity of the Midwifery Led Unit. A monthly audit programme is in place and is reported and shared with the Maternity Clinical Governance Committee (MCGC) and the Trust Clinical Governance Committee (CGC).

- **Must-Do Action 6:** The Trust must ensure that effective risk management and governance systems are in place to support safe and quality care within the midwifery-led unit. The Standard Operating Procedure (SOP) for the Manager on Call has been reviewed, updated, and implemented. The development of the community dashboard is progressing well and the service is actively working to refine and enhance data collection. Audit reports, actions, and compliance data are reported to the Maternity Care Governance Committee.

The Trust has formed an Evidence Group to monitor and evaluate the progress, effectiveness and embeddedness of the CQC actions outlined above. Updates on the progress are provided through established governance processes, which include the Maternity Clinical Governance Committee and the Trust Clinical Governance Committee as part of the maternity quality reports.

2.2 Keep the Horton General Campaign Group (KTHG) Birth Trauma Dossier

In May 2024, KTHG published a dossier of mothers' accounts of their pregnancy care at OUH since 2016. The dossier comprises 50 anonymised cases of women and families in the Banbury area who had childbirth experiences between 2016 and 2024. The cases were gathered following a media request by the KTHG and are part of a campaign to restore full maternity service to Banbury.

On receipt of the dossier the Trust thoroughly assesses the quality of maternity care in the 50 cases and identifies key themes and areas for improvement. These include distance and travel to the John Radcliffe (JR) Hospital, delays in the induction of labour, inadequate postnatal and bereavement care, lack of compassion and kindness, and poor estate and facilities.

The Trust has developed an action plan in response to the dossier enhance the quality and experience of maternity care. These actions include reviewing transport and parking arrangements, improving postnatal and bereavement care, addressing information needs, and dealing with the lack of care and compassion through visible and supportive leadership, training, education, and acting on feedback from service users. Progress has already been made on the actions summarised below. The Trust has extended visiting hours in the postnatal areas to allow birthing partners to stay overnight. Currently, two high-risk diabetes antenatal clinics are operating at the Horton, as well as a specialist mental health clinic. In addition, a Consultant Midwife clinic will be added to the schedule, and plans are underway to increase the scan capacity at Horton after receiving funding for a new scanner from the LMNS. Parking at the JR remains challenging due to congestion; four emergency patient parking spaces have been allocated outside Maternity to help address this issue.

The Trust has met twice with representatives from Keep the Horton General Campaign Group at the Horton General Hospital on 18 July 2024 and at the John Radcliffe Hospital on 13 September (this second meeting included BOB ICB colleagues) to discuss the response to the dossier and the associated action plan. The Oxfordshire

Maternity and Neonatal Voices has been actively involved throughout this process and are participating in the co-design and implementation of the improvement actions.

2.3 Independent Review Panel

In October 2016, the consultant-led obstetric services at the Horton General Hospital were temporarily closed due to obstetric staffing issues. A free-standing midwifery-led unit with a dedicated ambulance service was established. Obstetric services remained closed, and the governing body of Oxfordshire CCG decided on 10 August 2017 to remove obstetric care from the Horton permanently and replace it with a midwife-led unit. The Secretary of State referred this decision to the Independent Review Panel (IRP), which published their findings on 9 February 2018.

The IRP review acknowledged that the consultation process regarding these changes was limited to Oxfordshire. It called for a more inclusive and comprehensive consultation method for future healthcare transformations. Although the maternity service has remained unchanged since this review, any future changes require commissioning bodies to engage with all relevant local authorities with health scrutiny powers, ensuring their active participation. Additionally, the IRP recommended improved communication and collaboration with all stakeholders, including residents and healthcare professionals, to make their involvement and feedback essential to the decision-making process.

An action recommended in the response to the KTHG Birth Trauma Dossier is to review maternity services. The ICB (Integrated Care Board) aims to provide the best possible healthcare for the diverse populations across BOB (Berkshire, Oxfordshire, and Buckinghamshire) and values feedback from individuals who have used healthcare services. The new government has committed to developing a 10-year plan for the NHS, which will be published in the spring of 2025. This plan is expected to offer additional guidance for maternity services, women's health hubs, and support for children and young people (CYP). Through the Change.nhs listening exercise, patients and the public can contribute to identifying priorities and goals for both local and national services. This national initiative will also facilitate planning and prioritization across various clinical interdependencies.

BOB recently completed an internal restructuring to enhance its capability and capacity for long-term planning and adopt a more strategic approach to service commissioning. As part of this effort, BOB is committed to reviewing maternity services within the system and collaborating with other services, providers, and local authorities as part of this process.

3. Engagement with Partners, Stakeholders, and Patients

In the past two years, funding for the Oxfordshire Maternity and Neonatal Voices Partnership (OMNVP) has doubled, improving the breadth of activities and participation. This increased funding has allowed the Trust to include 'Neonatal' in its work plan. OMNVP representatives actively engage in the Maternity Clinical Governance Committee and Safety Champions meetings, providing valuable user perspectives. The OMNVP collaborates with the Trust on initiatives like the Culture Review and Maternity Development Programme. This includes co-facilitating events and establishing a Maternity Patient Experience Working Group.

The OMNVP also supports with improvement projects, such as enhancing parent education sessions, revising visitor policies, and improving the Maternity Assessment Unit. Theu also undertake regular feedback surveys, including those on baby loss and neurodivergence and help the Trust to better understand family experiences. These efforts have led to significant changes within the OUH Maternity Service, ensuring a patient-centred approach to improvements.

The service continues to value and incorporate feedback from external partners and service users. In response to a Healthwatch report, the Banbury Sunshine Centre has launched various support services for vulnerable families. This includes the Saplings group, which offers weekly antenatal classes on healthy eating, oral hygiene, and mental health awareness. The centre also hosts a baby group to foster community among families after birth and has established a Multicultural Team to provide peer support and help families connect with relevant voluntary services.

The Trust also works alongside internal and external partners to improve maternity services. External stakeholders include the Buckinghamshire, Oxfordshire, and Berkshire Local Maternity and Neonatal System (BOB LMNS), NHS England, The National Childbirth Trust, Sands, and the Maternity and Neonatal Safety Improvement (MNSI) programme. The focus of these activities is on enhancing patient safety, integrating digital solutions, and addressing health inequalities. Internally, the Trust works with the Executive team, divisional leadership, and specialist teams, such as those in Patient Experience, Patient Safety, Governance and Assurance.

4. Improvements in Safety Checks and Medication Storage

Significant improvements have been made in processes around safety checks and the safe storage of medications as discussed in section 2 of this report.

5. Risk Assessment Processes

Risk assessment and triage are vital for high-quality maternity care. Ongoing risk assessments are conducted at booking, antenatal appointments, during labour, and postnatally and audited in keeping with the Ockenden report and the Maternity

Perinatal Incentive Scheme (MPIS). The Trust has introduced digital tools such as BadgerNet, a maternity-specific electronic patient record system. This system enables dynamic information sharing and timely access to patient records, facilitating more accurate and comprehensive risk assessments. As a result, there has been a 20% improvement in the early identification of high-risk pregnancies.

The Trust has also recently implemented the Birmingham Symptom-Specific Obstetric Triage System (BSOTS). BSOTS establishes a structured and standardised process for triaging maternity care. This system prioritises care based on clinical need, ensuring that urgent cases receive timely attention. The Trust is implementing BSOTS across all relevant departments to improve the consistency and quality of triage services. In addition, the Horton Maternity Assessment Centre (MAC) has specific processes for effectively triaging women and birthing individuals. Low-risk cases can be assessed at the MAC, enabling care to be provided closer to home. A clear escalation pathway for high-risk cases is also in place for those women who require emergency transfers to the John Radcliffe Hospital (JR).

Efforts are also underway to establish a centralised triage phone service, with plans for expansion in collaboration with BOB Trusts. This initiative aims to enhance accessibility and coordination of care. The expansion is a strategic decision intended to ensure that triage services maintain a consistently high standard across the region.

6. **Tackling Inequalities in Maternity Care**

OUH are dedicated to addressing maternal and perinatal health inequalities with various initiatives aimed at improving access, experiences, and outcomes for women and birthing individuals at high risk of poor health outcomes. The Trust partners with communities through Equal Start Oxford (ESO), an initiative launched in early 2023 to improve maternal and perinatal health for vulnerable populations in Oxfordshire. Collaborating with local midwifery teams, ESO includes maternity advocates who address non-health-related issues such as immigration, welfare benefits, housing, and food insecurity. They also provide interpreting services and support drop-in spaces for pregnant women and new parents, particularly benefiting the East Timorese community. The Equal Start framework will expand to high-need areas like Didcot and Banbury later this year and will work with local communities to assess needs and implement initiatives to improve healthcare access.

A significant aspect of ESO is the Maternity Health Justice Partnership, where advocates assist midwives with non-health needs and support modifiable social determinants of health. This initiative features a joint Obstetric/Midwife clinic for vulnerable pregnant women, ensuring they receive necessary care. Overall, ESO aims to enhance access to maternity services for marginalized groups, promoting the well-being of every mother and baby in Oxfordshire.

Oxfordshire has seen an increasing number of dispersed asylum seekers arriving into Section 95-supported hotel accommodation. Pregnant women in these hotels often struggle to access maternity care in a timely manner for a variety of reason such as

language barriers, a lack of knowledge about how NHS maternity services operate, and challenges related to transportation to hospitals. In response to these challenges, a proactive approach has been taken. A monthly joint obstetric and midwifery clinic has been established at the Oxford Witney Hotel and Horton Hospital. This initiative is supported by a caseworker from Asylum Welcome to meet the needs of pregnant asylum seekers residing in the two hotels near the hospital.

7. Support for Staff and Workforce Culture

The Trust is committed to supporting and developing its staff to foster a positive workforce culture. This includes continuous training, mentorship programs, and initiatives aimed at addressing workplace incivility. The significant progress made under the NHS England Maternity Development Programme and results from staff engagement surveys, which show a 30% increase in job satisfaction and a decrease in poor workplace behaviour, demonstrate this.

The Maternity Development Programme, initiated in August 2022, focuses on culture, leadership, and staff well-being. Listening events generated 170 actionable solutions and a comprehensive action plan. The program's cultural changes have created a safe and supportive care environment for staff and service users.

Staff development has been a priority, with numerous Continuing Professional Development (CPD) opportunities available, including Level 7 Master's modules, conferences, and focused study days. Additionally, since April 2023, psychological support has been offered to staff, providing both individual therapy sessions and group interventions to address work-related issues such as stress, burnout, and trauma.

8. Resources and Workforce Sufficiency

The Trust has focused on maintaining safe staffing levels in maternity services. In response to the Ockendon review, it has increased its obstetric and midwifery workforce over the past two years, adding 1.5 full-time equivalent (FTE) obstetricians in 2022. To support safe midwifery provision, the Trust approved the Birthrate Plus recommendations in 2023, which call for an increase of 22.38 FTE staff members. This includes 3.89 FTE managers, 16 FTE clinical midwives, and 2.49 FTE maternity support workers. Recruitment efforts have been proactive, and the midwifery workforce is expected to be fully recruited by January 2025. This investment underscores the Trust’s dedication to maintaining optimal staffing ratios, enhancing patient safety, and improving overall maternity care.

As the maternity service is nearly fully recruited, work has begun to adapt recruitment and retention strategies to meet the preferences of different age groups. The service is conducting surveys and focus groups to gather insights into the career aspirations and expectations of various generations of midwives. The recommendations from this

work will focus on increasing flexible working arrangements and professional development opportunities.

9. Plans for Digital Integration between Primary and Secondary care

Since April 2021, the digital landscape of maternity care has improved significantly with the Maternity Digital Strategy. A key advancement was the implementation of the BadgerNet Maternity electronic patient record. The Trust transitioned from paper to digital records in February 2024 and enhanced safety through timely and accessible patient information. Upgrades to IT infrastructure, including replacing community devices and improving Wi-Fi, have further supported this transformation.

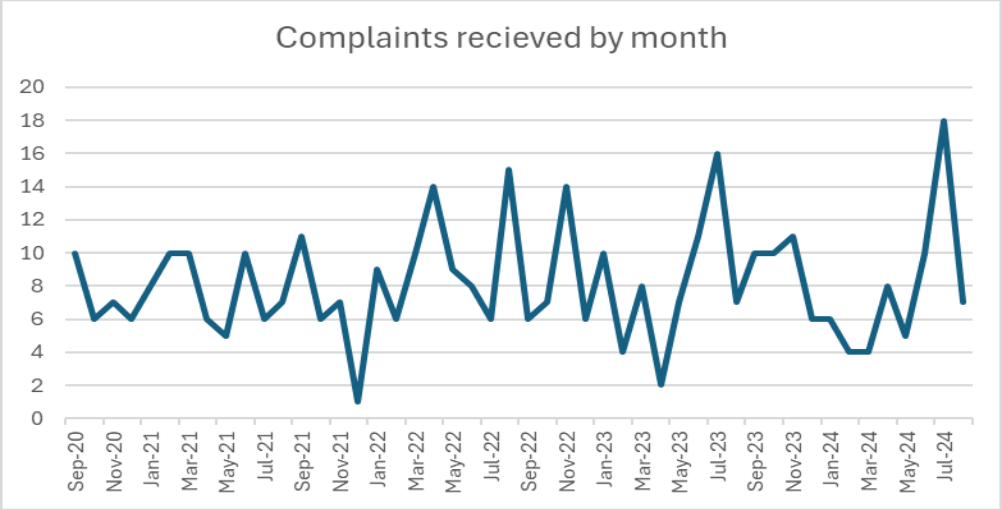
Plans are also underway to improve digital integration and enhance communication between primary and secondary care. As part of this strategy, the rollout of the ICE system for community midwives and necessary system upgrades will ensure a seamless flow of information and coordinated care. Across the BOB LMNS, efforts are being made to enhance existing systems and expand the Cerner Health Information Exchange, which will securely share data between EMIS Web users and the broader health sector.

Additionally, an information-sharing platform is being implemented between OUH and all London hospitals. These systems are scheduled to be launched within the next 12 months, providing clinicians with the most relevant and up-to-date information about their patients.

10. Patient Experience

Maternity services take a multidisciplinary approach to effectively address and respond to concerns and complaints related to pregnancy, delivery, and postnatal care. Initiatives such as the Postnatal Improvement Working Group and the Kindness in Action training have been implemented to improve service quality. The Friends and Family Test (FFT) allows for continuous patient feedback. Additionally, a new monthly Patient Experience Forum, chaired by the OMNVP, highlights service improvements based on patient feedback, complaints, and engagement. These efforts demonstrate the Trust's proactive commitment to addressing patient concerns.

Post-Covid-19, there has been a 10% increase in written complaints about maternity services across England. OUH, by contrast, has experienced a 3% rise compared to this figure.



As shown in the chart above, the OUH maternity service averages 8.1 complaints per month. The chart below illustrates the common themes which include compassionate communication, staff attitude, and delays in pain relief and nutrition. Analysis of maternity complaints data for 2024 shows four women reporting birth trauma or psychological distress after childbirth. These complaints will have a distinct category in Maternity complaints analysis to ensure the service is responding appropriately and compassionately and can offer the correct support for long term recovery.

In August 2024, the Maternity Leadership Team formed a Triangulation and Learning Committee with representatives from various departments and service users. This committee uses feedback from complaints, PALS, patient safety reports, and legal claims to enhance care quality. It reinforces positive practices, such as effective teamwork and emergency protocol adherence, while addressing areas for improvement, like timely pain assessments and postnatal discharge processes. This structured approach reflects OUH's commitment to continuous quality improvement and optimal patient safety and experience.

Conclusion

In conclusion, the report highlights the progress made in improving maternity services. The Trust has shown a strong commitment to enhancing patient safety, reducing birth injuries, and addressing both perinatal and maternal mortality rates. The implementation of the Birth Trauma Pathway and the Birth Reflections service demonstrates the Trust's dedication to supporting individuals who have experienced birth trauma. Additionally, the advancements made in response to the CQC action plan and the KTHG Birth Trauma Dossier reflect the Trust's proactive approach to continuous improvement and patient care. Moving forward, the Trust aims to build on these achievements by further enhancing its services and addressing any remaining challenges to ensure the highest standards of maternity care. The journey of improvement in OUH maternity services is ongoing. While substantial progress has

been made in enhancing safety, quality, and patient experience, the service recognises that there is still much work to be done. The Trust is committed to tackling these improvements and seizing opportunities for further development and enhancement.

Work Programme 2024/25
Joint Health Overview and Scrutiny Committee

Cllr J Hanna OBE Chair | Dr Omid Nouri Omid.Nouri@Oxfordshire.gov.uk

COMMITTEE BUSINESS

21 NOVEMBER 2024				
Oxfordshire Healthy Weight	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report with an update on Oxfordshire Healthy Weight 12 months since this item previously came to HOSC.	Overview and Scrutiny	Ansaf Azhar David Munday Derys Pragnell
Maternity Services in Oxfordshire	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents	To receive a report with an update on the state of maternity services within Oxfordshire.	Overview and Scrutiny	
Local Area Partnership SEND Improvement Journey	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report with an update on the Local Area Partnership's SEND improvement journey, with a view to examine the impacts of the improvement journey on the physical	Overview and Scrutiny	

		and mental health of Children with SEND.		
30 JANUARY 2025				
Oxford Health NHS Foundation Trust People Plan	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report from OHFT on the Trust's People Plan, with a view to examine the Trust's support for workforce.	Overview and Scrutiny	
Director of Public Health Annual Report	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents	To review the Oxfordshire County Council's Director of Public Health Annual Report, which has a specific focus on Childrens' emotional wellbeing and mental health.	Overview and Scrutiny	Ansaf Azhar, Director of Public Health.
Health and Wellbeing Strategy Outcomes Framework/ Delivery Plan	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report with an outline as to an outcomes framework/delivery plan for the updated Health and Wellbeing Strategy for Oxfordshire.	Overview and Scrutiny	
3 APRIL 2025				
Audiology Services Update	Prioritise the Health and Wellbeing of Residents	To receive an update on the current state of audiology services within Oxfordshire.	Overview and Scrutiny	

Musculoskeletal health services update	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report with an update on the current state of Musculoskeletal health services.	Overview and Scrutiny	
Emotional Wellbeing of Children	Tackle Inequalities in Oxfordshire Prioritise the Health and Wellbeing of Residents.	To receive a report with an update on the Emotional Wellbeing and Mental Health Strategy for Children.	Overview and Scrutiny	

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Action and Recommendation Tracker
Oxfordshire Joint Health Overview & Scrutiny Committee

Councillor Jane Hanna, Chair | Omid Nouri, Health Scrutiny Officer, Omid.Nouri@Oxfordshire.gov.uk

The action and recommendation tracker enables the Committee to monitor progress against agreed actions and recommendations. The tracker is updated with the actions and recommendations agreed at each meeting. Once an action or recommendation has been completed or fully implemented, it will be shaded green and reported into the next meeting of the Committee, after which it will be removed from the tracker.

KEY	No progress reported	In progress	Complete

Recommendations:

Meeting date	Item	Recommendation	Relevant Lead	Update/response
21-Sep-23	Oxfordshire Healthy Weight	**1.** To ensure adequate and consistent support as part of secondary prevention for those living with excess weight; and to improve access to, as well as awareness of, support services that are available for residents living with excess weight.	Derys Pragnell; Omid Nouri	Recommendation Accepted: Initial Response (additional progress update response to be provided in April 2024): We currently commission two healthy weight services at Local Authority level, one that works with adults and another working with children. We also link closely with partners (NHS) who offer services at tiers above and below our own with a view to offering a seamless pathway. We identified some gaps in service as part of the recent Health Needs Assessment (HNA) on Healthy Weight. The current

KEY	No progress reported	In progress	Complete

Meeting date	Item	Recommendation	Relevant Lead	Update/response
				contract is coming to an end, and we are planning to commission an 'all age service' with some additional elements to meet the gaps identified in the HNA. We are also planning a review and refresh of opportunities to raise awareness of support that is available. Update April 2023: We are in the process of recommissioning an all age, Tiers 1 & 2 service, and will know the outcome by late Spring 2024. The service will commence on 1st September 2023. The new Tier 1 and 2 service will include a range of programmes for residents to choose from, as well as developing innovation pilots with specific populations as identified by the HNA, to test and learn what works with these residents to support achieving a healthy weight. Communications and campaigns will be part of this contract to increase awareness of the service for residents and professionals.
		2. To ensure effective support for ethnic groups that are more likely to develop excess weight, and to raise awareness amongst these groups of the support available to them.		Recommendation Accepted: Initial Response (additional progress update response to be provided in April 2024): The current healthy weight service has specific programmes for ethnic groups who are more likely to develop excess weight. This includes innovation pilots working in mosques, women only sessions, and tailoring content to be specific (e.g. on food types) The new service will build on this learning/modelling and is likely to have

KEY	No progress reported	In progress	Complete

Meeting date	Item	Recommendation	Relevant Lead	Update/response
				community development as a delivery component within key priority areas and populations, including ethnically diverse. Update April 2023: This detail remains the same. We can provide specific numbers and details of groups if HOSC require
		3. To work on providing support to the parents, carers, or families of children living with excess weight, and to help provide them with the tools to help manage children's weight.		Recommendation Accepted, HOSC will receive future progress update in April 2024. Update April 2023: Current Tier 1 and 2 services commissioned by public health have bespoke services for children. From September 2024 the new service will have innovation pilots to test and learn what works with cohorts aged 0-3 and teenagers. In addition, a range of digital and print resources for adults and families will be available from the provider to support a healthy weight. The provider will also be part of wider systems working, linking up a range of partners, for example NCMP and 0-19 providers. A children's healthy weight toolkit for health, social and voluntary/community professionals is in redevelopment. A 'You Said, We Did' response has been developed for Early Years professionals following a survey and interviews to support knowledge and skills in healthy eating. This

KEY	No progress reported	In progress	Complete

Meeting date	Item	Recommendation	Relevant Lead	Update/response
				includes Lunchbox Planners, Child Feeding Guide Training and a range of other resources. Finally, Public Health have led a working group to develop a suite of resources and assets to support uptake of Healthy Start across the County, including in ethnic minority groups. This has recently gone live.
		4. To explore avenues of support for residents who may struggle to afford healthy diets in the context of the cost-of-living crisis.		Comment on Recommendation: This should be an action/link for Food Strategy work across Oxfordshire, which is led by Laura, Rushen, Senior Policy Officer at OCC– each District Council has been commissioned to undertake work for their District. Update April 2023: Action plans have been developed and adopted by the following councils: Cherwell – 4 March Oxford – 13 March West Oxfordshire – 9 March South Oxfordshire and Vale of White Horses' action plans are being finalised.
		5. In light of recent findings relating to the risks of excess weight medication (GLP-1 receptor agonists), it is recommended that the BOB Integrated Care Board review the availability of these medications and		A separate response to this recommendation will be sought from BOB ICB.

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		any associated risks; and to update the Committee on this.		
		6. To orchestrate a meeting with HOSC, to include senior Planning/Licensing officers, Chairs of Planning Committees of the District Councils and lead officer responsible for advertising/sponsorship policy as well as the relevant Cabinet Member to discuss the planning and licensing around the presence of fast-food outlets in certain areas around the County and the advertising of HFSS products.		Health Scrutiny Officer (Omid Nouri) to liaise with relevant officers to facilitate this meeting in the near future. Update April 2023: We believe this meeting was being co-ordinated by HOSC. We have met several times with planning leads and provided detailed backing information and evidence to support each District/City Council to put in place a policy to restrict Hot Food Takeaways if they choose. Public Health have commissioned Bite Back to develop a youth manifesto on food environments for Oxfordshire, including focusing on vending and HFSS advertising in different locations across the County.
21-Sep-23	Health and Wellbeing Strategy	**1.** To ensure careful, effective, and coordinated efforts amongst system partners to develop an explicit criterion for monitoring the deliverability of the strategy; and to explore the prospect of enabling input/feedback from disadvantaged groups as part of this process.	David Munday	Recommendation Accepted: Initial Response (additional progress update response to be provided in April 2024): The Health and Wellbeing board has committed to the development of a delivery plan and outcomes framework for this new HWB strategy. This is to ensure the strategy is delivered by the partnership. We expect that an initial version of this will be presented to the HWB in March 24 and it will build on the strong public engagement that has already occurred in the strategy formation to date.

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				Update April 2023: The Health and Wellbeing Strategy Outcomes Framework was agreed at the Health and Wellbeing Board in March 2024. The Outcomes Framework has broken each of the 10 priorities down into more tangible Shared Outcomes- between 3 and 5 of these per priority. It also maps existing programmes of work against each of the 10 priorities. The Framework also lists suggested metrics to monitor delivery- these are Key Outcomes (a measure of the strategic impact we want to see) and Supporting Indicators (the process measures that support achievement of the strategic change). Finally, the Outcomes Framework lists the governance forums within the Oxfordshire System that is the primary partnership responsible for delivery against each of the priorities. It is these forums and work programmes they have oversight of that ensure relevant engagement with residents over the monitoring of progress in their work areas. It has been agreed by the board that it will review progress, data against the metrics and received narrative update on only one part of the strategy at each of its quarterly meetings, so that over the course of a 12-month work programme it will have reviewed once delivery against all parts of the strategy.

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				Full papers on the Outcomes Framework are available on HWB March agenda.
19-Sep-23	Local Area Partnership SEND	***1.*** For Leadership over the Partnership and of Children and Young People's SEND provision to be explicitly set out and communicated clearly to families and all stakeholders; as well as clear measures of how leadership will be developed and demonstrated at all levels, and to demonstrate how new ways of working with stakeholders will put families at the heart of transformation.	Stephen Chandler; Anne Coyle; Rachel Corser	Initial Response (additional progress update response to be provided in April 2024): Partnership leadership, assurance, and oversight of SEND provision is by the Oxfordshire SEND Improvement Board (SIB). The Board provides transparent visibility of progress, constructive and robust challenge, as well as celebrating what is working well and improving. The progress of improvements will be routinely scrutinised by appropriate scrutiny arrangements (People Scrutiny, HOSC and ICB Quality Group). Operational delivery of the Priority Action Plan (PAP) is via the Partnership Delivery Group (PDG), supported by time-limited Task and Finish groups. SIB, PDG, and Task and Finish groups all include Parent/ Carer representation. Continued improved communication with families and stakeholders is a key focus of our SEND action planning. It underpins our governance arrangements, is a key priority within the PAP, and is a focus area of our Working Together Task and Finish group.
		2. To ensure good transparency around any action planning and the improvement journey for SEND provision for Children and Young People, and to develop explicit Key Performance Indicators for measuring		Initial Response (additional progress update response to be provided in April 2024): The Priority Action Plan includes development of an Integrated Local Area Partnership SEND dashboard, based on partnership KPIs, with performance overseen by

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		the effectiveness of improvements that are open to scrutiny. The Committee also recommends for more comprehensive action planning after the publication of the initial action plan requested by Ofsted, and for this action planning to be made fully transparent. The SIB will consider at its inaugural meeting how best to ensure information easily and publicly available.		the SIB. As above, ongoing PAP action planning is operationally overseen by PDG and Task and Finish Groups. PDG reports monthly to the SIB.
		3. For the Leadership to adopt restorative thinking and practices with utmost urgency to reassure affected families, and for this thinking to be placed at the heart of any co-production exercises to help families feel their voices are being heard as well as for the purposes of transparency.		Initial Response (additional progress update response to be provided in April 2024): Restorative Approaches are well-established within Children's Services. Co-production with children and families is at the heart of PAP and wider action planning. As noted, they are represented within all leadership & delivery bodies for SEND improvement.
		4. To ensure adequate and timely co-production of action planning to improve SEND provision, and for the voices of Children and their families to be considered in tackling the systemic failings highlighted in the report. The Committee also recommends that the Partnership considers timely allocation of seed funding for the development of		Initial Response (additional progress update response to be provided in April 2024): SIB responsibilities include ensuring that co-production is embedded in the culture of SEND services. Our Multi Agency Quality Assurance (MAQA) forum has the purpose of setting out consistent, service specific processes for the quality assurance of Education, Health, and Care Plans, ensuring that good practice and learning is shared, informs

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		co-production involving people with lived experience; and for joint commissioning of training and alternative provision across Oxfordshire, involving multi-agency stakeholders, the voluntary sector, and families.		training and professional development for all professionals involved in the process, underpinning our vision for shared responsibility for improving outcomes, on the improvements achieved and next steps. Partnership training, and impact measures, are included in the PAP. All PAP actions are time-specified, ranging from December 2023 to post-July 2025, dependent on prioritisation and practicability.
		5. To continue to improve working collaboration amongst the Local Area Partnership to integrate support mechanisms and services as effectively as possible, and for rapid improvements to be demonstrated on clear and efficient information and patient-data sharing on children with SEND.		Initial Response (additional progress update response to be provided in April 2024): There are existing arrangements to enable the sharing of information across partners. The effectiveness of these will be considered as part of the improvement journey.
		6. For every effort to be made for children and young people with SEND to receive the support that is specifically tailored toward and appropriate to their own needs and experiences; and for those involved in providing support services to be aware of the additional/ alternative services available which a child may also need a referral to. It is also recommended that improvements in one-to-one		Initial Response (additional progress update response to be provided in April 2024): Priority actions within the PAP include co-production of both refreshed Local Offer and development of local area partnership early help and early intervention strategy. Together with improved EHCP assessment process, and Team Around the Family, this will enable the delivery of needs-led provision, and the progression of outcome led plans with families. As noted above (Paragraph 8),

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		communications with families should be prioritised by Oxfordshire County Council, using the budget agreed by cabinet immediately following the Ofsted report.		continued improved communication with stakeholders and families is a key priority.
		7. To consider the use of digital resources for enablement, including at an individual level; and to ensure EHCPs are up to date and that they constitute living documents for families.		Initial Response (additional progress update response to be provided in April 2024): Timeliness and quality of EHPCs, along with improved parental access to the digital portal, are addressed within PAP item 3. Actions include ensuring accurate, timely, and effective assessment, and effectively meeting needs, particularly at points of transition. Assessment timeliness is improving, despite increasing demand. Timeliness of completion within 20 weeks has improved from 40% in June 2023 to 50% in the last month.
		8. For SEND commissioning to be developed using the Ofsted report as a baseline, and to place person-centred mental and physical health of children and their families with SEND at the centre of decisions on how funding is spent to maximise social value. The Committee also recommends for the Local Area Partnership to map all funding sources available for, and to explore joint commissioning of services and training that could improve the		Initial Response (additional progress update response to be provided in April 2024): PAP priority actions include a focus on improved commissioning and strong relationships with commissioned providers, to improve capacity, meet demand, and meet the needs of children, young people, and their families. The PAP is also focused on ensuring commissioning arrangements support timely decision making and transition arrangements, and that there is a multi-agency approach to meeting the needs of children with emotional and mental health difficulties. The Leadership and

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		overall health and wellbeing for children with SEND.		Partnership Task and Finish group has responsibility for integrated commissioning of SEND services. The Oxfordshire Joint Commissioning Executive, which plays a key role in the delivery of many Priority Action Plan actions, reports into the Partnership Delivery Group.
		9. To ensure that there is clarity of information on any physical or mental health services for children with SEND, to reduce the risk of confusion and lack of awareness of such services amongst parents, carers or families of children who require support for their mental or physical health.		Initial Response (additional progress update response to be provided in April 2024): A local area pathway is being developed for children and young people with emotional wellbeing and mental health concerns. The i-THRIVE framework (an integrated, person-centred, and needs-led approach to delivering mental health services for children, young people, and their parents/carers) will be linked to the Early Help Strategy and Team Around the Family.
		10. To exercise learning from how other Counties and Systems have provided well-coordinated and effective SEND provision; particularly where measures have been adopted to specifically reduce the tendency for poor mental or physical health amongst affected Children and Young People.		Initial Response (additional progress update response to be provided in April 2024): Our response to the SEND inspection, including development of PAP and KPI dashboard, has been informed by learning from other local authorities. Children's Services senior leadership bring a wealth of experience in delivering transformation and service improvement within other local authorities. This includes both the recently appointed independent chair of the SIB, Steve Crocker (Former President of Association of Director of Children's Services) and new SEND/ Children's Services Improvement. We have invested in an additional Assistant

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				Director for Early Help & Prevention, and Strategic Lead for Specialist Projects. Deputy Directors for Children's Social Care/ Education are likewise experienced.
		11. To ensure that staff involved in Health, Care, Education, and any relevant Voluntary Sector organisations are sufficiently trained and aware of children that may be neuro-divergent, have a learning difficulty or a disability (SEND); and for such staff to be adequately aware of the support and resources available, and the processes for referring such children for any relevant mental or physical health services that they might require.		Initial Response (additional progress update response to be provided in April 2024): As noted above, partnership training is embedded within the PAP. The Working Together Task & Finish group leads on Workforce Development.
		12. For HOSC to continue to follow this item and to evaluate the impact of any changes or improvements made, with specific insights into the following; the Partnership's Action Plan as requested by HMCI; the overall measures taken to address the concerns raised by the Ofsted/CQC inspection; the progress made by CAMHS in reducing waiting times for treatment of children with SEND who require mental health support; and on how the NHS is working to increase the overall		Initial Response (additional progress update response to be provided in April 2024): There are clear governance and reporting structures, as outlined above. We can provide updates as required.

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		acquisition and availability of data on SEND children's mental health from key mental health providers.		
14-Nov-23	Children's Emotional Wellbeing & mental Health Strategy	***1.*** To work on developing explicit and comprehensive navigation tools for improving communication and referral for services at the neighbourhood level and within communities. It is recommended that piloting such navigation tools in specific communities may be a point of consideration.	Cllr John Howson; Cllr Kate Gregory	Recommendation Partially Accepted: Initial Response (additional progress update response to be provided in June 2024): We work closely with partners across Oxfordshire who offer advice, support and interventions for children, young people and their families and are currently tendering for a peer support app for CYP to support their mental health and well-being with a directory of local services to meet their needs. We recognise the importance of ensuring that local communities and neighbourhoods are connected to service provision in their areas. This is also important to the workforce so that they know who their local link is for support and services. This recommendation applies to all system partners to ensure that information is made available. HOSC can also support this approach with members of the scrutiny committee sharing information through their networks. The new SEND Local offer also provides details how to apply for help and includes a directory of local provision that both CYP and their families as well as professionals can access. This has been co-produced with Oxfordshire Parent Carer Forum and is key action in the priority action

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				plan the link for the new website: Oxfordshire SEND local offer | Oxfordshire County Council As part of the early help strategy refresh this year OCC Children's Services will be ensuring the offer of early help is accessible to all families to find information to support them along with resources available within the local offer and linked with FIS. Co-production is a critical part of the strategy development and the commissioning cycle. This approach was adopted for the development of the emotional health and wellbeing strategy and in the commissioning of the digital offer. The Council recognises that improvements can be made and in future tenders we would like CYP to be able to be part of the evaluation process. We are working with procurement and legal colleagues to enable this to happen without being at risk of breaching contract procurement regulations and legal challenge. We have built reviews and service improvement into the digital offer and will be able to provide updates in due course.
		2. To ensure adequate co-production with children and their families as part of continuing efforts to deliver the strategy, including considerations of how children and families can be placed at the heart of commissioning. It		Initial Response (additional progress update response to be provided in June 2024): Co-production is a critical part of the strategy development and the commissioning cycle. This approach was adopted for the development of the emotional health and wellbeing

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		is also recommended for an early review with the users of the digital offer once this becomes available; to include testing with neurodivergent children and other children known to be at higher risk of mental ill health.		strategy and in the commissioning of the digital offer. The Council recognises that improvements can be made and in future tenders we would like CYP to be able to be part of the evaluation process. We are working with procurement and legal colleagues to enable this to happen without being at risk of breaching contract procurement regulations and legal challenge. We have built reviews and service improvement into the digital offer and will be able to provide updates in due course.
		3. To continue to explore and secure specific and sustainable sources of funding for the Strategy to be effectively delivered in the long run.		Recommendation Accepted: Initial Response (additional progress update response to be provided in June 2024): Funding for supporting emotional health and wellbeing comes from a number of government departments and organisations. This includes Department for Education and NHS England as well as funding provided to the voluntary and community sector and for research and evaluation to grow the evidence base on what works. As a system we will strive to identify sustainable sources of funding for Oxfordshire. Local funding streams will be determined by the financial envelope provided to us nationally for this work. Any proposals to increase resources to better meet the needs of CYP in Oxfordshire are being managed by the

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				SEND Priority Action Plan to address priorities identified during the Local Area SEND inspection by OFSTED and CQC.
		4. To ensure that children and young people and their families continue to receive support that is specifically tailored toward their needs. It is recommended that a Needs-Based Approach is explicitly adopted, as opposed to a purely Diagnosis-Based Approach. This could allow for early intervention to be initiated as soon as possible.		Recommendation Accepted: Initial Response (additional progress update response to be provided in June 2024): System partners recognise the recommendation to be needs led and provide support to children, young people and families at the earliest opportunity utilising the Think Family Approach and as endorsed within the Early Help Strategy to offer the right support at the right time. Oxford Health are already taking this needs-led approach through Universal Public Health Services for CYP. Oxford Health CAMHS service also commission Autism Oxfordshire to give CYP and their families pre-diagnoses support for those waiting for a Neuro-development Conditions assessment. We are exploring different ways of commissioning and delivering Neuro-development Conditions assessment services across the BOB ICB as long waits are a national issue. Addressing waits for Neuro-development Conditions assessments is also an action in the SEND Priority Action Plan.
		5. That consideration is given to the use of a simple and evidence-based standardised evaluation measure, that is suitable across all services that are		Recommendation Partially Accepted: Initial Response (additional progress update response to be provided in June 2024):

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		working on Children's mental health in community settings.		Evaluations tell us what works and what does not. An evaluation should be a rigorous and structured assessment of a completed or ongoing activity, intervention, programme or policy that will determine the extent to which it is achieving its objectives and contributing to decision-making. Collecting feedback, data and local intelligence from children and young people, communities and services is essential to inform a needs-led approach. We will explore what guidance and evidence-based practice is available to address this recommendation. We would also like to recommend that this is broader than 'children's mental health in community settings' to recognise the impact of wider determinants on emotional health and wellbeing for children, young people and their families. Children's Services already utilise SDQ's to measure and evaluate children's Mental Health for Children We Care For and we could look to expand this practice to a wider cohort of children to further explore their needs.
08-Feb-24	Director of Public Health Annual Report	***1.*** For the fully published DPH Annual report to come to a future HOSC meeting, with a view to further scrutinise the report and the	Ansaf Azhar	Recommendation Accepted: We have agreed to bring the 2023/24 DPH Annual Report to a future HOSC meeting to enable members to consider the deliverability of its recommendations.

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		deliverability of the commitments around climate action and health.		
		2. For the full DPH report to incorporate a section with insights into Population Health, and to include an update on progress on recommendations from the previous DPH Annual report.		Recommendation Accepted: The DPH report now includes a summary profile of Oxfordshire's Health and Wellbeing with signposting to the Joint Strategic Needs Assessment which provides more detailed and live data.
		3. For there to be clear and thorough engagement and co-production with key stakeholders around the commitments to climate action and health after the publication of the report. It is recommended that the local contexts and sensitivities are taken into account, with a view to balance these with national directives around climate action and health.		Recommendation Accepted: This recommendation is reflected in the engagement plan for the report.
		4. For there to be clear transparency and indications as to the barriers and enablers surrounding commitments to climate action and health. It is recommended that sufficient avenues of funding and resources are secured for the purposes of delivering these ambitions, and for collaboration with key system partners for the purposes of this.		Recommendation Accepted: All relevant avenues of funding and resources will be pursued to support delivery of the Report's recommendations.

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		5. For there to be clarity around any governance structures or processes around climate action and health. It is recommended that there is transparency around any key leads responsible for relevant policy areas around climate and health to understand individual/organisational commitments, as well as to understand any associated regulatory or legislative barriers to these commitments.		Recommendation Accepted: The report has already been submitted to the Future Oxfordshire Partnership Environment Advisory Group, which provides governance of system wide action to address climate change; it was welcomed and endorsed by this group. Within OCC the Climate Action Programme Board provides internal governance mechanisms for monitoring progress.
		6. To ensure that clear processes are in place for monitoring and evaluating the measures taken as part of climate action, with specific attention to the implications that such measures may have on residents' health and wellbeing.		Recommendation Accepted: The report's recommendations are aligned with metrics that are reported against as part of OCC's Unity performance monitoring system. In addition, impact on health outcomes will be reported through the Joint Strategic Needs Assessment.
		7. To raise educational awareness and understanding of the importance of climate action and its implications on health.		Recommendation Accepted: As part of the engagement plan, schools will be engaged as part of a coordinated approach to secure the support of schools' strategic leadership teams for action on climate and health.
		8. For next year's DPH Annual report to be brought as a full draft to the Committee's Spring meeting, with a view to scrutinise the draft and provide		Recommendation Accepted: Next year's DPH Annual report will be brought to the Committee's Spring meeting with a view to scrutinise the deliverability of its recommendations.

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		feedback in a public meeting ahead of its official publication.		
18-Apr-24	GP Provision	***1.*** To ensure continuous stakeholder engagement around the Primary Care Strategy and its implementation; and for the ICB to provide evidence and clarity around any engagements adopted, to include evidence on key feedback themes and from which groups within Oxfordshire such themes were received from. It is also recommended that there is a clear implementation plan to be developed as part of the Primary Care Strategy, and for this to be shared with HOSC and key stakeholders.	Julie Dandridge; Dan Leveson	Recommendation Partially Accepted: The ICB has publish a summary of feedback received. This feedback has not been collected on an Oxfordshire footprint. The summary feedback can be found 20240521-bob-icb-board-item-11-bob-icb-primary-care-strategy.pdf More details on the implementation of the strategy is now included in the Primary care strategy. This will be further developed over time.
		2. To continue to work on Prevention of medical and long-term conditions besides cardiovascular disease.		Recommendation Accepted: The ICS has a number of clinical networks including stroke, diabetes and respiratory that focus on prevention and improved pathways for these long term conditions. More details can be found in the BOB ICB Joint Forward Plan.
		3. To review ICB capacity with a view to increasing this to ensure adequacy, with a view that the ICB can work in a timely way with all District/City Councils across Oxfordshire on the securement and spending of health-infrastructure funding.		Recommendation Rejected: The ICB is not in a position to increase its workforce capacity but welcomes the opportunity to work closely with all District/City Councils across Oxfordshire on the securement and spending of health infrastructure funding

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		4. That the ICB checks which practices are closing e-connect and telephone requests for urgent appointments and for what reasons, and that it is also checked as to whether/how the public have been communicated with around such closures. It is recommended that there is improved clarity and communication about the statistics concerning access to appointments.		Recommendation Partially Accepted: Practices that are temporarily unable to receive telephone requests for urgent appointments should inform the ICB. The main reason for this request is staff sickness. When informed the ICB advises practices to update their answer machine message and their website so informing patients. We do not currently have a method of monitoring when practices close of online consultations but are exploring what might be possible.
		5. For there to be clarity and transparency around the use of any competency frameworks as well as impact and risk assessments around the role of non-GP qualified medical staff who are involved in triaging or providing medical treatment to patients. The Committee urges that the advocacy needs of patients are considered/provided for, and that patients are clearly informed about the role of the person who is treating them and the reasons as to why this is a good alternative to seeing their GP.		Recommendation Accepted: There are some national sources of information for patients about the different roles in general practice. We will look to making these available on the ICB website.
		6. That an expected date for the signing of the legal agreement on Didcot Western Park is provided to the		Recommendation Accepted:

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		JHOSC, so there can be reassurance about the likely timescale for the tendering process.		There are many legal agreements that need to be in place to progress the Great Western Park project. The ICB will update JHOSC when progress is made.
18-Apr-24	Dentistry Provision	***1.*** It is reiterated that underspends should be spent in Oxfordshire, and that priority is given to areas within Oxfordshire that have experienced the worst shortfall in capacity. It is recommended that the ICB prioritises areas within Oxfordshire in light of the increased need within the County relative to other areas under the BOB footprint.	Hugh O'Keefe; Dan Leveson	Recommendation Rejected: BOB ICB is the delegated commissioner for dental services across the footprint. With this comes a BOB level budget for provision of services The ICB does not receive separate budgets for each county. However, the first principle being pursued is that the levels of activity should be re-commissioned, at the very least to the levels that have been lost as a result of contract hand backs and reductions. There has been a loss of 91,049 UDAs in Oxfordshire since April 2021 and BOB ICB is actively looking to replace these. The ICB will prioritise areas of greatest need across the whole footprint.
		2. To support the creation of new practices within Oxfordshire with urgency, and to explore avenues of funding to support the ICB in developing solutions in this regard.		Recommendation Accepted: The ICB has agreed to commission 5 new NHS practices (in Abingdon, Bicester, Carterton, Faringdon and Witney). The re-commissioning of services in these areas is being carried out as part of an NHS South-East programme. Significant levels of activity have been handed back in all SE ICBs. The Commissioning Hub for Dental services (hosted by the Frimley ICB) is working with each of the ICBs to understand proposed levels of activity to be

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				commissioned with the aim of commencing the process in late 2024. The BOB ICB is investigating how it may move the programme forward more quicker if necessary.
		3. That urgent progress is made in improving the accuracy and the accessibility of information on dentistry services available to people; and that where groups are targeted for help, they can benefit from an effective outreach.		Recommendation Accepted: The ICB has carried out a review of practices' reporting new patient acceptance on https://www.nhs.uk/service-search/find-a-dentist in June 2024. This information is available to all patients. In Oxfordshire: •25 practices are advising they open to all new patients (when availability allows). •4 practices are open children only •28 practices are not open to new practices. The ICB has written to these practices who have not recently updated their profile to seek confirmation of their plans to update their information.
		4. For the Oxfordshire system to seek to influence a timely consultation in Oxfordshire on the fluoridation of the County's water supply.		Recommendation Partially Accepted: 1. Whether the ICB or other relevant system partners have any ability to play a role in supporting a local public consultation/engagement around fluoridating Oxfordshire's Water Supply.

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				The ICB would not have a role as the responsibility for consultation on water fluoridation lies with the Secretary of State and central government. 2. Whether the ICB/partners are even supportive of fluoridation in the very first instance. The ICB has not considered water fluoridation, but officers are aware of the benefits for the oral health of the local population and the potential to reduce oral health inequalities.
06-Jun-24	Palliative/ End of Life Care in Oxfordshire	***1.*** To ensure that carers receive the necessary guidance as well as support in being able to maximise the support they provide to palliative care patients.	Dr Victoria Bradley; Kerri Packwood; Karen Fuller; Dan Leveson	**Partially Accepted** RIPEL staff provide direct support to carers as well as patients and are trained with the oversight of the OUH Palliative Care Department. We continue to support our staff to sign-post patients and their carers for appropriate further care or support. This is primarily to local authority or community and voluntary services but may also involve resources within our services provided by our Living Well service such as the carers support group.
		2. To secure sustainable sources of funding and resources for the RIPEL project, as well as Palliative Care Services more broadly.		**Accepted** We are actively seeking sustainable sources of funding and resources and welcome the support of Oxfordshire HOSC.
		3. To secure additional and sufficient resourcing and support for palliative transport services. It is recommended		**Accepted** Due to recent changes in OUH ambulance transport arrangements, plans to pilot alternative ambulance

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		that transport services for palliative care patients are organised in a manner that avoids delay and distress for patients.		solutions for 2024/2025, initially funded by Sobell House Hospice Charity, have been altered. Nevertheless, we remain committed to our negotiations with providers to identify more suitable transport solutions. We continue our negotiations with ambulance providers to find a suitable transport solution. The newly establish Patient and Public Involvement and Engagement Group (PPIE) will be included and asked to feed into this work.
12-Sep-24	Winter Planning	***1.*** To continue to ensure that clear plans and processes are in place to help reduce time spent in emergency departments by patients during the winter months when pressures are likely to be higher.	Dan Leveson; Lily O'Connor	*Sent to NHS/Cabinet*
		2. To continue to ensure a careful balance between providing patient flow on the one hand (including through reducing lengths of stay across step down beds), whilst providing the personalised care that each patient needs.		*Sent to NHS/Cabinet*
		3. To ensure that there is sufficient capacity within primary care (particularly with GP services) to cater for any increased pressure during the winter.		*Sent to NHS/Cabinet*

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		4. To ensure that adequate preparations are in place for a potential surge in infection rates, and to secure the availability of vaccinations. It Is recommended that there is also clear communication with the public in relation to both viral infection patterns as well as how residents can reduce the likelihood of spreading/contracting diseases.		*Sent to NHS/Cabinet*
12-Sep-24	Adult and Older Adult Mental Health in Oxfordshire	***1.*** To ensure that adult eating disorder services are personalised in a manner that takes the unique needs and experiences of each individual patient. it is recommended that this service is coproduced with adults with eating disorders as much as possible.	Rachel Corser; Dan Leveson	The adult eating disorder service provides personalised care and treatment planning for all patients assessed and treated within the Community Adult Eating Disorder service. This includes delivering NICE recommended treatments for the core diagnostic groups and treatment pathways for people experiencing first onset of eating disorder (aged 18-25) and people who have enduring eating disorder needs despite having received evidence-based care and treatment. The service also offers enhanced physical health monitoring for people whose eating disorder is presenting a high risk to life, and where needed patients can access Specialist Eating Disorder Unit (SEDU) inpatient care and 'Stepped Care' (intensive community-based support) as an alternative to admission. Recently Oxford Health have developed (in conjunction with service users) the eating disorder provision within our Keystone Hubs which is being delivered in partnership with a VCSE partner (SWEDA). This will provide early

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				intervention and prevention involvement for people with emerging or mild eating disorder presentations. Service users have been involved throughout this development and the Community Adult Eating Disorder team continue to work proactively with service users via the Trust-wide Adult Eating Disorder forum that meets monthly as both a reference group and source of people willing to support service developments as the need arises.
		2. To take adequate measures to tackle loneliness amongst older adults, and to make every effort to reach out to older adults (with lived experience) and to include them in the designing of older adult mental health services. It is recommended that there is liaison with the Oxfordshire Mental Health Partnership to explore avenues to improve coproduction here.		This is being addressed as part of the Adults and Older People Mental Health Transformation programme currently in place where we are looking at the partner offer and a more focus on Prevention. There will be continuous feedback from people using services via the Community Metal Health Framework stream of work which will allow evaluation and realignment of services based on what people are saying.
		3. To ensure that patient history is effectively communicated and shared amongst professionals/organisations providing mental health support, and to avert the prospects of patients being or feeling bounced between various mental health services.		a. <u>Information sharing</u> • This is an ongoing and national issue regarding interoperability between EPRs and something we continue to struggle with in Oxfordshire. There is a plan in place to improve this across Oxfordshire, and I understand that work in underway to roll this out. Nationally there is work underway in NHSE to improve this and guidance is being developed. • In OH we do have a partnership data sharing agreement and we expect relevant information to be

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				shared when people are open to more than one service, or move between services • Where there are embedded partnership workers in OH teams they do have access to and use either Rio or EMIS community as their EPR as well as their home organisation systems. Where there are Mind options workers and Specialist MH practitioners (ARRS) in PCNs they have access to GP EMIS and for the latter they also have RIO. • The Keystone MH Teams use EMIS community as its EPR which means they are able to access and view a patients GP records (unless the patient has opted out) and GPs can see patient records from the Hubs – there has been very positive feedback from both GPs and Hub staff regarding this. • We do expect OH clinicians to share the outcome of any SMI physical health reviews they complete with the patient's GP – this is usually shared via docman, or in letter form, which the GP has to input in to the patients records manually. I don't believe there is a way of monitoring whether this information is shared in practice as a matter of routine. At present OH teams do not have any notifications from Primary Care to confirm whether a patient has had their annual health check or the outcome. Some GPs do inform MH teams if there are concerns, but this is not consistent. This can lead to patients having their PH monitored by both GP and OH or neither. There are plans in development to improve the take up of

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				PH checks for those with SMI – which involved the OH Physical Health SMI teams, the Keystone Hubs and PCNs communicating and ensuring those patients on the SMI QoF register who do not attend for their annual check are followed up by either OH team and either supported to attend the check at the GP practice or are offered a home visit by the Hub team to complete. PH of people with SMI is a priority in the development of the new contracts, and will be included in the outcomes being developed across the partnership. b. <u>Access to services (people not being 'bounced' between services/ falling through gaps)</u> • Part of the development of the Keystone MH teams (KMHT) was to provide a local point of access for all routine mental health referrals in to OH. The KMHTs are expected to develop close working relationships with their aligned PCNs, OH teams, Partnership organisations and other statutory and non-statutory organisation in their locality, and understand the services they provide and who to. The KMHTs have daily triage meetings and are regularly joined in these meeting by Oxfordshire Talking Therapies (OTT) clinicians, AMHT/ CMHT clinicians, Turning Point and the SMHTs/ ARRS workers where discussions around where the patient is best suited are agreed and the referrals processed by the agreed team. Where more

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				information is needed, or there is a decision that the patient does not meet the threshold for assessment by the team, attempts are made to contact the person to discuss and share either self-help material, or refer on to a more appropriate service. The team should not reject the referral back to the referrer – which we know leads to patients feeling 'bounced' between services or rejected. • Work is in development as part of the MHOIP programme to review mental health referrals across the Oxfordshire MH system, the task and finish group is in place and a workshop is being set up to look at the opportunity to further develop the KMHT model to provide a local point of access to the wider Oxfordshire system for all non-urgent MH referrals (so all referrals to OH, Mind, Elmore, Connections support, Restore etc…) – we will also be looking to develop self-referrals across the organisations including OH – this will hopefully reduce delays in referrals coming through (people having to wait weeks for a GP appointment and then MH teams having to ask for more information etc…), which will hopefully mean people are seen earlier in their relapse or development of an SMI so the impact of that on their lives are reduced with an early intervention. Current partners are fully engaged in this task and finish group. This work would also enable current partners to refer directly in to OH

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				services via the KMHTs, rather than the person having to go to their GP to ask for a referral.
		4. That voluntary sector stakeholder organisations who work in Oxfordshire on suicide prevention are invited to register with a VSO suicide prevention stakeholder register. It is also recommended that there is adequate resource, engagement, and a collaborative system inclusive of the VSO registered stakeholders to tackle suicide.		As part of the transformation of Mental Health Services we will invite new partners to deliver services for individuals with Mental Health and is inclusive of Suicide Prevention. We will work with providers and Public Health professionals to ensure we work with the voluntary sector to build on what we have and maintain a central register. This is something that can be managed jointly with the Mental Health provider.
		5. That there is collaborative system work to develop KPIs on serious mental health to maximise the impact of the existing resource available across Oxfordshire, with a view to prevention and to increase the support available to people and families in distress. It is recommended that there is engagement with the local authority and Region on KPIs relating to patients residing in long-term inpatient settings away from their families.		This is a gap that has been identified within the existing contract and a working group has been set up to further define KPIs as part of the wider Mental Health Contract that can be measured more accurately and appropriate action plans can be developed to ensure service improvement. This will also allow for a co-ordinated and systemwide approach to enable resources are used in the most efficient manner meeting an individuals need.
12-Sep-24	Medicine Shortages	***1.*** To ensure that policies are in place to recognise and identify patients with cliff-edge conditions, and to ensure that mitigations are in place to reduce	Julie Dandridge; Claire Critchley;	*Sent to NHS/Cabinet*

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		the risk of harm to these patients in the event of supply disruptions.	David Dean; Nhulesh Vadher	
		2. To ensure effective communication, coordination, and transparency within and between the local and national levels to help mitigate risks associated with medicine shortages.		*Sent to NHS/Cabinet*
		3. To work on reducing any prospect of additional excessive workloads on both clinical and administrative staff in the event of medicine shortages, and to provide meaningful support for staff as well as additional resource if need be for the purposes of tackling any additional demand/burdens.		*Sent to NHS/Cabinet*
		4. To continue to improve sharing of information and transparency, including through a potential digital local database, for helping professionals to easily identify where supply issues exist.		*Sent to NHS/Cabinet*
		5. To work on improving communication and coproduction with patients and involving those with cliff-edge or long-term conditions, regarding the pharmacy services and the availability of medicines (including through the use of frequently asked questions). It is also recommended		*Sent to NHS/Cabinet*

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		that patients are signposted to any support that could be available from pharmacy services and the voluntary sector.		
12-Sep-24	Epilepsy Services Update	***1.*** For the ICB and Oxford University Hospitals NHSFT to: ***a.*** Give priority to patient safety for people with epilepsy and their families in Oxfordshire, and to the welfare of the Oxfordshire epilepsy team, and to set out how that priority will be addressed through their governance and management at a board level. The governance and management of these priorities should also be inclusive of people with lived experience and their charity representatives, as well as their concerns regarding tailored and balanced communications and the use of existing empowerment tools. ***b.*** To secure further funding and resource for epilepsy services.		*Sent to NHS/Cabinet*
		2. For NHSE Region to give support to the ICB and Oxford University Hospitals NHS Foundation Trust to help achieve the above prioritisations.		*Sent to NHS/Cabinet*

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		3. For OCC Cabinet: For Oxfordshire County Council Cabinet members and senior officers responsible for education and residential care for children and adults with Learning Disabilities and/or autism (who are affected by patient safety concerns), to consider the likely impacts of the valproate policy for the local authority commissioning arrangements and the provision of residential care and out of county placements.		*Sent to NHS/Cabinet*

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Actions:

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