

Reading Patient Voice Group Draft Minutes

BOB Integrated
Care System

Reading locality

Treasurer: Jill Lake Information Officer: Tom Lake
Membership Officer: Tom Lake Data Officer: Francis Brown

1 Welcome and Apologies

Date	15 th January 2025
Location	Committee Room 1, Civic Offices, Reading & online
Present	Catherine Mustill, Emmer Green Paul Williams, UHC Jill Lake, Pembroke Surgery Cathy Cousins, Pembroke Surgery John Walford, University Health Group Adrian Barker, West Berks Patient Voice Raymond Emmet, John Missenden, Melrose Surgery John Starr, Pembroke John Norris UHC David Cooper, UHC Helena Turner, Milman & Kennet Tom Lake, Pembroke Surgery Simon Shaw, Healthwatch Reading Mark Drukker, Longbarn Lane Jamie Gordon Anne Harringdon Phil Lowry, UHC Nisha Sharma, Reading Cancer Awareness Champions Shaheen Kausar, Western Elms Surgery Libby Stroud, Pembroke
Apologies	Sarah Dixon, Pangbourne Alex Oesterreicher, The Advocacy People Valerie Gardener, UHS Sunila Lobo, UHC Joan Lloyd, Balmore Park Laurence Napier-Peele, Milman & Kennet Francis Brown, Balmore Park Monica Morris, Theale Surgery, Valerie Gardiner, University Medical Centre

NB: Matters arising indicated by an asterisk in the margin.

Catherine Mustill took the chair.

2 Talk on Autism by Jane Stanford-Beale, CEO of Autism Berkshire

N.B. Jane's slide set is available in PDF at this URL and in MS Powerpoint at this URL.

Autism Berkshire is a charity founded 30 years ago. It holds 2 contracts from the local NHS - one for the whole of Berkshire and one for young people in the BOB area of Berkshire.

Jane Stanford-Beale explained that she herself was the parent of an autistic child and a licensed autism trainer and trainer-trainer.

Autism is a spectrum condition with different presentations, some known as Asperger's syndrome and a type of neurodiversity.

Autism is neurodevelopmental - you are born with it but may only notice a difference in brain wiring later. In USA there is early screening for autism at 2 - which can be followed by intensive training after a positive diagnosis. Autism can have a different presentation in different people eg men and women.

It was once thought to be extreme maleness - but that is not the case. Often people with a diagnosis of EUPD (Emotionally Unstable Personality Disorder) are found to have autism.

Autism makes social situations difficult. People with autism struggle to understand other people. Some can commit crimes through lack of understanding. Autistic people can have special interests to the exclusion of all else. A certain group of bus spotters would line up 2 hours before Reading Buses open day - keen to take down numbers and model types and identify special buses. They are more likely to be diagnosed with anxiety or depression than the rest of the population.

People with autism may have specific sensory issues - be over stimulated or understimulated. They may be sensitive to noise, smell, texture - eating can be a real challenge, chairs, clothing texture. They may want to use headphones or dark glasses to reduce the stimulus.

As employees people with autism are very attentive to detail and loyal. Most whistleblowers are autistic. Many lawyers, police officers, surgeons, accountants and auditors are also autistic and see rules as absolute; they see things in black and white and have a love of routine.

Autism Berkshire uses the Thrive model from the work of the Anna Freud National Centre. We offer individual support and have found that 1 booked appt 80% effective as course of 6. Reading Recovery College delivers autism support and arts and crafts, coffee mornings, walks

We offer autistic people in employment advice about how to be assertive and ask for reasonable adjustments - under the Disability Act. Coming in when the workplace is less busy, or not being moved around departments can be very helpful.

We offer adult workshops written by autistic adults, particularly on understanding other people (what do neurotypical people expect). That works better than teaching social skills. We also run art workshops and course on cooking and living independently.

We run a drop-in at the Atrium café at 1.30-3pm on alternate Mondays.

We have a key worker to support autistic people on discharge from Prospect Park hospital. We also offer emotional support if sectioned.

2.1 Questions to Jane Stanford-Beale

Q: Anne Harrington: My organisation offers private Hydrotherapy with individual facilities. Do you think this useful for people with learning difficulties?

A: Autism Berkshire focusses on Autism without learning difficulties but only those with learning difficulties are in residential care. Reading Mencap would be the appropriate organisation. There has been a great deal of discussion about Hydrotherapy. There is no medical evidence that it is helpful for autism.

Q: Libby Stroud: Do you have particular diagnosis for very young children? I used to teach hearing impaired children - and had to decide whether they might be autistic or hearing-impaired.

A: In the UK pre-school we do a hearing test - the neo-natal hearing screening. My son has 95 decibel hearing loss. His younger brother had no screening - but no hearing loss. Paediatricians at the Royal Berks Dingley Centre look at language and speech problems and other genetic conditions. Autism is diagnosed more frequently now.

Q: Catherine Mustill: Is there a pathway for the parents to follow?

A: Referral from school with evidence of what works is preferred to GP referral by Berkshire Healthcare.

We are now getting schools to put in early needs-led support not support dependent on a diagnosis. Very bright children may need extra support e.g in forming peer relationships.

Q: John Missenden: What happened to the Autistic shop in Whitley Street - and is there a group in West Sussex?

A: There is a list of branches and support on the National Autistic Society website. The shop was part of a different organisation.

Q: Jamie Gordon: I am part of Ethical Reading. what support is there in Reading for ADHD?

A: The Autism Act imposes a duty on the local authority to produce an Autism Strategy, which it has done. There is a

movement to widen this to dyslexia, dyspraxia, ADHD. We would need a further act of parliament to do this.

Q: David Cooper: Is difficulty in relationships related to autism?

A: Autistic women can have a difficult work history and difficulty in forming relationships in employment. Autistic parents may differ in ideas from neurotypical. We use evidence based parenting strategies. We often see Married couples at drop-in - drop-in couples and younger people (40% under 35).

Catherine Mustill thanked Jane Stanford-Beale for a really interesting talk and discussion to general approbation.

3 Minutes of Previous Meeting

Catherine Mustill introduced herself as a co-chair elected at the recent AGM.

The minutes of the meeting on 16th October and matters arising were considered.

John Norris: I have not long joined the University Health Centre. I find the system of taking appts only on the day is deeply frustrating.

Paul Williams: The matter of the announcement of names not being clearly audible in the crowded A&E waiting room at RBH has not been accepted as a problem by the hospital management.

Libby Stroud: I am pleased that Paul Williams was able to resolve the matter of getting a DNACPR (Do Not Attempt Cardiac Pulmonary Resuscitation) form. **Please see notes after the end of these minutes.**

The minutes were approved.

3.1 Actions Log

No.	Action	Date	Who	Status
1	Ask ICB whether money follows the patient in acute collaboratives	24oc16	TL	Pending
2	Ask HWB about evidence behind ratings on HWB dashboard	24oc16	FB	pending
3	Follow up problem with audibility of calling of names in A&E waiting room	24oc16	SL	pending
4	Arrange Xmas social lunch	24oc16	TL;LNP	Done

3.2 Suggested Meeting Topics

1	How does a GP practice work?	24oc16	Pending
2	Resuscitation, DNACPR, choices and forms	24oc16	Pending
3	Hydrotherapy - how did we get to this?	24oc16	Pending
4	Weight management - drugs and lifestyle	24oc16	Pending
5	NHS 10-year plan	24oc16	Pending
6	Moving care back to the Community - Brazilian Model	24oc16	Pending
7	Meet Dr Ben Riley, BOB CMO and sponsor for Berkshire West	24oc16	Pending
8	Meet Matt Rodda MP	24oc16	Pending
9	BHFT/UoR Health Inequalities Project - Prof Carol Wagstaf	24no20	Pending
10	Future of the NHS app - Marta Fischer	25ja29	Pending

4 Report on BOB Integrated Care Board Meeting - 14th Jan

Tom Lake: The BOB Integrated Care Board met online and at the John Radcliffe hospital on 14th January. Sound wasn't too good online.

The recent cuts in ICB staff budget have resulted in the Place Directors positions being removed. Instead, and far less effectively, each of the 3 places (Oxfordshire, Buckinghamshire and Berkshire West) are represented by one of the executive board directors. Berkshire West is represented by the new Chief Medical Officer, Dr Ben Riley.

Commissioning of 70 specialist services has been devolved to ICBs.

Primary Care receives a 4.8% uplift in 2025-26. There will be a review of "red tape" i.e. reporting (can't this be automated anyway) and more flexibility with regard to the employment of "additional roles" in primary care (the ARRS scheme). The number of QOF targets will be reduced. Continuity of care for specific groups of patients - e.g. frail - will be mandated.

There is £100M extra for hospices nationally and 5000 more dental appointments in BOB.

Anticipating the cuts the BOB ICB staff recruitment had been frozen so there were now 190 vacancies.

The chief executive reported that it is very likely that "BOB Integrated Care System (ICS) is at risk of being unable to manage its expenditure within its available resource" and considered likely "The risk of the health and care system being unable to achieve the restoration of NHS services in line with 2024/25 priorities and operational planning guidance", saying that the risk is broad, covering all areas of care. Processes in place to strengthen and eliminate any gaps in controls and assurances specific to each service area and in a systematic way.

The quality and performance report is now quite useful - it can be found at this page of our website at rpvg.org.uk .

The meeting received a new report on "Developing our patient engagement". The board realises that it has not done enough yet in user involvement and intends to increase the resource and funds devoted to it. Principles of user involvement are cited. Healthwatch and the BOB VCSE Alliance are cited as important channels for involvement, but both direct engagement e.g. through the "Your Voice" web site, and outreach to specific groups who might otherwise not contribute, are cited as avenues for development.

5 Report from RBH Governors

Paul Williams: There have recently been high levels of attendance at A&E. The majority of attendances are down to respiratory issues.

Cathy Cousins: My daughter took her daughter to A&E on New Years Eve - both caught flu there. Couldn't the A&E waiting room be a safer place for patients?

Paul Williams: Staff are masking up now. We are believed to have passed the flu peak now. Planned as this is an annual event. Managers feel they have done well in dealing with the problems c.f. Basingstoke - which was full as patients could not be discharged.

Norovirus is also circulating.

The trust's new chairman has been selected - they are taking up references. I participated in a focus group during the selection.

The RBH staff survey is complete - with an increased number of responses showing greater engagement. There is lots of focus on funding. The trust faces the challenge of making savings - or it will be many millions short at the end of year.

Regarding our new hospital - an announcement is expected shortly - maybe 20th January¹. Probably others are much more in need. e.g. RAAC hospitals like Frimley. RBH has kept up the pressure with lots of information - two sites identified - one near Thames where Microsoft and Oracle are situated and the other in the Reading Science Park.

Catherine Mustill: I took part in analysis of last Autumn's survey of the impact of a move. There is an online meeting to present the results - see this webpage.

Paul Williams: Some of the parts built in 1970s are in the worst state. They are putting in a new block in the South car park as a new surgical facility. The trust will make incremental improvements subject to getting capital each year.

The NHS has lacked strategic planning. In other countries this has been better done. Here we have had piecemeal funding.

Jill Lake: Parking is a big problem. It is in a residential area, improved since having residents' parking with parking meters. This can't be solved on site.

Paul Williams: Facilities have been moved to Thatcham, Bracknell and Henley (but that has its problems).

Libby Stroud: Lots of clinics from East Berkshire are now held at Bracknell as well so it can be difficult to get a car parking space there too.

John Walford: My idea for a grand solution - replace Didcot power station with a nuclear power station with a by pass for A4 and a new hospital - needs to be outside the Aldermaston ring.

Ray Emmett: I read that the new hospital planning group at the RBH is being disbanded.

Paul Williams: That will happen when the preparatory work is complete.

Paul Williams: There is pressure from waiting lists so we have funding to use private hospitals to reduce waiting lists.

I asked chairman to find information on waiting times for hip operations but he could not²..

¹Since the meeting we have learned that the need for new build is recognised but likely only to start in the late 2030s.

²See Waiting times for treatments at RBH

Ray Emmett: My wife was ill and trying to get a blood test. Phoned at 8am every day. Then I found out that the RBH phlebotomy service had 25 cancellations in a day.

6 News from PPGs

?: Practices have been impacted by the NI increase. Patients are sked to lobby MPs for an exemption³.

Tom Lake: Pembroke has a new triage system - Rapid Health - I found it quite effective.

Ray Emmett: Many appts concern mental health.

Tom Lake: Practices, or rather, their Primary Care Networks (PCNs), can have an adult mental health worker under the ARRSS scheme - along with pharmacists, physios etc.

7 AOB

Xmas social - agreed successful lunch at Alto Lounge.

Jill Lake: We appreciate holding our meetings at the Civic Offices where we can have good quality hybrid meetings. The cost of meetings hsa been quite reasonable. But now we are being asked for an extra charge for security at meetings despite there being council meetings on same night.

TL: Health and Wellbeing Board meets at 2pm on Friday 17th Jan in the Council Chamber.

8 Notes on Decisions on CPR

One can make one's decisions know on medical treatment in general through a Living Will - see this NHS web page.

See also this web page from Compassion in Dying.

But for cardio-pulmonary resuscitation (CPR) there is a specific procedure. A decision on whether to decline CPR can be made known by completing a DNACPR form as part of a RESPECT process - and this can be done with with one's GP or hospital clinicians.

A specimen DNACPR form - described as a specimen RESPECT plan - can be found here - click on "Supporting Files". A guide to the RESPECT process can be found in the same place. Each area or hospital will have a specific version of the specimen plan.

There is a little information about this on the Royal Berkshire Hospital web site at this web page.

³Practices get an uplift of 4.8% for 2025-26