East Staffordshire District Patient Engagement Group Minutes of the meeting held at the Voluntary Services Centre, Union Street, Burton DE14 1AA Thursday 7th December 2023, between 14.00 and 16.00

1. Present

| John Bridges, JB | Vice Chair East Staffs District Patient |
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| | Engagement Group, (Tutbury Patient Forum) |
| BJW | (Tutbury Patient Forum) |
| LL | (Alrewas PPG) |
| HS | (Alrewas PPG) |
| RJB | (Trent Meadows PPG) |
| SG | (Yoxall PPG) |
| ТВ | (Yoxall PPG) |
| LT | (Carlton Group PPG) |
| КВ | (Rocester PPG) |
| JW | (Barton PPG) |
| IL | Support Staffordshire Community Officer, Burton |
| | on Trent District |
| DB | Healthwatch Staffordshire |

2. Apologies.

| Sue Adey-Rankin, SAR | Chair East Staffs District Patient |
|----------------------|---|
| | Engagement Group, (Tutbury Patient Forum) |
| KL | (Peel Croft PPG) |
| EM | (Alrewas PPG) |
| BP | (Wetmore Road PPG) |
| LK | (Peel Croft PPG) |
| LH | (Peel Croft PPG) |
| DH | (Tamworth) |
| CD | (Trent Meadows PPG) |
| SMcK | (Trent Meadows PPG) |
| DM | East Staffordshire Community Manager |
| | East Staffordshire PCN |
| | |

3. Speakers

RB

East Staffs PCN Research & Support Mgr.

4. Welcome

The Vice-Chair, JB, welcomed everyone to the meeting. JB will be chairing the meeting as SAR was currently unwell.

Before the start of the meeting the Vice-Chair, JB, informed members that the car parking scheme in Sainsburys car park had changed in November. Apparently, the cameras at the entrance are operational and if you stay over 2hours you will get a fine. This is regardless of the free cost after 3pm. He advised in future members do not use this car park and any of those present prior to the start of the meeting ensure they leave before the two-hour window expires.

5. Minutes of the Meeting held on 19th October 2023

The Vice-Chair, JB, went through the minutes and asked if there were any amendments. The Vice-Chair indicated that under Agenda item *PPG Updates, a correction needed to be made for the Alrewas report.*

The Vice-Chair will amend the minutes so that the correct record is put onto the website.

No further issues were raised, and the minutes were accepted as a true record.

6. Matters arising from the Minutes.

There are no matters arising that will not be covered under the agenda.

7. Action Log Update

(i). My Health, My Way Project

The Vice-Chair, JB, is a patient representative on the My Health, My Way project. At the last meeting, a presentation had been given followed by a detailed discussion which raised several both +ve and -ve comments which were to be raised by JB at the next project meeting.

JB informed everyone present that all the comments received plus those from other patient discussions had been fed back to the project team. The team were grateful for all the comments, and all will be taken into consideration. JB is to compile a full report of the comments for the project team and a copy will be forwarded to all the district members.

Update: The meetings have been put on hold until early 2024.

(ii). Can we have someone to come and speak on the procedure that takes place to set up a DNR, (do not resuscitate). Update: As previously mentioned, this has been put on the list of speakers for 2024

There were no further outstanding actions.

8. Update on the Primary Care Network Research Projects by RB

The Vice-Chair introduced RB to all those present. RB was our speaker and will be giving an update on the Staffordshire Primary Care Network Research Projects.

The following information was given by RB:

- I started my career in the NHS 22 years ago. 10 of those years being as a Practice Manager in a local surgery. In September 2024 I took up a role in the Staffordshire PCN as Research Manager. Known by all the practices in East Staffordshire and therefore building on the relationships that were already there in my new role.
- Working across 18 Practices in the locality to deliver Research at scale and progressing research across the locality.
- Have 3 GPs based at Practices within the locality who review research opportunities to ensure they are relevant and deliverable across the locality, Practices can be confident that research study is deliverable and are therefore more willing to take part. This gives us the opportunity to work at scale delivering research across all the Practices in the locality.

Some of the studies we've taken part in include:

- The **PANORAMIC** study looked at antiviral treatments for patients symptomatic to Covid.
- ACTIVE BRAINS web-based tool to determine whether monitoring patients with or without cognitive impairment through a web-based tool maintain their cognitive function or prevented a decline. East Staffs was the Leading PCN in the West Midlands in recruitment.
- **MULTICATH** Looked at comparing reusable catheters as opposed to single use was safe and acceptable for patients performing intermittent catheterisation.
- UK EDI for Pancreatic Cancer More recently we have taken part in a study that looks at newly diagnosed diabetic patients and obtaining over a period of time blood samples as biomarkers, these samples will be reviewed to see if there are changes in blood samples in patients who then go on to develop pancreatic cancer, this will make early detection of this type of cancer easier.

- Attended Health Events
- Looking more into Commercial research so that we can re-invest in research within Primary care.

Currently looking at:

- **PALOMA** Study Patients diagnosed with Parkinson's disease within the last 5 years, study sponsor looking at a visual aid to monitor the progression of the condition.
- **RESTORE** Looking at patients with severe insomnia to evaluate the safety and effectiveness of Chloral Hydrate drug.
- **BE PART OF RESEARCH** Website where patients can add their details and will be contacted about research opportunities specific to the information they have entered.
- **TREAT 2 TARGET** Looking at Gout and the clinical and cost effectiveness of using a goal-directed allopurinol-based treat-to-target protocol in people with recurrent gout flares.
- ELSA1 Diabetes detection in 3–13-year-olds, looking at linking in with schools.

What's next:

Greater involvement in research from patients, increase involvement with diverse populations and areas within the locality. Increase knowledge of research opportunities being directed to patients through the PCN, communication is key therefore the more patients are aware the greater the potential uptake. Increase knowledge through attendance at PPG meetings, health events, research bus within the locality. Discussions with patient groups around research and areas they would like to be involved in. Happy to come out to PPG groups to talk about up-and-coming research opportunities.

In addition to the above, there were discussions on the various research topics by those present. In addition, the following questions/comments were asked/made.

- What about people who are not on-line or have the technical knowhow to take part in research projects? RB It is hoped that a family member or carer may be able to assist. The study team is provided with patient data and the patient is connected to see if they agree to have other people to assist them regarding any research projects, they wish to participate in.

- Would you be involved in the evaluation of any of the local Integrated Care Board streams of work? Looking at pain clinics and the long-term use of medications- are they now as effective and cost effective against the new drugs coming onto the market. Discussion on this topic and the psychological aspects of coming off medications is considered ineffective. Look at other alternatives such as holistic methods and acupuncture.

The Vice-Chair thanked RB for a very informed discussion and talk. The members responded in the usual manner. RB was grateful for the opportunity and found the discussions useful. Asked if the group would like one of her clinical research colleagues to attend a future meeting to speak about their role and some of the studies from a clinical perspective. Members were in full agreement and RB will liaise with the Vice-Chair.

Update: The Vice-Chair, JB, has followed this up and Richard Hibel, Primary Care Research Nurse | LCRN West Midlands Core Team | NIHR Clinical Research Network (CRN), will attend the meeting in March 2024.

9. Patient Stories

(i). Blood Tests

At the last meeting there was a story around blood testing. Details below: Carlton group surgery no longer has a contract with Queen's hospital to take blood tests from their patients. Patient told they could not have a form to take to Queen's as they would refuse to take it. This would have been easier than trying to wait for an appointment with the surgery and the patient also works as a volunteer at the hospital.

This is because Carlton group have their own phlebotomist, they have advertised for another one to ease pressure on surgery appointments. Patient thought the NHS was free at the point of contact but cannot have a simple blood test.

Update:

The situation has been resolved to the patient's satisfaction.

(ii). Appointment System at Trent Meadows.

- IL, Support Staffordshire, had to arrange an appointment for a blood test for a PSA test. No appointments at the time and none, time after time when the surgery contacted. Now six weeks since the original request and still no appointment, (some of the delay due to IL not contacting the surgery).

There followed a discussion around the topic of surgery appointments and the many daily issues that both surgeries and patients face.

These discussions included the role of the care-coordinator, clinical pharmacists, nurses, and other staff that the patient could see rather than always asking to see a GP.

(iii). Ambulance Issues

- DB, Healthwatch Staffordshire mentioned a case where a 35year old with severe chest pains had to wait for an ambulance from lunchtime until 1am the following morning to get an ambulance. On arrival at the Derby Royal there were 21 ambulances waiting to discharge patients. Due to no space put into a side room with other patients.
- The Vice-Chair, JB, informed the members of what happened with KL recently, (had her permission to mention), and waiting for an ambulance after collapsing with severe chest pains in the public lounge at Trent and Dove, Horninglow. Manager informed no ambulances for 2-3hours and could she make her own way to hospital! Went via a taxi and the driver took her into A&E and had to explain the situation before people came to assist.
- The Vice-Chair, JB, related his experience when at the surgery late afternoon in November. Following an examination and tests by the GP and nurse an ambulance called at approx. 5.45pm due to heart related condition. Ambulance arrived at 6.45pm, after full discussion with the GP and me decision to go to Burton A&E. On arrival no other ambulances waiting and within A&E within 10mins of arrival. Later that evening after they had brought another patient in came to see how I was.
- KB, Rocester, yes there are times when the health service does not get it right but at other times they do. The stories above illustrate this. There are also times that the issues that patients can cause issues by not helping themselves.

10. Healthwatch, Staffordshire Update.

DB, Healthwatch, Staffs gave the following update.

• UHDB Maternity Services have been rated inadequate by the CQC. An extensive improvement plan is in place and some 25 different pieces of improvement work is being undertaken. A new Director of Midwifery recently appointed, 43 new midwives recruited, new scanning equipment purchased. The free-standing birthing Unit at Sammuel Johnson Hospital in Lichfield the community birthing service remain suspended due to staffing shortages.

- **Reduction of harm from Opioid Prescribing** there is an ICB working group looking at this issue and E Staffs PCN is developing a pilot project to tackle this issue. Healthwatch encouraging involvement of people with lived experience.
- **Continuing Care Review** Healthwatch have been approached to contribute to the ICB NHS continuing Care review to support public engagement.
- Publication of three Healthwatch Deep Dives including Access to Primary Care are now available on the Healthwatch website under reports (<u>www.healthwatchstaffordshire.co.uk</u>)
- **Appointments** In August 2023 there were 6,000,000 appointments across Staffordshire which was a 25% increase on August 2020. There is a variation between surgeries for face-to-face appointments, however 90% of appointments given within two weeks. It is imperative assistance is given to those people who cannot get an appointment.

11. Support Staffordshire Update.

IL gave the following update:

- Been visiting the usual voluntary groups within the area. Two have now ceased due to lack of funding.
- A new dementia café starts the following Monday in Uttoxeter. This is called by Forget-me-Nots and is to be run by Kate Nash.
 KN was the original person in charge of the Pirelli COVID vaccination centre.
- Been having a conversation on the way events and groups advertise themselves. The wording, colouring, timing for example. All vital for getting the correct message across.

Those present then had a discussion on the best ways to communicate. Best proven way is by word of mouth. Get people to tell 3 people and they to do the same. A base of what is going on will gradually build up.

12. PPG Updates

CD, Trent Meadows PPG. (In the absence of CD the following update given by the Vice-Chair, JB)

Prior to COVID the PPG had held a prostate information event, within the surgery waiting room, for men over 55. This was extremely successful, and a further event was held on Saturday 25th November at 10.30pm in the Trent Meadows, Branston surgery.

25 men attended and listened to a presentation from the local Prostate Support Group. Again, it was successful which the Vice Chair, (JB), concurred with as he had attended.

LL, Alrewas PPG

LL informed the group that she will be resigning as Chair and as a committee member of the Alrewas PPG at the AGM in January. This will mean that she will therefore no longer be attending District Group meetings. LL indicated it had been very difficult decision, but since her husband, Tom, died she has been reprioritising her commitments.

LL has been a member of the Alrewas group for nine years, (and Chair for five of those years), so now had decided now would be a good opportunity for someone else with fresh eyes to take the lead.

All present thanked LL for her dedication and support she had given to the Alrewas PPG and the District Group. She would be sadly missed but everyone could both understand and respected her decision.

JB, Tutbury PPG

Held our last meeting in November. As mentioned at the last meeting in early October a text was sent to all patients, above 16, asking if they were interested in joining the PPG and if so how to contact the Secretary JB. This was immediately successful we had 12 new members.

In November four of these members attended the meeting.

The new Practice Manager attended the meeting, and a good discussion was held. Appointments were the main topic, and a small group are meeting with him to look at various scenarios and what assistance the PPG can give.

KB, Rocester PPG.

The surgery has appointed a pharmacist because of being a dispensing surgery. Worked superhard to supply patients with the Covid and flu vaccinations. However, they were required to accept a 25% cut in monies compared to previous payments.

DB, Healthwatch, patient, and former member of Bridge surgery PPG. The local Labour candidate has sent a letter to both complaining about the practice.

13. The East Staffs and Surrounds Diabetes UK Patient Network

The Vice-Chair, who is also the Chair of the Diabetes Patient Network, gave the following update. Due to illness the Chair had to cancel all meetings/events due to take place from early Nov until Jan 2024. A full report on 2023 activities, of the network, will be given at the next meeting.

14. Any Other Business

No topics raised under this agenda item.

15. Review of the Meeting.

Highly informative, good discussions.

16. Date of Next Meeting

Date of Next Face-to-Face Meeting: Thursday 15th February 2024 14.00 – 16.00. The Vice-Chair, JB, thanked everyone for their contributions to the meeting and wished everyone and their families to happy festive season. This will start with an AGM and a look back on 2023.