

Parent Carers Together Feedback Form

Name: Maureen Rolfe

Meeting description

Health Action Group

Where was Meeting Held:

VIS Teams

Meeting Date:

JUNE 10TH 2021

Start & finish time:

10-30- 12-30

Future Meetings on :

SEPTEMBER 23RD 2021

Feedback can be in any format; it should contain important points that came out of the meeting, your opinions, any related work that you think overlaps, action points that you might be involved with, any areas of concern. This will be shared with all PCT reps and committee.

Please email to info@parentcarerstogogether.org.uk within 2 weeks of meeting

FEEDBACK & COMMENTS *(please use further pages if necessary)*

Today's meeting was attended by reps across BCP and Dorset Health.

Laura White CCG CHAIR and new admin Kelly Swyre mins replacing Lorraine Bailey retires end of June.

Peoples First Forum attended along with new Dorset Advocacy rep Sini Lucas who has experience across the board.

A reminder to that all GP surgeries should have a Learning Disability Register so check with your surgeries to see if you are on the Register.

In Sept meeting Annual Health Checks will be under discussion along with the regular feature of Transforming Care.

BCP should hold a Learning Disability Register of their own?

Action Log was reviewed no points of further action at this time.

Cancer Screening was next topic both Male and Female. Deemed best early intervention was better than later. How to get the importance across of checks. Levels of understanding.

At this time there is no EASY READ leaflets on Screening this will have to change not good enough anyone with LD /AUTISM HAS A RIGHT TO THE SAME TREATMENT AS ANYONE ELSE.

Could a point be raised at the Annual HEALTH CHECK as screening is not yearly each test varies



Further investigations would denote more tests. About getting the point across that tests are important. Hospitals have screening tests available to assist in some cases needs signposting more openness support and help of Community Teams to get message over.

LW will go back to the Wessex Cancer Group to discuss today's findings and report back in Sept.

Point was raised in regarding to understanding levels of L/D.

LW going to see what other areas have done which could help here.

A learning disability nurse in BCP goes out to patients but only to raise awareness not testing in their own homes which could be less stressful in the long run a need for a team possibly hereto trial if this could work in the long term.

Portland only had 2 nurses for the whole area and only in exceptional circumstances would they carry out any tests of this level.

PRIOR TO Covid "ACTION HAMPSHIRE" under grant funding did workshops to promote education giving out packs and general information. More hands on support required. There was a lot to think about here getting results without distress. LW said could be linked to other groups who do tests?

Sarah Bramall then spoke on Leder (Looking at lives and Deaths of people with Learning Disabilities and Autistic tendencies. This is still known as Leder. Works by way of an initial review following death with focus on GP notes families friends and carers were the right paths of care being followed prior to death? Ethnicity has become more to the fore now due to the death rates among the population due to Covid. Now there is a more focused review done by teams initially 4 people (still being set up). Relevant to see if any patterns form or points of issue. So reports will go when completed to LW. A way of learning within the system better detailed outcomes for families in their time of loss and grief overall better Governance.

Need for data to be shared and good communications. Timeline for this to be fully functional starts June 1st through to April 1st 2022. Covid cases 4-10 per month as opposed to 6-7 prior to Covid. New team will be based in Dorset.

We then turned to the Yellow BOOK Review done by Peoples First Forum

64 people completed the survey including 4 family carers and 2 p/time Staff.

Comments were interesting 16-25yrs – 20 not heard of book 37 did not use their books and 12 did not want one. Work is being finalised as to next stage.

TRANSFORMING CARE update: In Patients 16 adults which has risen to 20 - 3 housed in South west and 1 in South East so numbers rising along with costs. Bear in mind these are across all age ranges. Four Care Reviews have been carried out in hospital. So we now have the

DYNAMIC SUPPORT REGISTER

There is a Commissioner CCG who will OVERSEE AND VISIT patients every 8 weeks. CCG WILL NOW HAVE THEIR FINGER ON THE PULSE TO SEE WHERE MONEY IS BEING SPENT.

For each area updates will follow monthly to see if money can be saved moving people when safe closer to home or permanent settings. There is still set up work to complete in this area.

ASSURING TRANSFORMATION DATABASE

Will give live information from visits and hospitals.

St Anns currently has 5 patients 2 of which are in FORSTON-DORCHESTER travelling long distances for visits is hard for families. When discharge comes about careful planning is required by all CTR REVIEWS are now done Face 2 Face. Moreso now Families and Carers

Are a vital part of planning reviews along with friends all have a part in decisions.

Care Co-Ordinators too have their part to play in positive long term outcomes.

Meeting Closed.