

PDUG Minutes of 18/03/ 04

In Attendance

Philip Bradley
Sue Davis
Hilary Peckitt
Norma Naylor
Tony Beswick
Jim O'Rourke
Gill Beswick
Zoë Crutchley
Kym Abel
John Groves
Jenny Osborne
Lynne Jones
Julia Pearson
Ian Topp

Apologies

Carole Morrison
Roger Hall

Informal chat 13.30 Tea /Coffee

1.Meeting Started 1400.

Welcome & apologise. Thanks to Kym and Lynne for attending.

Safe environment. It was explained that a safe environment was achieved when Users felt secure that they could voice their opinions on services without feeling at risk that it could have a negative effect on the care they received. Kym was complimented on the fact that Users had stated that they felt safe in Kym's company. This had not always been the case in the past with other professionals.

AOB none.

- Transport.
- User Groups response to Manfield re-provision.
- Medication.
- Representation on site meetings

Minutes of User Group meeting of 17/2/04 were accepted as a true record.

Actions carried forward.

Action Kym and Lynne to invite to meeting.

Completed

Action. Ian to update Group on meeting with Andy Howard.

It was explained that although Andy had taken our concerns onboard relating to a lack of integration between Favell and Cynthia Spencer the feedback he received from Jackie Phillips (Manager of Cynthia Spencer and Cransley Hospice) was that it could not be

done. It was thought that this may be because Jackie Phillips believed that the clients were different and that Jackie Phillips thought that palliative care only related to those individuals who were at the terminal stage of their illnesses. In the light of the following facts the User Group did not except this as a valid reason for not integrating the two services.

- Palliative care includes those with a degenerative illness.
- The Countywide needs assessment that was conducted into palliative care appeared to have included only cancer sufferers.

ACTION John to obtain copy of countywide needs assessment into Palliative care.

ACTION Ian to see if there are any Cancer User Groups that can come to User Group meetings.

ACTION Ian to firm up with Andy Howard when he can next attend our User Group meeting.

2. Building bridges with the Team.

It was expressed by various Users that there had been a breakdown in the working relationship between the Team and the User Group.

This was made apparent by only one of the User Groups survey forms being returned with nothing filled in and an E-Mail not answered querying why this was so. There had also been no names of any new Users for a good number of months.

It was pointed out that the PDRT User Group had always had a positive working relationship whilst coming under Jenny Smith. Since Jenny Smith had left this relationship had deteriorated. This was thought to be due to either the fact that the User Group had refused to give its backing to the FBC and/or the PDRT now coming under the Management of Favell. It was also pointed out that the Favell House User Group had never had a good working relationship with the “Management” at Favell and the User Group were just paid lip service. This was apportioned to the Favell House User Group coming up with various proposals to improve the service such as transport, staff patient ratios, physio service, key workers, interviewing new staff, User surveys etc. none of these proposals had been taken onboard freely or implemented correctly.

ACTION Ian to look out hard evidence to substantiate this claim and pass it on to Kym

Phillip stated that the newsletter Bright Ideas had been criticised for its content in relation to the integration of the two services of Favell House and Cynthia Spencer by Management of Favell during a Staff Patient meeting.

Phillip went on to say that the criticism related to a Favell Management view that there was no justification for integrating the two services. Ian clarified the point that both the Management of Favell House and Cynthia Spencer took part in the option appraisal. This resulted in the preferred option of integrating the two services, it is only now that the project has passed into the hands of Nurses and architects who all have a vested interests that we have ended up in the predicament we are in now.

3. Way Forward

Kym stated that the Team thought that they were no longer welcome as Ian had requested that no members of the team attended. Ian explained that in the past only one member of the team came to the meetings and this was through an invite. When 4 staff members had attended a User Group meeting a safe environment cannot be maintained and this was one of the reasons why Ian had requested that no staff members attend unless invited. It was also a User Group responsibility to ensure that any staff member attending did so with a specific purpose. This was to prevent the meetings just becoming a talking shop with no measurable benefits of holding User Group meetings. It was requested by the Users that Kym continued to attend User Group meetings, as they felt safe.

ACTION Kym requested to attend next User Group meeting with her findings.

ACTION User Group to consider inviting Bridget Peet and/ or Nichola Carter to a User Group meeting to discuss PCT's strategy regarding User Groups.

4. Update on Physical Disability Strategy (Lynne Jones)

Lynne gave the social services perspective on where they were at now. Lynne stated that it was for developing services for adults under 65 years of age with physical impairments. The strategy that had been agreed upon back in February 2001 had been on the shelf for at least two years as far as commissioning was concerned due to the person leading it retiring (Brendan Sheehy).

Lynne went on to say that she had been in post now for 12 months with a remit of picking this up and looking at how this could be implemented. Lynne went on to say that while Social Services would be looking at community teams etc specialist health services would be left up to the PCT's. Lynne went on to say that for the last 6 months she had been talking to such people as Kym and Karen about specialist community teams, community based services and centres for independent living and specialist health services. It was apparent that there was a duplication of both resources and tasks within care management and the PDRT. They were heading towards teams that were multi disciplinary, one assessment etc. Lynne stated that her task last year was to try and formulate this into what is known as a strategic plan for physical disability. Things were heading the way where Users would knock on one door resulting in one assessment leading on to all the services needed. The new strategic director did not wish to see any distinction between services for people who were over 65 and those that were under. This had resulted in the path they had put together during the last year and heading along changing and was a big shift in where they thought they were heading.

The Group responded to Lynne's comments with the following points.

It was highlighted that it was a shame that Lynne was working to a plan where there was a distinction between services for those under and over 65 as Users had voiced a wish that there should be no distinction between care groups such as brain injury and other

impairments and the services should include all ages. This was in fact documented in appendix three “Physical Impairment Consultation Statistical Information”

It was also thought it was unfair to blame the lack of progress on Brendan Sheehy’s retirement as Jim Golcher was still around and was the responsible officer for implementing the strategy. Concern was also expressed that it appeared that those people with a degenerative illness would be receiving their respite/rehab care in a nursing home, which was what this group fought against when Favell was threatened with closure. The question was asked that with beds being lost at Favell and Pine lodge where would the increasing need be met that would accommodate the increasing needs of an ageing and growing population. To say you will receive your care in the Community and this was working was unacceptable and not true as far as this Group was concerned.

Lynne replied by stating that the beds at Norborough house and Pine lodge were under used in the past so it was very hard to put a case forward for more beds.

The Group stated that the project appeared to have gone astray due to.

- The County Wide Physical Disability strategy was not being followed
- No correct needs assessment available on which to base future service provision.

ACTION Ian to contact new Director of Community services.

5. Patients and Public Involvement In Health (John Groves)

It was explained to the Group that John would continue to represent the User Group on Daventry and South Northants PCT PPI group. Sue informed the Group that she was also involved in joining a local PPI Group.

ACTION John & Sue to keep the Group up to date.

6. Website development and extra funding approval.

The Group agreed that no one should be out of pocket for promoting the Group. The case that Zoë was subsidising the Web Site for the Group out of her own monies was unacceptable

ACTION Ian to obtain clarification on availability of User Group Funds and procedure for claiming running expenses of the Group activities.

7. Stakeholders event. Hydrotherapy provision.

Ian informed the Group that he had been invited to take part in a Stakeholders day with regards to re-provision of a Hydrotherapy service. The Group were asked to confirm that it was still their wish that the Manfield site re-provision should include a hydrotherapy service as stated in the original output specification. Those present agreed this.

8. A.O.B.

- **Transport.**

Phillip and Ian raised concerns about the present situation whereby only certain people were accessing the new ambulance for transport into Favell. Some had to provide their own transport into the unit, whilst others have to pay for their own transport if they use Northampton Door to Door service. There also appeared to be no rhyme or reason to who can use the Favell House dedicated ambulance.

ACTION Kym to update the Group on her findings

- **User Groups response to Manfield re-provision.**

The background behind the way the design had been arrived at was explained to the all present. The Group was asked if they wished the dictated letter to be sent to Sir Richard Tilt CEO of the strategic health authority requesting his intervention. After a few amendments it was agreed that the letter be sent.

ACTION Ian to send letter to Sir Richard Tilt

- **Excessive requests required for repeat prescriptions.**

ACTION Ian to place on next Agenda

- **Representation on site meetings.**

ACTION Ian to place on next Agenda for debate.

9. Expenses

**Next meeting at the Doddridge Centre. Friday April 16th
13.30 tea/coffee 14.00 start**