

## **Making the PD Clinic fit for the 21<sup>st</sup> Century- Changing the Delivery of Services for People with Parkinsons in the New Forest.**

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### **Background - Setting the scene:**

There are approximately 450 patients in the New Forest (NF) with Parkinson's disease (PD), of whom 300 are seen by the PD team based at Lymington New Forest Hospital, a part of Southern Health NHS Foundation Trust. There is a weekly clinic with Consultant Geriatrician and Consultant Nurse presence. There is also Consultant Neurologist presence in this clinic monthly. The NF PD Nurse Specialist role is currently vacant.

### **Background - The Challenge:**

The PD National audit 2016 highlight two areas which the NF PD service should aim to improve. This included the use of a structured questionnaire to assess non motor symptoms (NMS) in PD. It also highlighted the need for the service to explore wishes around advanced care planning (ACP). Separate to the PD audit results, we noted that the service was limited by clinic capacity constraints.

### **Aim:**

To improve the service and experience of People with Parkinson's (PwP) in the NF, through collaboration between the local PD service, PwP and their families.

### **Co Design Plan:**

The audit results were discussed at a local branch meeting of PD UK, with members proposing that a group consisting of PwP, spouses and former carers work together with the local service to improve the service: collaborative co design. What has followed is four hour long group meetings with email communication between.

The meetings were chaired by Dr Turner and Dr Vardon coordinated the group meetings and managed the written communication.

### **The (Shared) Agenda:**

A shared agenda was developed between clinicians and the PwP group. This meant taking time to listening to the priorities, concerns and ideas of the group and weaving together with the ideas of the clinicians. The shared agenda included:

- PwP handbook - the PwP group were keen to develop an individualised comprehensive patient handbook.
- Pre clinic questionnaire - this would use ideas from the PD UK NMS questionnaire, as well as specific ideas from the group.
- PwP Education Group - both to support the PwP journey, and as well an opportunity to create capacity for clinic.
- New thoughts re role of PD specialist nurse - the PwP group felt the key theme for this role was the 'softer' skills such as caring and compassion rather than specific PD knowledge.

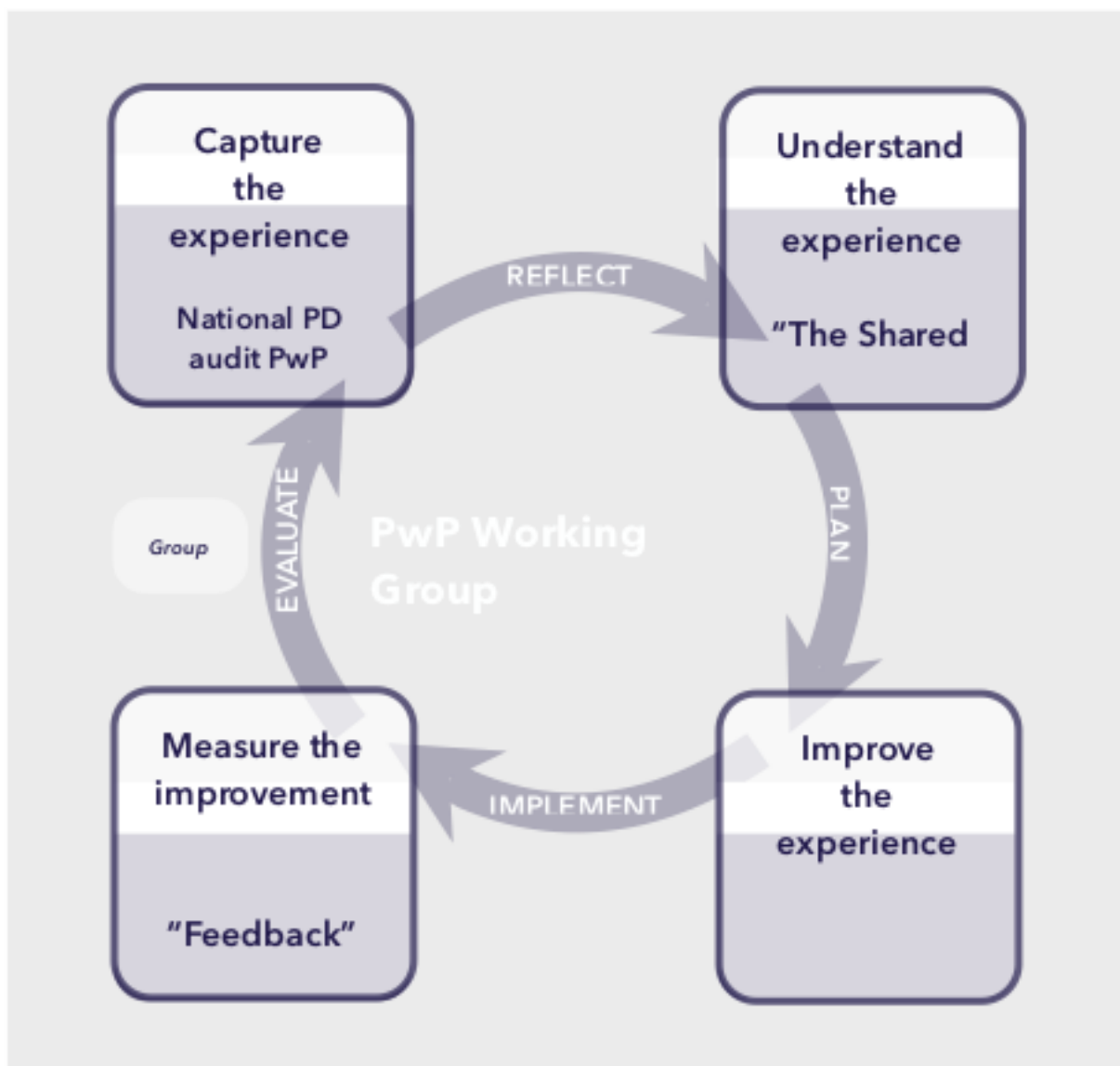
## Outputs:

One of the most rewarding outcomes was that of creating a forum for open dialogue between the service and PwP as well as developing a shared understanding of each others ideas, concerns and priorities.

The tangible outputs include:

- A pre clinic questionnaire - including ACP, is being sent out with PD clinic appointment letters. This will help our patients focus on key areas that have been affecting them since we last saw them.
- A PwP handbook - The local PDUK branch will fund a pilot for 30 patients. This will need further evaluation.
- PwP Education Programme - in progress.
- ACP joint working - article for the local branch newsletter (Parky News) and ACP is included in the pre-clinic questionnaire. The group are now actively seeking information on this topic.

## The process - Collaborative co-design:



## Evaluation - Qualitative Feedback from the PwP group:

*"Collaboration .... has to be the best way to improve the service"*

*"Privileged to be part of the project"*

*"Grateful for GT and LV's dedication to the NF PD service"*

*"Frustrated...we've not actually delivered anything those attending the clinic would see"*

## Discussion Points:

The process of collaborative co-design, compared with the more "traditional" audit process has enabled us to work towards jointly improving services. It has opened up communication, and enabled some interesting conversations. Although this is a more time consuming process, we hope that it will be a good investment in the longer term. Our initial (NHS) agenda has developed into a shared agenda - the trade off is that it may not fulfil National audit criteria as quickly.

We acknowledge that the project outputs are limited by the constraints of resource as reflected in feedback from the PwP group. The process was limited by resource in terms of time (relying on the generosity of PwP group & authors) and there was no budget provision for travel or refreshments for the meetings. This would need to be considered for future such ventures.

## Next steps for the project:

We will pilot the PwP handbook with 30 NF PwP and then evaluate it's use. We will gather feedback from the pre-clinic questionnaire. We have another meeting with the group where we will be able to discuss progress with the project to date, and start looking at the proposed education programme.

## References:

Using a Design Approach to Assist Large-Scale Organisational Change: Helen Bevan et al *Journal of Applied Behavioural Science* 2007; 43; 135.

The Point of Care Foundation: Experience-based co-design toolkit.

NHS Institute for Innovation and Improvement: The Experience Based Design Approach