

Canterbury and District Mental Health Forum

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Giving a voice to mental health service users in the Canterbury and coastal locality

The Patients Council; a 10 year review of an exemplary collective advocacy service.

Patients Councils are not new, of course:

In 1620, Bedlam Hospital introduced a Patients Council.

~ It then took St Martin's Hospital, Canterbury, 379 years to catch up, and recognize the untapped energy of patients' know-how!

Canterbury & District mental health forum is an independent charity committed by its constitution to "promote User-lead initiatives". St Martin's Hospital, Patients Council which the Forum has run for 10 years in collaboration with the mental health service trust (KMPT) is the most persistent example of this.

Matthew Sands, a Service-user/survivor employed by the Forum as Patients Council Worker since May 2000, provides this personal commentary on the founding and the work of the Patients Council.

Methodology

Without modesty I offer the independently run collective advocacy project, which I have custody of at St Martin's Hospital, Canterbury as a model of good practice:

- *I go to each hospital ward regularly to offer in-patients a chance to meet and share comments on the service ~ and make proposals for improving hospital life for **all** patients. I also collect patients comments that may be found posted in a secure suggestions box on the ward.*
- *The comments are recorded, - without ward staff present until-*
- *At the end, I seek the ward manager or senior nurse to join and respond to, what patients said on each raised topic. This response is recorded and included, in minutes, with patients comment.*
- *First names of patients involved are noted, and listed at the start of the minutes, but, in reporting concerns to staff, and in minutes, the one making the comments is not identified.*
- *The ward meeting minutes are reviewed in a monthly Joint Patients Council meeting, typically involving with the ward managers and the Modern Matron, and appropriate outcomes are sought. That joint meeting's minutes are circulated to all appropriate Trust managers.*

It was intended here to be the means for collective (not individual) advocacy; considering issues that affect all patients. But, after many patients were dismayed at having their *individual* concerns [e.g. "The medication I am given is wrong..."] cast aside as out of order, the Agreement was modified to allow individual concerns to be recorded, but still recognise that the Patients Council is not the intended means to resolve those.

How it began

East Kent service-user groups lobbied the public services for some time about the (then) lack of an Advocacy service locally for mental health service users. In reaction to this, Social Services prompted discussions linking Canterbury's user forum with St Martin's Hospital senior staff, and patients, about setting up means for patients to comment on and make improvements to the service; a Patients Council. ~ They agreed conditions for a 'pilot' project to run for four months from November 1999. At the close of this period a Partnership Agreement was negotiated between the responsible NHS Trust and the service-user Forum defining terms to continue regular hospital ward Patients Council meetings. The agreement was based on experience of the trial period, and informed by results of a multiple-option questionnaire completed by the patients at that time.

In essence, under the Agreement (a) *the NHS Trust* agrees to provide space for the ward Council Meetings and their follow-up 'Joint Patients Council' meetings; and to consider fairly the collected patients views and to act on clearly expressed patient requests, which are representative of patient opinion, or give clear reasons for not doing so.

And (b) *the service-user forum* agrees to hold regular Patients' Council Meetings on adult wards at St Martin's Hospital; to produce minutes for the meetings, and display these on ward notice boards it has provided; working collaboratively with Trust staff to resolve issues raised.

KCC Social Services awarded the forum a slight increase to the Service Level Agreement funding. With this money, the forum employed me, from May 2000, as part-time 'Patients Council Worker' to undertake the Forum's side of that agreement.

Staff outlook

As it's the NHS staff who have the power to initiate, maintain or end changes, either in what is provided, or in their staff custom and practices on the ward, sincere co-operation of the staff is the key factor that determines if the Patients Council can get results. Fortunately, very few staff involved indicated that they cannot accept the idea that patients can be more than passive recipient of *Care* administered. On Amber House, which had the best 'take up' of any of the ward patients councils, one ward manager would respond to his patients concerns with derisive scorn: Payphone not working? *Patients can get mobile phones!*; No wall clocks on the ward? *Patients should have their own watches!* - After this extended to compliments on the treatment provided, patients stayed away from meetings. But, as another ward manager put it, seeing that their view is considered and is evidently valued (by being in print) *can* help boost the patients self esteem.

The UK Advocacy Network (UKAN) argues that those who have experience of using the health services should run patient advocacy services. (This one is!)

UKAN identified three functional levels of independence needed:

Structural ~ Not constricted by funding or structure.

Operational ~ Not connected to Service Provider; not compelled to conform to expectation.

Intellectual ~ Client instructed (independence of mind)

Frequency issues

After the trial period, Patients Council meetings were offered *fortnightly*. In the first three years of the Patients Council the patients' "take up" of

opportunities to meet fell from 60% at the start of 2000 to 32% in the latter half of 2002. ~ Longer-stay patients could feel they had no new comments to contribute after their first attendance. Patients had also indicated that they found getting involved in a meeting every two weeks too much to take on. A change to offering meetings just once a month was proposed but after resistance from the Trust's PALS office staff, the Forum agreed to postpone the change until a twice-monthly schedule had been given a trial run: - If, in the first 4 months of 2003 Patients Council take up did not return to the overall average of 'take-up' - 47% - then (the forum decided) the frequency of PC visits would change to *monthly*. ~ This was exhaustively advertised to patients as "*Use It or Lose It*". Informed patients then made the choice: Take up fell to 22% in this 4 month period! Then, in the first year in which PC meetings were offered *monthly*, more meetings in total were held on the three treatment Wards than were taken up during the last year of offering meetings every 2 weeks.

The prime reason given by a few resisting the cut in visits was that having the Patients Council gives a good impression to reviewing agencies like the Quango called the Commission for Health Improvement. On the other hand, on one ward, two of the occasions when all Patients Council notices were removed from the boards were, [*by coincidence*], just prior to the statutory inspection by the external Mental Health Act Manager!

What has Patients Council ever done for us?

Some results for prominent topics that raised patients comment at Patients Council meetings:

Food and Drink provided; For many years, this topic gathered more issues or comments from in-patients than any other at the Patients Council. The Trust's Hotel Services department often modified menus informed by views collected at Patients Council meetings: - Kitchens use of a wider range of foods for the protein element in vegetarians meals; - a wider variety of mixed salads was provided in the menus; - on one ward, staff remedied a reported shortage of breakfast bowls & cereals; - on another ward, the time allowed for patients to get up for breakfast was extended; also, drinks of water or squash were

made accessible throughout the day for patients whose medication had a side effect of mouth-drying, creating thirst.

On Dudley Venables House ward (DVH)

Occupational Therapy; Both patients and ward staff recognised a need to provide purposeful activities for in-patients confined to this low secure ward. But it seemed as if the only occupational therapy available would be chain-smoking! Finally, informed by the Patients Council, Canterbury's service-user delegates at the East Kent Health Authority's commissioning board meetings were key to overcoming reluctance of some managers, and secured funding to start employing an occupational therapist for the ward.

Medication; a reference folder was established in the staff office, which patients could apply to look at, for details of their medication's effects.

Pool Table; After the Health Authority's Chief Executive attended a Joint Patients Council meeting as observer, funding was secured from the Health Authority's trust fund to pay for a new pool table for the ward. The desire for a working replacement for this therapeutic equipment had been a recurring issue at Patients Council meetings.

On Amber House

Therapy groups; In the first six years of the Patients Council, Amber House was essential a day-hospital, to which referred out-patients could come in on perhaps two or three weekdays to attend a selection of therapeutic groups. The group timetable was revised every six weeks according to current client's needs. In the early years, Patients Council here took complaints of a lack of helpful practical group, such as managing a small budget. As one patient put it *'What will learning to carve my name on a bit of soap do for me?'*

Sometimes the groups scheduled did not run; this could be due to the nurse assigned to convene the group being switched to the night shift duty. Discontent at Patients Council prompted better co-ordination between changes in the allocated staff's shift rota and the therapy group timetable. Switchable "Vacant / Occupied" signs

were attached to the room doors to deter visitors from interrupting groups. This innovation was a Patients Council proposal.

In 2006 Amber House was closed, therapeutic groups were dispersed to other facilities; Anselm ward (which had shared the building) was reconstructed to occupy the whole building.

On Anselm Ward

Doorbell; After a patient's suggestion from PC, the ward installed a doorbell. (Previously, visitors had to wait to catch the eye of a passing staff member inside the ward in order to be let in!)

'No violence or aggression allowed' notice; A patient put a suggestion that there should be an official notice stating *"bullying and intimidation will not be tolerated"* finding that no such poster already existed, managers formed a group involving the NHS and the police, to design such a notice. The notice, which has logos of those bodies, is now used in all east Kent NHS premises.

Extra Payphone;

Complete reconstruction and enlargement of the ward left the payphone on what became the women-only bedroom corridor. At Patients Council, patients repeatedly objected to this at patients council as it gave male patients a reason to intrude into the area intended to be a women – only space. After 18 months the Trust found funding and installed an additional payphone in the ward communal area.

While reasserting Patients Council's operational independence, I am grateful for the positive support from many Health Trust staff: ~ To the ward managers and the nurses who each agree to come in at the close of ward PC meetings to give immediate consideration to concerns of patients there; to the Modern Matron, for the times they have represented the Trust at JPC meetings, ensuring that patients' issues were considered. chiefly, my grateful thanks to contributing patients who attended the meetings to comment on the service. They, - the experts on life in St Martin's Hospital, - are the key players in all this!

M. Sands

CaDmhf Patients Council Worker. June 2010