06 FEB 2004

CONTINUING CARE AND ASSESSMENT CLINICAL GOVERNANCE MEETING

(Hosted by East Hants PCT) 21.01.04 Minutes

Present

Kim Bezzant, Senior Nurse Specialist, Dept. of Medicine for Older People (DMOP) (KB)

Dermot Charlton, Charge Nurse, Jersey House (DC)

Gina Cooper, Continuing Care Co-ordinator, F&G PCT, Fareham Reach(GC)

Penny Holms, Staff Nurse, Briarwood, St Christopher's Hospital (PH)

Anne Hobbs, Staff Nurse, Cedar Ward (AH) Claire Keene, Staff Nurse, Jersey House (CK)

Helen Russell, Sister, Dryad ward, GWMH (HR)

Val Vardon, Associate Specialist, Charles Ward, QAH (VV)

Sonia Welch. Sister, Jubilee House (SW)

Suzie Stansby, Staff Nurse, Cedar ward (SS)

| Item | Discussion | Action |
|---|--|--|
| 1. Apologies | Teresa Dunn, Sister, SCH Sylvia Morris, Service user, c/o Dermot Charlton, Jersey House Jenny Hazel, PALS, QAH Jane Salter, Senior Staff Nurse, Jersey House Gill Gould, Nurse Specialist, DMOP Div Offices, QAH Barbara Robinson, Chief Nurse, DMOP Div Offices, QAH Flora Smith, continuing care co-ordinator, EHPCT Raebarn House Jan Hoggarth, team manager, intermediate care, SS dept, Haslar Hospital Carol Norris, George Ward Wendy Ball CG facilitator, Raebarn House Copies also to: Jeremy Martill, SS Dept, QAH Sue Damerel- Kewell, Raebarm House for info | |
| Minutes of last meeting and matters arising | Flora Smith's role. Gina Cooper helped to clarify this by describing her own role. This focusses on assessing people for the categories 1 and 2 of Continuing Care. Toolkit | |
| | It was thought that the Strategic Health Authority had reformed the group to look at this. It was felt that this group should input into the SHQ group Terms of Reference These were accepted | KB to contact Jane Brent |
| | Single Assessment Process Draft Assessment document out for comment. Some members have not yet seen | Copies to those who have not yet have |
| | Patients who are out of area. Particular problem with Southwick area. Val has written to Lesley Humphrey. | Await reply |

| T | Tony Warnes from Social Services has responded | KB to invite |
|----------------------|---|---------------|
| | positively to the invitation to this meeting, and would like | to a |
| | to attend to talk about his role in discharge planning | meeting |
| | Suggestions for audit: | |
| CLINICAL AUDIT | Documentation | |
| | The new documentation is auditable. Invite Gill to next | |
| | meeting to describe new forms and systems. | |
| | | |
| | Referrals to Continuing Care | ļ |
| | Suggestions for audit form: | |
| | Is a referral form filled in? | |
| | Does person live in the area | |
| | What is their Bathel score? | |
| | What is their specialised need? | |
| | If they are due to go to a Nursing Home, has a planning | |
| | meeting taken place? | |
| | Have they and their relatives received the leaflet, and | KB to |
| | letter? | devise form |
| | Do they have challenging behaviour? Trial for 1 month | devise form |
| | i rial for 1 month | |
| | Helen asked to see the Nursing Homes procedure | KB to send |
| | Heien asked to see the Naising Homos prosecure | сору |
| CLINICAL RISK | Nil | |
| MANAGEMENT | 130 | |
| TRAINING, ED, & | Claire said that the continuing care course at | |
| CONTINUING | Southampton University was undersubscribed. | KB to talk to |
| PROFESSIONAL | | Barbara |
| DEVELOPMENT | NVQ level 3 was discussed and thought to be a good | Robinson |
| | idea for the future | about this |
| PATIENT | Sylvia Morris at Jersey House has agreed to attend | |
| CONSULTATION | meetings | |
| & INVOLVEMENT | | KB to send |
| | Good article entitled 'The myths of patient involvement' | KD to selid |
| | has come from DMOP patient Experience Group | |
| RESEARCH AND | The milestones for the first 4 standards were examined | |
| EFFECTIVENESS | with the following issues arising: | |
| | Some PCT services are not still equitable | KB to |
| | We have a continence service, but non-one knew The service of the servic | enquire |
| | if someone was leading on feacal incontinence Confusion over intermediate care services – | KB to seek |
| | = | clarification |
| OTAFFING AND | different in each area | |
| STAFFING AND | Nil | |
| STAFF | | |
| MANAGEMENT USE OF | Nil | |
| 1 | INI | |
| : INICODNIATIONI | | |
| INFORMATION | HR would like to set up a support group for shared care | |
| ANY OTHER | HR would like to set up a support group for shared care people. Advice was offered from other members of the | |
| | people. Advice was offered from other members of the | |
| ANY OTHER | HR would like to set up a support group for shared care people. Advice was offered from other members of the group DC said that Margaret Owen was retiring in September | |

Next meeting: Wednesday 24th March, 2004 at 2pm at St Christopher's Hospital

Continuing Care and Assessment Clinical Governance Group

Terms of reference

Agreed Jan 2004

- 1. Group to meet bi-monthly
- 2. Meetings to last 2 hours
- 3. Chair to rotate every 6 months
- 4. Venue to rotate
- 5. Meetings to be booked well in advance
- 6. Specific aims for meetings are:
 - To debate current issues
 - To work towards integrated Continuing Care services across the district.
 - To share research and good practice
 - To stimulate and support Essence of Care working
 - To determine how to be involved in the National Service Framework milestones
 - To influence the local approach to the Single Assessment Process
- 7. Clinical Governance framework to be adhered to as standing agenda;

Clinical Audit
Clinical Risk Management

Education, training and continuing personal and professional development
Patient consultation and involvement

Research and Effectiveness Staffing and staff management

Use of Information to support Clinical governance and health care delivery

Five myths of patient involvement

spend a lot of time speaking to NHS audiences about patient involvement. Everybody in the NHS knows they ought to do it (it's included in the CHAI review for a start) but nobody quite knows how or why. Patients don't seem to be queuing up in droves to get involved (too busy queuing for treatment perhaps?). In speaking and listening to these audiences I have found several myths in wide circulation. I'd like to explode some of them here.

Myth number one

Patients want to be involved No we don't, and the NHS is right to be suspicious of committee types and axégrinders who do. Most of us just want a health service that is designed and run to meet our needs. We don't want to go out on rainy nights to meetings, and we don't want to spend our free time filling out guestionnaires. What we want is an effective means to influence the nature and quality of services. We don't have to "get involved" to get what we want from Tesco or Ryanair: we influence their activities by our power of consumer choice. Similarly, if we are unhappy with our governments, we can vote them out. The NHS is not accountable to patients either as customers or as citizens. True choice is denied us - the government's pathetic offer of treatment at another hospital if we have waited long enough at the first one is not choice, it is system failure. Patients' Forums are no substitute for direct democratic control.

Myth number two

Clinicians and managers adequately serve patients' interests

No they don't. There are many stake-holders in the NHS, and the only ones with no real clout are the patients. What sanction do we have? Can patients work to rule, or withhold their labour? Can we take our business elsewhere? Can we fire the managers if we consider they are not performing in our interests? Do we have access to information and skilled negotiators and advocates? Do we have a trade union or a Royal College? Clinical and professional staff and administrators make the decisions, and they are ultimately decisions that suit them. Pharmacists

Thinking the unthinkable and saying the unsayable, IAN KRAMER lists five very good reasons why do-gooders' ideas about patient involvement might just be wrong

have more influence on prescribing policy than patients. No one with real power on behalf of patients sits at the tables where decisions are made.

Myth number three

There is a representative patient No there isn't. One of the difficulties advanced as a reason for not getting patients involved is the problem of securing a 'representative' sample. I'm occasionally criticised for not being a representative or typical patient. If someone can tell me what a representative or typical patient is, I will try to be more like one. I'm told I'm too professional, articulate and well informed to represent the typical patient. One wonders whose interests inarticulate, ill informed and unprofessional patient representatives would serve. More attention seems to be paid to making patient groups 'representative' than effective. For example, the governance guidelines for foundation hospitals foresee all sorts of gerrymandering to ensure that different groups, including faith groups, ethnic groups, children, and for all I know, folk-dancing groups, are included on the board of governors. If a patient panel has no real power, it doesn't matter much who sits on it. Patient panels are not patient parliaments, and should be judged by their performance, not their composition.

Myth number four

It's all too complicated for patients
This is closely related to myth number
three. The perception of patients as
lacking the basic skills to be trusted
with any real power or influence in the
health service is linked to the perception of empowered patients as 'atypical'
and therefore not to be taken too seriously. Patients are no more and no less
intelligent than the general population,
since we are the general population:
we are, when not wearing a hospital
gown, parents, teachers, lawyers,
builders, policemen, and plumbers. We
are apparently responsible enough to



We pay for our treatment through our taxes, the same way we pay for our rubbish collection, but no one expects us to volunteer on the dustcarts

decide whom to marry, whom to vote for, where to live, and whether or not to have children. Surely we can be trusted to participate in healthcare policy too, and at a level above that of menu choices and décor decisions.

Myth number five

It's cheap

Patient involvement is not free. We need training, information and support. We need to have the costs of participation, such as travel, childcare, and communications paid for. We also deserve to be paid for our time. There is a long and honourable tradition of voluntary service in healthcare, dating back to biblical times. Payment is not inconsistent with that tradition. Rather it expands the pool of people available to serve, beyond the sort of people that have the time, money and inclination to volunteer. We rightly honour NHS staff for opting for a career in public service, but we do not expect them to work for nothing. Patients though, are expected to work for the NHS for free. The French had a revolution about forced labour for the state. We pay for our treatment through our taxes, the same way we pay for our rubbish collection, but no one expects us to volunteer on the dustcarts. The NHS pays its staff, architects, lawyers, decorators, cooks, and PR consultants and all the other experts that collaborate to deliver and improve services. Why should it not pay its patients for their time and expertise?

There is no mystery to patient involvement. Connect the levers of patient participation to the real machinery of the health service, and teach us how to use them, and we will be queuing up to have a go. The problem at the moment is that none of the alternatives on offer do what they promise. Make us an offer we cannot refuse, please.

lan Kramer was a California attorney and English barrister until medical retirement in 1997. He has been living with HIV since about 1982. He now advises and trains for the National Health Service Modernisation Agency's Clinical Governance Support Team. The opinions expressed are entirely his own however. Ian can be reached on waitingroom@btinternet.com