MEDICATION INFORMATION PROJECT

Meeting information needs of psychiatric inpatients: Staff and patient perspectives.

REPORT OF THE PROJECT GROUP

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Introduction

The mental health services provided by the NHS have involved service users in the design and implementation of satisfaction surveys for many years (Bond, Newnes and Mooniaruch, 1992; Goodwin, Holmes, Newnes and Waltho, 1999; Holmes, Dawson, Waltho, Beaty and Newnes, 1998; Myers, Leahy, Shoeb and Ryder, 1990; Trinder, Mitchell, Newnes and Todd, 1994; Turner and Newnes, 1993). The early questionnaire technique was rapidly replaced by a quantitative plus qualitative methodology. In-patient, community and day hospital settings have been surveyed. In general, as with other surveys of this type, the response rate was relatively low and the satisfaction rates consistently high. Satisfied people tend to respond and it is unclear what non-respondents feel about services (Stallard 1996). Dissatisfied respondents are thus an important sub-group who might indicate potential areas of service improvement (Beesley 2000)

In spring 2001 the Adult Division of a Midlands Mental Health Trust (UK) commissioned the Departments of Psychological Therapies and Pharmacy to lead a project exploring the concerns surrounding information about medication. Previous in-patient surveys had consistently shown significant dissatisfaction in three areas: ward rounds, food and information about medication. Reports detailing the results of surveys were previously presented to the Adult Division of the Mental Health Trust, latterly the Community and Mental Health Trust. Since the earliest surveys, medication information had been identified as a problem despite various attempts to solve it ("drug boxes" on wards containing books and leaflets, locally produced leaflets and increased availability of the pharmacist). The project group consisted of two service user consultants, a consultant clinical psychologist, the in-patients services manager and two independent researchers. The lead occupational therapist joined the group, the in-patient services manager devolved the responsibility to a G grade and E grade nurse and no medical representative volunteered. The group decided to report to the Drugs and Therapeutics Committee as this is a Trust wide group and its work, though focused on the acute wards, has Trust wide implications. The project group first met in October 2001.

Methodology

Discussions within the project group made it clear that there were a number of perspectives on the 'real' nature of the problem about information on medicines. It was agreed that focus groups would provide an appropriate methodology for the study. A focus group involves a free ranging discussion of a given topic. It is made up of a number of people who have been selected because they share one or more key characteristics. In this study focus group members had in common an involvement with the Hospital, either as patients, carers or professionals. A focus group study involves a number of different group discussions with representatives from a range of different interest and stakeholder groups. Each group is made up of participants from one of these categories, e.g. nurses or patients, and is led by a facilitator who introduces and guides the discussion. There is also a scribe, who takes notes and organises the recording where permission to tape has been agreed by all members of the group (Krueger and Casey, 2000).

The defining characteristic of a focus group is that it generates data through the interaction of group members, and uses the dynamics of group discussion to stimulate

the disclosure, formulation and comparison of participants' views. (Bowling, 1997; Kitzinger, 1994, 1995; Barbour and Kitzinger, 1999).

 Focus groups are suited to getting several perspectives about the same topic (Krueger and Casey, 2000). Respondents are selected to be a member of the focus group according to some common quality. In this study it was their role within the mental health care system that individuals within a group shared, for example, former patients, current patients, psychiatrists, nurses on the ward. Focus groups differ from group interviewing in that the interest is in the data generated by the interactions of group members rather than between interviewer and group member. The rationale is that the social setting is more likely to lead to attitudes, beliefs, feelings, experiences and reactions to others attitudes beliefs etc being expressed verbally and non-verbally between individuals within a relatively short time frame This approach is felt to be particularly appropriate where the research is carried out in complex organisations, in situations where a range of different stakeholders are involved, and where there are power differences between types of respondent such as between patients and professionals in the health care setting. (Gibbs, 1997; Kitzinger, 2000) In revealing the nature of alterative viewpoints and arguments focus groups can reveal the complexity of problems and their solutions, and stimulate a change in attitudes or receptiveness to future innovation. This is a particularly useful feature where organisational change is an intended goal or outcome of the research.

Focus groups also sit nicely within the goal of patient involvement that led to the surveys on mental health service users' experiences where the lack of information on medicines came to light. Focus groups can be an effective way of directly involving members in the research process (as 'participants' rather than 'respondents'). They can also be empowering where those with relatively little authority such as patients or junior nurses can be valued as experts on an equal footing with professionals (Gibbs, 1997; Barbour and Kitzinger, 1999). This process is more likely to promote a forum for change than other methodologies where a distance is maintained between the researcher and the researched, and the researcher retains 'ownership' of the recommendations, which result from the study.

As well as advantages, focus group methodology also has limitations (Murphy, Dingwall, Greatbatch, Parker and Watson, 1998). The composition of the groups may not be representative and individual groups may be skewed by the views of one or two dominant individuals or the momentum generated by a particular line of discussion. Some people may be reluctant to take part in a group event (although others may find the stimulus of group discussion enables them to overcome their shyness and inhibitions). Not only is a degree of confidence required to take part but also so is trust that other members of the group will respect sensitive information. There is usually a distance between what people do and what they say they do, and there is likely to be an element of idealisation in the accounts produced within a group setting. The views expressed within a focus group are (like any others) products of the contexts in which they are produced. They cannot be taken as representations of definitive or stable internalised beliefs. However, participants' talk occurs in a more naturalistic form than in conventional interviews, and focus group discussions can reveal a great deal about group norms and consensus and are an accessible way of investigating what people think about a particular issue.

A total of 90 respondents took part in the research. Fourteen groups were held involving a total of 88 participants. In addition one patient who could not attend a focus group took part in a face to face interview, and another submitted an extended written account of his experience of medication. The focus groups were made up of patients (five groups), carers (one), psychiatrists (two), nurses (three), occupational therapists (one), psychologists (one) and managers (one). Patients were recruited to the group in different ways. One of the two former patient groups was drawn from a network set up as a user consultancy for management. Members of the other group had all received specialist psychological therapy. The three inpatient groups were recruited via the nursing staff on the acute adult wards. No payment was offered but refreshments were provided and travel expenses were paid where appropriate. The members of the health professional groups were recruited through representatives of their professions on the working party. Most were held during or immediately after a regular meeting slot of the group but two of the nurse groups were convened specially.

One of the aims of focus groups is to reveal the underlying hierarchy of participants' priorities, rather than impose the researchers' predetermined structure of questioning. Consequently the content of the discussion and therefore the precise input from the facilitator was not predictable in advance. Each group was asked about the current provision of medicines information, perceived shortcomings of existing practice and their impact on patient care, treatment outcomes and relationships between staff and patients. Participants were also asked to recommend improvements to existing practice and to suggest measures for realising these as well as consider what difficulties they envisaged in implementing such changes. Findings from early groups were used to inform issues to raise with later groups.

Each group consisted of four to ten members and lasted for approximately 60 to 90 minutes. There was a facilitator (moderator) and at least one scribe for each group. All but three of the group discussions were taped and transcribed in full. In the three groups for which unanimous permission to tape was not obtained a summary of the discussion was developed from a comparison and compilation of the detailed notes made by two scribes during the meeting. and the written profile of each group subsequently written by the facilitator. Thematic identification and content analysis of all relevant texts (transcript and notes) were carried out. At the outset, the project group decided that verbatim extracts from the focus groups should not be included in written output of the research in order to ensure anonymity and maintain confidentiality for those taking part in the research.

The Local Research Ethics Committee approved the research.

Patients' and Carers' Concerns about Medication Information

Patients and particularly carers expressed many uncertainties about the illness diagnosis, course and prognosis, as well as information about treatment. There was concern that medication was given as the dominant and often only therapy, and about lack of choice or treatment alternatives. Additional forms of support, e.g. counselling and psychological therapy, were regarded as important in achieving recovery and long term health gain. It was not possible to access alternative treatments inside the hospital, and difficult outside. Information about medicines was only part of the information gap. Patients and carers also sought information about the nature of the illness and other forms of treatment. As the remit of the working group was to investigate medication information the findings presented below have been restricted to a consideration of this issue. However, it should be noted that members of the focus groups raised broader information needs in their discussions.

Patients and carers saw medicines as being important and necessary in treating severe forms of mental illness, particularly during episodes of acute distress. However, they felt they had received very little information about their medicines during their hospital stay. Carers did not always feel valued in their dealings with health professionals. In particular, both carers and patients described how they had experienced difficulties in making their voice heard and in taking an active part in discussions and decisions about treatment. There was a widespread desire for additional written information that could be kept for reference and absorbed at leisure, and also for verbal reinforcement and reassurance in face to face discussions with staff.

Written and reference information

The most frequently mentioned source of information was the leaflet inside the drug packs. In contrast to prescriptions collected from pharmacies in the community, however, these were often not available in the hospital setting, and were not given out routinely to patients. The leaflets were acknowledged to be a useful source of information although they did not answer all queries, and were sometimes felt to be lacking in 'user-friendliness' and difficult to read. As products of the drug companies that manufactured the drugs, their independence was sometimes doubted. Patients and carers, especially the more experienced, had consulted a wide range of sources in their search for additional information about medication. These included books, pamphlets and other leaflets, reference libraries, the internet, the BNF, newspapers, radio and television. Some participants had acquired an extensive and quite specialised knowledge of psychiatric disorders and drugs. The experience and knowledge of friends, family and other patients were an important source of information – sometimes the only one. Anxiety and uncertainty resulted from awareness of inconsistency between different sources of information, especially where this related to knowledge acquired from external sources conflicting with information given out by professionals. There was a strong consensus that all patients and, where appropriate, their carers should be provided with independent, high quality written information about each drug at the point of prescription as a matter of routine. Access to a wider range of information sources and media would also be welcomed.

Verbal information
Written information was important as a source of reference material which could be referred to and absorbed over time - especially useful when patients were not able to concentrate or retain information during acute episodes of illness. It was also valued for its significance in demarcating medication information issues as an appropriate and legitimate topic for discussion between patients and staff, as well as providing a useful tool for structuring such dialogue. Written information could not substitute for verbal communication, however. Regardless of how well informed they were patients and carers wanted also to talk directly with nursing and medical staff about their treatment. The quality and openness of this communication was an important determinant of how relationships with staff were perceived and built. Patients and carers wanted the opportunity to raise concerns, receive verbal confirmation of what they had learned elsewhere, and reassurance that staff could give them on the basis of their experience and professional authority. For example, such discussion could help patients get a better perspective about how likely they were to experience specific side effects, or what it would feel like to take particular medications.

Patients and carers reported a range of experiences in their contact with staff, but a desire for more extended discussion of medication was common. With very few exceptions, they described themselves as being passive recipients of treatments and decisions that they felt were made on their behalf and without their consultation or involvement. Several patients reported having rejected drugs that were prescribed for them because they had not been given enough information to make an informed decision about whether or not to take them. Discussion of medication usually depended on the patient specifically asking staff for the opportunity. However, these were not always easy to find. Staff members were obviously busy, and patients expressed uncertainty about their entitlement to make demands, or whether their concerns and questions were sufficiently important to confer entitlement to such dedicated professional time and attention. Our participants would clearly welcome more extensive and open communication about medication, and for this to be formally scheduled as part of their care.

Critical pathways
There were critical points during the care pathway when patients and carers felt that adequate information was crucial, and at which designated time should be set aside for the provision of both written and verbal information. These will be considered in turn.

<u>Diagnosis and admission</u>
Diagnosis and admission to hospital is likely to coincide with the time of starting or changing medication and a steep learning curve about the illness and its treatment. Patients acknowledged that it was often difficult to concentrate or take in information during an acute crisis, when decisions about care might have to be taken over by staff. However, they still felt that it was important that their treatment was explained to them and that this could help them fashion some coherence and meaning from a frightening and chaotic experience. Not to be told what was happening, or why, could simply intensify confusion and uncertainty. Some of the points which patients and carers made about the value of adequate information during hospitalised are listed in Box 1.

Box 1: Patients' and carers' perceptions of the value of information

- Patients cannot exercise choice or make an informed decision about treatment if they do not know what is being prescribed, or understand what the intended effects of specific drugs will be.
- Information is reassuring. An understanding of what is being prescribed, and why, helps patients to evaluate the efficacy of different drugs, and build up knowledge of what works best for them. It also helps to inform their decision about the acceptability of proposed treatments and whether the likely benefits outweigh the personal costs.
- Advance knowledge of side effects helps patients to cope better with the experience if this arises.
- Good communication about treatment helps to build and improve relationships with health professionals.
- Being well informed enables patients to take responsibility for their treatment and to become actively involved in their recovery. Passively following 'doctor's orders' has the opposite effect.
- Information about the significance and strength of the prescribed dose of drug (e.g. mild, moderate or high) helps patients calibrate the severity of their illness and the process of their recovery.
- Knowing about their drugs helps patients to use them more safely and effectively, e.g. when combining different prescription items, or prescribed with over the counter remedies.
- Good information enables carers to provide better support for patients, and to provide more effective monitoring and supervision of their medicine taking.

Change of medication or alteration of dose

Having their medicine (or dose) changed was a frequent experience for many patients. Where they lacked a clear explanation of what was going on, and particularly in the absence of a written record to be retained for their personal reference, it was easy to lose track of their medication history. This could make them appear unknowledgeable and incompetent to staff. Patients contrasted their active management of drug taking in the community with the passive acceptance of treatment administered in the hospital. At home, they knew the name of their tablets, could recognise them by shape, had access to the information insert and could ask the pharmacist if they had any queries about their treatment. This contrasted greatly with their experience in hospital. In addition, patients felt that professionals often did not appreciate how the effects of particular drugs they prescribed in hospital translated into the experience of returning to live in the community. Patients described having to trade off the effects of treatment in reducing symptoms against side effects that could impair their ability to fulfil responsibilities of work or childcare, or interfere with their capacity to achieve more valued personal and social goals. Where patients had preferences for particular drugs, and felt that these had a positive effect on their ability to cope with their illness, it is understandable that they felt apprehensive and resistant to change, especially if they were not clearly informed about the purpose and rationale for such a

change. Patients varied in the extent to which they wanted to become actively involved in treatment decisions. However, the desire for better and more extensive information, and for professionals to take patients' experiences and knowledge of medication more explicitly into account, was widespread. Specific concerns which patients and carers voiced about medication are listed in Box 2.

Box 2
Patient and carer concerns about medication.

- Concern that there might be permanently damaging side effects from long term use of prescribed medication: such anxieties were sometimes exacerbated by observation of the personal experiences of friends or other family members.
- Confusion and anxiety resulted from discrepancies in information acquired from different sources.
- Apprehension about the experience and effects of new medication and what it would *feel* like to take a new drug.
- Concern that because staff had never seen patients in an 'undrugged' state, they could not be aware of what they were 'really' like and which symptoms were caused by illness rather than medication. This was an important factor in decisions about changing or stopping a particular course of treatment.

Experience of being an inpatient
Patients felt that they had very little input into treatment decisions made for them after they were admitted to hospital. The nursing staff assumed responsibility for administering drugs. Patients reported that they often did not know the identity or dosage of their prescribed medicines: this made it very difficult to find out about their treatment. It also meant that patients were unable to check that they had been given the correct medication. Some patients were concerned that they could be given the wrong medicine as mistakes could easily happen on a busy ward. Patients reported that medication information was not given unless they asked for it, and was supplied in an ad hoc and non-systematic manner: some had received opportunities to discuss their medication with nursing staff while others had not. Patients were often intimidated by the busyness of staff, which put them off asking for time and information. Some reported that their requests had been unproductive, when staff had not had time to deal with their enquiry before going off duty. The provision of information is not something that is accomplished as a 'one off' procedure. Questions and concerns about medication are formulated in the light of experience and changing knowledge. It is important that patients should feel able to access advice and information about their medicines throughout the entire course of treatment. Patients and carers looked to the nursing staff as the most obvious source of information during periods of hospitalisation. However, they also valued the opportunity to discuss their medication with their psychiatrists and consultants.

Discharge from hospital
Patients and carers needed information to take up the responsibility for medicine taking after discharge from hospital. Lack of understanding about why a drug had

been prescribed, its intended effects, or how it should be taken prevented patients from using them effectively. Some patients were uncertain that the medication prescribed for them in hospital would still be available on their return to the community. They were also unsure about how different medicines would interact and the consequences of taking over the counter remedies with their prescription drugs. Others felt apprehensive that drugs which had helped them feel better in hospital would be insufficient to help them cope with the pressures and difficulties they would again be confronting when they returned home. Another concern was that the side effects of treatment would impair the ability to resume normal roles and responsibilities, such as childcare, driving, or return to work. Some respondents did not feel confident that their GPs were sufficiently well informed about the treatment of mental illness to provide them with effective care after they were back in the community.

Box 3: What information do patients and carers want about medication?

Diagnosis
Name of medicine
Dosage
Purpose of medicine
Intended therapeutic effects
All side effects, with an indication of the *likelihood* of their occurrence
Long term effects and risk of permanent damage
What it feels like to take the drug
How long the drug was likely to be prescribed
Other forms of treatment for the condition – both drug and non-drug
The consequences of not taking the medication

Mental Health Professionals Views About Medication Information
The range of views from the various professional focus groups has been pulled together for the purposes of the following account. There was considerably less consensus within and between the groups than was the case with the carers and patients. This is reflected in the contrasting perspectives described below. There was a widespread acknowledgement that the provision of medication information to patients could and should be improved. The perceived importance of this issue varied substantially between groups and individual participants of each group. However, in general, staff did not seem to consider the information deficit as substantial or as pressing a matter as the patients and carers regarded it to be. Some participants commented that there had been a change in culture in recent years. Traditional professional paternalism was giving way to more open relationships with patients, and their greater involvement in treatment decisions. There was broad support for patients' right to be informed about their medicines both as an end in itself, and as a means to increasing compliance. However, especially among the nursing staff, there was a good deal of ambivalence about the possible negative consequences of patients acquiring information about their medicines: the pros and cons are summarised in Box 4.

Especially among staff whose work was centred in the hospital there was a strong commitment to medication as an effective therapy. Given that patients' prospects of recovery were seen to depend largely on prescribed treatment, it is understandable that many staff members regarded securing patient compliance with this as an important part of their role. There was also recognition that the drugs prescribed for patients often had distressing side effects. It was natural for patients to be reluctant to continue taking such medication especially following discharge, and when they were keen to calibrate the extent of their recovery in terms of their ability to function independently without drugs. From this perspective, patients' active evaluation of their continuing need for medication could be a positive response, and a sign of recovery. It was not 'healthy' to want to take medicines, and indeed some respondents referred to the problem of patients who wanted to extend or increase treatment inappropriately. There was a tension between the recognition of patients' autonomy and right to choose whether or not they accepted treatment, and the desire to assist their recovery in the most effective way possible by encouraging them to do so. Hospital staff tended to view the job of the acute wards as helping patients through a period of acute crisis precipitating admission, in which medication was the sole and appropriate treatment modality. Additional forms of therapy came into play after the patient had been discharged from hospital. Professionals whose focus of work was outside the hospital tended to be more ambivalent about the primacy of medication as the dominant treatment, and to regard it as an adjunct, rather than a determinant of recovery.

Box 4 Professional ambivalence about giving patients information about medication

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Positive factors
- Patients have a right to information about their treatment: providing this is part of good professional practice and helps to build trust and confidence in relationships between patients and staff.
- Patients cannot make informed choices about treatment if they are not well informed.
- Good information and understanding of their medication helps patients to take these effectively and so derive the greatest benefit from them.
- Information about possible side effects helps prepare patients for the experience, and to tolerate these when they do occur.
- Well informed patients are more likely cooperate with staff and comply with prescribed medication.
- Patients bringing their own information for discussion with staff present an opportunity for each party to extend their understanding of the other's point of view, and for staff to provide reassurance and perhaps correct misapprehensions on the patient's part.

Negative factors
- Information about side effects and adverse consequences of medication leads patients to reject treatment and increases non-compliance.
- Anticipation of side effects encourages some patients to imagine that they are suffering from them.

- Widening access to information, especially through the internet, is likely to result in patients being misled by inaccurate and unreliable information. Such information can be actively harmful, as when patients have been found to access internet sites relating to suicide.
- Informed patients are likely to be more demanding, and there is an increased likelihood of tension between staff and patients where sources of information about medication are in conflict.
- Widening access to information may lead to patients discovering things which staff judge to be unhelpful, and would prefer to be withheld, e.g. diagnosis.

Written and reference information

There was widespread agreement among staff that little written information was currently available to patients, and that the amount and quality of reference material should be improved, along with a robust procedure for ensuring that these were given out to patients routinely. Some respondents were aware of a previous initiative to provide information 'boxes' for each ward. However, there was little use or knowledge of the information leaflets that had been included in these and it was evident that they were not generally available to patients on the wards. Staff agreed that patients would not normally be provided with written information unless they asked for it. Respondents varied in their assessment of patient demand for such knowledge. The information leaflet inside the drug packs was the most frequently used source of information given to patients who wanted to discuss their treatment. Staff on some wards removed the leaflets from the boxes and kept them to give to patients. Otherwise there appeared to be few sources of information for either staff or patients to access on the wards: the BNF, the WHICH Guide to Drugs and a video that had to be booked from pharmacy constitute an exhaustive list. However, staff reported undertaking commissions to find out about a specific topic to answer more specialised questions that patients sometimes raised while on the ward. Each ward has recently been provided with internet access but neither patients nor staff appeared to be making much use of this at present. Staff worried that patients would find damaging and inaccurate information from poor quality websites. Incidents had already occurred where patients had been found viewing 'unsuitable' sites (re pornography and suicide). As a result patients on one ward were only allowed internet access when chaperoned by a member of staff. This restriction had, in effect, quashed demand. Few respondents were aware of the enormous potential of the internet for meeting patients information needs or how to exploit this positively, e.g. by directing patients to a list of accredited high quality sites.

Verbal information

Ward staff placed greater emphasis on verbal than written information in their interaction with patients. Information was usually supplied on a 'need to know' basis, with staff members using their judgement about the amount and timing of the information that it was appropriate to divulge. This practice reflects the common concern that information could have negative and damaging effects on patients and was motivated by a genuine concern for patients' best interests. However, as was described above, a consequence was that patients experienced difficulties in accessing the information – often because they had no way of discovering what it was they needed to know. This barrier to information was compounded by patients' lack of

confidence in troubling staff when they appeared to be too busy attending to other matters on the ward. Staff pointed out that patients were often admitted to the ward in a state of extreme distress, and their professional priority was to treat first and explain later. At such times it was felt to be inappropriate and also impractical to go into lengthy explanations about treatment which the patient was unlikely to be able to understand or remember later. Furthermore, patients frequently lack insight into their illness. When they do not recognise that they are ill, they may see no need for medication. Simply giving more information will not resolve this. Staff felt that they furthered the patient's best interests in these situations by assuming responsibility for decisions that he was at least temporarily unable to make.

Shortage of time was mentioned as a constraint on dedicating sessions to discuss medication issues with patients: staff sometimes forgot to give information. Individual staff members varied in terms of the importance they ascribed to this task. However, there was a recognition that it was easy to lose sight of the importance of information for patients and for staff responses to frequently asked questions to become mechanical and routinised. In the absence of a clear cut policy or established procedures, it was not always clear who should be responsible for providing information to patients on the ward. Some respondents felt this was part of the consultant's job, while others felt it fell more naturally to the nursing staff. It was widely recognised that the hospital ward round can be a daunting experience for patients when it is either inappropriate for them to be given extensive information about their treatment, or unrealistic to expect them to remember what they had been told. It often fell to the nursing staff to follow up the ward round with a direct discussion with patients afterwards.

Both on the wards and outside the hospital there was sometimes uncertainty about what and how much individual staff members felt it was appropriate to discuss with patients about their medication without overstepping the boundaries of their professional role, and causing potential conflict with the consultant psychiatrist in charge of the patient's care. A number of respondents felt that it was inappropriate to 'advise' rather than merely 'inform' patients about their medicines, but the distinction between advice and information was often unclear. Consultants were thought to vary widely in their approach to informing patients about their medicines and other staff tended to take their lead from their perceptions of such individual policies. Among the nursing staff, in particular, there was a concern with the medico-legal requirements of informing patients about treatments, which the nurses had to administer. Another source of tension arose from the different models of mental illness held within, and especially between, different professional groups, which placed differing emphases on the contribution that medication can make to recovery. This could cause frustration where staff felt constrained in what they could discuss about treatment with patients, or courted conflict with colleagues if they took a radically different perspective and gave out different and inconsistent information. Conflicting information about medicines within as well as between authoritative sources (written and verbal) was recognised to be confusing and unsatisfactory for both staff and patients.

Conclusion
There was general agreement within the professional focus groups that most patients were given little information or opportunity for discussion about their medication,

especially if they did not specifically request this. Individuals and groups varied in their assessment of the importance of this issue. Many staff did not seem to be aware of the high level of importance patients and carers place on receiving medication information, or the frustration they experience when these needs are unmet. However, the development of a hospital policy and implementation procedures to ensure that all patients have easier access to a wider range of medication information was broadly welcomed. Some staff participants wanted to operate with a single authoritative information source to be developed and sanctioned by the Trust. Others recognised that such an aim was not realisable, given that knowledge about treatment is inherently provisional, subject to change and development and also to conflicting interpretations. Another view was that standardised information would be too limiting, given the variable and individual needs of patients. In spite of their uncertainty about how a robust and enduring system for meeting the information needs of carers and patients could be achieved, the professional participants put forward many innovative and positive suggestions which have been incorporated in the recommendations of this report.

Recommendations

1. A system should be developed so that information is given to patients routinely and not left to chance or dependent on patients having to ask for it. At critical points, such as time of diagnosis, change of medication or dose, discharge from hospital, checks should be in place, perhaps through the patient's record, to ensure that medication issues have been discussed with the patient and/or carer.

2. Patients must be given the opportunity to ask questions and raise concerns not simply be the passive recipients of information.

3. The minimum information to be given when a new drug is prescribed or the dose changed should include the following:
   - Name of condition that medicine is to treat
   - Name of medicine
   - Purpose of medicine
   - Rationale for choosing this particular medicine
   - Dosage
   - Intended effects
   - How drug will make the patient feel
   - Side effects
   - Contra-indications
   - Long term effects
   - Expected length of time medicine will need to be taken
   - Additional health checks (e.g. blood tests) that will be necessary
   - Alternative medication
   - Interactions with other drugs including OTC medicines
   - Other forms of treatment for the condition

4. A record of this information should be given to the patient and a copy, signed by the patient, included in the Integrated Mental Health Case-file (IMHC). Patients should have their experience of medication added to their record. The patient should be offered a record of all medication prescribed in addition to those recorded in the IMHC.

5. Patient information leaflets (PIL) that are inserted into medicine packets should be routinely given to inpatients.

6. As well as the PIL, other leaflets that are independent of the pharmaceutical companies should be written on each type of medicine. The written language should take into account different levels of reading ability and be available in other languages. These leaflets should be readily accessible by patients. They should not have to ask for them.

7. Leaflets should be widely available in the community, for example in GP surgeries.

8. The British National Formulary should be available to patients both in the hospital and in the community.

9. Written information should be backed up with verbal information from psychiatrists and nurses. Written information should not replace direct communication between professional and patient but rather be used to stimulate more informed discussion between them. Provision will need to be made for those who do not have a fluent understanding of English.

10. A pharmacist should be accessible to answer patient/carer queries. This might be done by scheduling regular question and answer sessions for patients

individually, or patients/ carers should be able to make an appointment to see a pharmacist

11. The hospital admission booklet should detail what information patients can expect to receive about their medicines and where to go if there is a problem.

12. The organisation of the ward round should be more facilitative of discussion between patients and psychiatrists. Ward rounds should include the pharmacist. At the very least after a ward round the patient's key worker should discuss with the patient the treatment plan, any changes to medication and any arising patient concerns. This meeting should be documented.

13. A pre-discharge meeting between patient and key worker should include a discussion of any concerns, queries and preferences that patient may have about their medicines and anticipated medicine use, and seek to address these prior to the patient's return to the community.

14. Training should be provided for both staff and patients on the use of computers, conducting internet searches, and how to critically evaluate information materials accessed on the internet.

15. Hospital pharmacists should take the lead in building up a set of information resources across a range of different media. These resources should be available for loan to patients and also their carers. Patients should be helped to evaluate the reliability of information.

References:

Barbour, R and Kitzinger, J eds. (1999) Developing Focus Group Research, Politics, Theory and Practice, London: Sage.

Beesley, F. (2000) A survey of patient satisfaction in two admission wards of a psychiatric hospital. Unpublished Doctoral Research: University of Liverpool

Bond, J., Newnes, C. and Mooniaruch, F. (1992) User views of the inpatient psychiatric services at Shelton Hospital. **Clinical Psychology Forum, 49**, 21-26

Bowling, A (1997) Research Methods in Health, Investigating health and health services, Buckingham, Open University Press.

Gibbs, A. (1997) 'Focus Groups', Social Research Update 19, University of Surrey.

Goodwin, L., Holmes, G., Newnes, C. and Walthi, D. (1999) A qualitative analysis of the views of inpatient mental health service users. **Journal of Mental Health, 8**, 1, 43-54

Holmes, G., Dawson, O., Waltho, D., Beaty, J. and Newnes, C. (1998) User views of two psychiatric day hospitals. **Psychiatric Bulletin, 22,** 352-4

Kitzinger, J (2000) 'Focus groups with users and providers of health care', in Catherine Pope and Nicholas Mays eds. Qualitative Research in Health Care, 2nd ed. London: BMJ Books

Kitzinger, J (1995) Qualitative Research: Introducing focus groups, **BMJ, 311**: 299-302

Kitzinger, J (1994) 'The methodology of focus groups: the importance of interaction between research participants', **Sociology of Health and Illness**, **16** (1): 103-121.

Krueger, R A, Casey, M A. (2000) Focus Groups, A Practical Guide for Applied Research, London: Sage Publications

Murphy, E, Dingwall, R, Greatbatch, D, Parker, S, Watson, P. (1998) Qualitative research methods in health technology assessment: a review of the literature. **Health Technology Assessment; 2** (16).

Myers, D. H., Leahy, A., Shoeb, H. and Ryder, J. (1990) The patients' view of life in a psychiatric hospital. A questionnaire study and associated methodological considerations. **British Journal of Psychiatry, 156,** 853-860

Stallard, P. (1996) The role and use of consumer satisfaction surveys in mental health services. **Journal of Mental Health, 5,** 4, 333-348

Trinder, H., Mitchell, S. A., Newnes, C. and Todd, L. M-K. (1994) Valuing patient feedback II: Shelton Hospital's rehabilitation wards. **Clinical Psychology Forum, 74**, 21-25

Turner, I. and Newnes, C. (1993) Inpatient views of the service at Shelton Psychiatric Hospital. **Clinical Psychology Forum, 56,** 23-29