Meeting the treatment information needs of users of specialist mental health services. A study of users' experience of information provision within a complex system of care

Final Report of the Concordance Research Fellowship

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Acknowledgements

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Introduction

The UK policy drive to develop health services centred on patients and responsive to patient needs and preferences, and the development of therapeutic partnerships between patients and health professionals is well established (Department of Health 1996;Department of Health 1998;Department of Health 1999c;Department of Health 2000;Department of Health 2001a;Department of Health 2001b). The attempt to shift from traditional professional paternalism to patient centred medicine is also a reflection of wider social changes including an increased consumerism in modern industrial democracies, where individual choice and autonomy are highly valued as determinants of citizenship and indicators of personal competence.

In addition to a concern with improving the quality of health care the government 'modernisation' policy aims to develop a more accountable, efficient, cost effective health service. Rising drug costs are a major concern prompting close scrutiny of current patterns of prescribing and consumption of drugs (Audit Commission 1994;Dukes et al. 2003), including the extent to which patients do not take prescribed medications in accordance with medical instructions. Extensive research has established consistently that between one third and one half of patients are non-compliant in their use of prescribed medication (Carter, Taylor, & Levenson 2003;DiMatteo 1994;Donovan 1995;Dowell & Hudson 1997;Gottlieb 2000;Gray, Wykes, & Gournay 2002;Haynes, McKibbon, & Kangas 1997;Haynes & Sackett 1979;Ley 1982;Ley 1997;McDonald, Garg, & Haynes 2002;Perkins & Repper 1999;Sackett & Haynes 1976). No distinctive characteristics of non-compliant individuals have been established, and the range of illnesses eliciting non-compliant behaviour runs across the spectrum from trivial to life threatening (Chesney, Morin, & Sherr 2002;Rovelli et al. 1989;Wright 2000). From a professional perspective, patients' persistence in jeopardising their health and the resulting failure to optimise health outcomes is irrational and perplexing. From a rational economic perspective non-compliance results in substantial waste of expensive and scarce health service resources (Donovan 1995;Dowell & Hudson 1997;Gottlieb 2000;Perkins & Repper 1999).

In 1995 the Royal Pharmaceutical Society of Great Britain undertook an investigation of non-compliance, with a view to developing practical recommendations and strategies for improving medicine taking among patients. This inquiry led in an unanticipated direction, and resulted in the usefulness of the concept of compliance being seriously questioned. In 1997, it published a report *From Compliance to Concordance* in which the concept of 'concordance' was advocated as a tool for radically changing the culture of prescribing and the substance of the relationship between health professionals and patients (RPSGB 1997). The report was wide ranging, and the

members of the working party had consulted extensively in the course of their investigations. However, in developing the concept of concordance, the discussions that were held with groups of patients and patient representatives were held to be particularly significant. These led to the realisation of the importance of patients' attitudes and beliefs about illness and treatment in determining their use of medicines and illness behaviour (RPSGB, 1997).

A distinctive feature of concordance is that it opens up the problem of non-compliance by explicitly recognising and valuing the *patient perspective* in medicine taking, rather than confining consideration of the issue to a narrow focus on medical values and rationality. It involves the development of a negotiated agreement in medical consultations which is based on shared understandings between patients and health professionals and an explicit focus on patient values and outcome goals relating to treatment. In all ordinary circumstances, including cases of disagreement between participants, it is the patient's preferences that should be given priority. It is assumed that patients will be committed to implementing a treatment programme that they have played an active part in choosing, and which they feel is most acceptable to them. This should result in a much more efficient and cost effective use of medicines, and a substantial reduction in wasted expenditure from medicines that are prescribed but not, or inappropriately, used. The process of shared understanding and negotiation involved in a concordance consultation requires skilled communication which builds trust and openness in the doctor-patient relationship. Concordance promises to improve the quality of patients' experience, as well as the outcomes, of care.

As a model for medical consultations concordance promotes the development of a genuinely patient centred practice which is the basis of the government policy for improving the quality of health care, facilitating patient choice and optimising the appropriate and cost effective use of medicines. However, concordance also represents a substantial challenge to the prevailing professional culture based on the dominance of biomedical models of disease and technical-rational solutions advocated for evidence based practice (Bensing 2000;Cronje & Fullan 2003;Haynes, Devereaux, & Guyatt 2002;Muir Gray 2001;Sackett et al. 1996;Sackett et al. 1997). The incorporation of the patient's perspective, as well as the acceptance and accommodation of patient *expertise* in contributing discussions about treatment and evaluation of health care is a radical departure from customary practice. Placing the patient at the centre shifts the centre of gravity from an evaluation of outcomes to an evaluation of *processes* of care. This not only involves subjective instead of quantitative assessment, but shifts the focus from professional to patient as a primary agent in evaluating the quality of service provision.

Following the publication of *From Compliance to* Concordance in 1977, the Concordance Working Group embarked on a three year programme of Department of Health funded work to develop and promote the concept and practice of concordance in health care. This has subsequently been carried on by the Task Force on Medicines Partnership (www.medicines-partnership.org). A five year Concordance Research Fellowship was jointly awarded to Kristian Pollock and Janet Grime in July 1999. Its aim was to support a programme of original research into concordance issues: to extend an understanding of patient and professional perspectives of medicines and medicines use, and to develop strategies to promote genuine and balanced partnerships between patients, doctors and other health professionals as a means of optimising the potential benefits of health care.

This final report of the Concordance Fellowship summarises the first two stages of the research into lay and professional perspectives of depression, and the medication information needs of acute psychiatric hospital patients. These have been described in detail in our earlier reports and a number of published articles (Grime et al. 2002;Grime & Pollock 2003;Grime & Pollock 2004;Landers et al. 2002;Pollock et al. 2004;Pollock & Grime 2001;Pollock & Grime 2002a;Pollock & Grime 2002b;Pollock & Grime 2003). The main part of the report presents findings from the third and last stage of the research. This focused on users' experience of information provision within a complex system of health care. In addition to making an original research contribution, the Fellowship was intended to provide an opportunity for career development and wider academic involvement. An outline of the range of the additional roles and activities we have undertaken over the last five years is given in Appendix B. Finally, we conclude this report with an overview of current issues relating to concordance, and a consideration of the contribution the Fellowship research has made to the analysis and development of the concept.

Part One

A summary of completed research projects 1999 – 2003

**UNDERSTANDING DEPRESSION AND ITS TREATMENT: GP AND PATIENT
PERSPECTIVES
JULY 1999 – JUNE 2002**

The first phase of the research funded through the Concordance Fellowship involved a qualitative, interview based investigation of how patients, GPs, general practice counsellors and community pharmacists understood and communicated about depression, and viewed the effectiveness and appropriateness of treatment within primary care. A concordant consultation presumes a high degree of mutual understanding and effective communication between participants. Studying depression was a particularly appropriate way of investigating concordance because of the extent to which depression is 'constructed' during the course of one or a series of consultations. The recognition of depression is largely determined through the ways that patients and professionals understand and communicate with each other rather than as a result of some professional appraisal of 'objective' symptoms.

Method

The study involved semi-structured interviews with GPs and patients. Nineteen GPs and two counsellors were enlisted from eight West Midland practices. The practices were purposefully sampled to cover different socio-economic and geographical settings. Thirty two patients recently diagnosed with mild to moderate depression were recruited through the GPs who took part. These patients had a follow up interview after six months. Another thirty patient respondents who had more extensive experience of depression and its treatments were enrolled from the regional membership of Depression Alliance. Depression Alliance is a leading voluntary organisation supporting sufferers from depression.

Findings

1. Patients' expectations of the consultation

Our research indicated that genuinely concordant consultations were rare, though this did not mean necessarily that patients were dissatisfied with their care. In certain contexts such as acute distress, patients may be relieved to hand the responsibility of their care over to their doctor, at least for a time. More commonly, however, the possibility of a concordant consultation was pre-empted by patients' existing and deeply ingrained expectations of how a consultation should be

conducted. It was evident that patients did not generally expect consultations to be concordant. Indeed where a GP adopts a 'partnership approach' which is not anticipated, patients may have difficulty in interpreting or understanding their doctor's suggestion. For example being offered a choice between counselling and medication led one patient to conclude that the doctor must think his problems were not very serious otherwise the doctor would certainly have taken charge of treatment and prescribed antidepressants.

Most patient respondents adopted an etiquette of consulting in conformity with the traditional role of patient as passive recipient of authoritative professional judgement and instruction. This did not mean that they necessarily understood, accepted or complied with their doctor's advice. However having decided to seek professional help for their problem, many patients thought it was inappropriate - as well as discourteous - to openly appear to question professional judgement.

Patients expressed a sense of low entitlement to health care resources, especially consultation time (Pollock & Grime 2002a). An intense sense of time pressure and self imposed rationing of time were frequently reported by patients when consulting for depression. They took upon themselves some of the responsibility of managing time in the consultation in order to relieve the time burden they perceived their doctor to be under. Their ability to talk about their problems was affected as a consequence. By contrast the GPs in the study did not feel time was a limiting factor in providing care for patients with depression (Pollock & Grime 2003). This mismatch in perceptions meant, for example, that a doctor might ask an open question to encourage a patient to talk about his problems but the patient, fearing there is not enough time to give a complex answer, side steps the question. GPs seemed largely unaware that patients rationed time in the consultation.   However, patients' rationing of time is a barrier to developing concordant consultations.

2. Doctors' and patients' attitudes towards antidepressants

Patients' and doctors accounts of antidepressants differed in a number of respects. These helped to explain patients' use of these drugs and raise some significant issues for concordance in relation to starting and stopping antidepressants.

Starting and stopping antidepressant treatment

Patients came to the consultation with a wide range of views about antidepressants. These views were partly tied up with whether or not they anticipated/agreed with the diagnosis. Where the

diagnosis was not expected or accepted then patients either rejected the idea that antidepressants were an appropriate treatment for them or they struggled for a period to accept the idea of depression and the need for treatment. It was very unusual for patients to openly disagree with a diagnosis. Uncommitted patients were more likely to appear to concur with their doctor, but then either fail to collect their prescription or take a token number of tablets but not return for follow up or further prescriptions.

GPs recognised that some patients were not keen on taking antidepressants. In some cases the doctors described attempting to persuade patients to start taking them by offering explanations of depression that they did not fully believe themselves, for example that this resulted from some kind of biochemical disruption in the brain. Whatever their starting position on antidepressants, patients' initial attitudes often modified in the light of further knowledge and experience of taking them. An early concern for some patients was that they would become addicted to the tablets. GPs anticipated this as an issue and most gave reassurance that antidepressants were not addictive.

Nearly a half of patients stopped taking their antidepressant ahead of the date set by the GP. Patients began to reappraise the information they had been given by their GPs about antidepressants soon after the initial consultation (Grime & Pollock 2003). A few patients felt better even after the first tablet while others either felt no different or gradually came to realise they had improved. The lack of any sudden change in their symptoms gave rise to uncertainty as to whether the improvement was due to the antidepressants at all. One way to find out was to experiment by stopping the drug to see if the symptoms returned. Patients did not usually share these plans with their GP, or even with close family and friends. One reason given for this was that they feared risking their GP's disapproval and anticipated being discouraged from experimenting and persuaded to carry on with the medicine.

This is an interesting concordance issue. A traditional professional view of such non-compliance would be that patients are jeopardising their recovery. From the patients' perspective this was reasoned decision making and taking charge of their own recovery. The possibility of achieving a concordant consultation is diminished if either the professional is unable to see the patient's perspective or the patient feels unable to discuss their plans with their GP.

Uncertainty about the role of antidepressants in affecting the course of depression led some respondents to become fearful about stopping treatment at the appointed time even in some cases when they were uncertain about their effectiveness. Lacking any objective means to assess

the effectiveness of treatment, some patients continued to take their antidepressants, albeit ambivalently, because they felt more averse to the risks of stopping than the continuing uncertainty of carrying on. GPs on the other hand had confidence in the effectiveness of antidepressants and did not appreciate the extent of the ambivalence often experienced by patients.

Addiction versus psychological dependency

Patients' anxieties about antidepressants often came to centre on psychological dependency not physical addiction. They worried that if it was the drug treatment that was responsible for their improvement then each time they had to face, or even anticipate facing, a stressful situation in future they would need antidepressants again. Thus patients' confidence in their capacity to cope with the demands of everyday life was undermined, and with it their sense of themselves as autonomous, competent persons. Although their symptoms may have improved it was hard to see themselves as recovered or as being their normal self if they still needed to take a tablet.

This issue of psychological dependency did not feature strongly in the medical accounts. GPs who took part in the study saw antidepressants as safe and effective drugs. They were aware that patients were often reluctant to accept antidepressants, and assumed this was at least partly due to a fear of becoming (physiologically) addicted to them. However, patients were not forewarned about the risk of psychological dependency and so could not anticipate how they would feel about this in future. The initial consultation for depression tended to be considerably longer than subsequent visits, when there was a more limited time for patients to voice concerns as they arose. During follow up, GPs tended to focus their efforts on persuading patients to carry on taking the tablets. Concentrating on concordance between doctor and patient in relation to a long term view of treatment decisions rather than short term compliance, would have provided the opportunity to develop treatment plans that would help patients recover on their own terms.

3. Information on antidepressants

Almost all Depression Alliance (DA) respondents had at least two years experience of taking antidepressants either episodically or continuously. In a few cases this extended to several decades. As part of their membership of the DA they received written information on the nature of depression and how to treat it. We compared respondents' experiences of medication with a DA information leaflet on antidepressants (Grime & Pollock 2004). The leaflet gave a conventional professional biomedical perspective that depression results from a disruption of biochemical activity in the brain that can be safely and effectively treated with antidepressants.

Depression was considered to be a 'disease' (like diabetes) requiring professional diagnosis and therapy. This biomedical approach was helpful to some patients as it moved the cause of depression away from personal weakness (inability to cope) to physiological malfunction. However this explanation comes at a cost since it underlines the point that sufferers need medical rather than self help. A paternalistic model of patient dependency on professionals is reinforced which serves to discourage the active acquisition of patient expertise. In fact, respondents frequently struggled with issues of identity and a sense of compromised personal integrity, and most were strongly committed to some form of self help as a strategy for coping with their depression. Antidepressants were, at best, considered to be only part of the solution by most of our respondents.

The experiences of respondents were much more complex than the DA information leaflet suggested and raised concerns and uncertainties over treatment which were not considered in this professional account. In particular, the leaflet downplayed the problems many people experienced in taking antidepressants. These included side effects, difficulties coming off medication, cases (an acknowledged 30%) where antidepressants have no therapeutic benefit or the extent of misgivings and uncertainty that many people had about taking them, especially long term. This latter finding echoed the views of the 'new' patients reported above.

The discrepancies between the information leaflet and the accounts of our respondents raised the questions: 'What counts as knowledge?' and 'What knowledge counts?' in health information. Many of the respondents in this study had taken antidepressants for a much longer period than clinical trials run for and had considerable 'know-how' gained from the lived experience of their mental health problem and its treatment. A concordant approach to information exchange would recognise that lay expertise should inform professional understanding as well as the reverse. We suggest that an information leaflet which draws on patient *experience* (rather than professional expertise) would place the use of antidepressants within a psycho-social as well as a biological framework. A concordant approach would recognise the reality of patients' *use* of antidepressants by incorporating practical advice about stopping medication since it is clear that most patients do this on their own initiative - rather than merely reiterate advice that GPs should be consulted first. The purpose of treatment information leaflets should be to increase understanding, inform choice and promote self-help. It might be expected that information leaflets written by lay led organisations such as DA would do that and it was disappointing to find this was not the case. It cannot be assumed that self-help groups will promote a concordant approach to decisions about medicine taking.

Patient's access to good information is a prerequisite for the exercise of genuine choice and consent to treatment. The depression research showed how important also is the professional's understanding of the patient's concerns and outcome aspirations, and his recognition that these might be underpinned by personal goals which are at variance with conventional medical 'rationality'. It is important for each party to know what the other knows. This is in contrast to the traditional model for a consultation in which the transmission of 'knowledge' passed unilaterally from professional to patient. A concordant consultation involves an exchange of information between patient and professional, as a result of which mutual understanding and accommodation is achieved. It leaves the patient with considerably greater scope for active involvement and decision making and redefines the professional's role as primarily one of facilitator, rather than director, of illness management.

4. Perspectives of community pharmacists

An MSc student, Mary Landers, working under our joint supervision carried out a series of interviews with twenty community pharmacists to investigate their experiences and contributions to the management of depression in primary care, and to explore their interactions with patients and GPs (Landers, Blenkinsopp, Pollock, & Grime 2002). Her analysis of the interview data revealed a wide range of pharmacists' experience in dealing with depression, and very differing views of the role of the pharmacist in supporting patients with depression. On the whole pharmacists thought that patients were more reluctant to initiate discussion about depression with pharmacists compared with other disorders. For their part pharmacists were not as comfortable responding to or asking patients about depression. The main reasons for this was that they were not confident in their knowledge of depression and its treatment or how to approach patients with depression. They also felt that lack of time or privacy in a busy pharmacy meant it was not the right place for such conversations.

Most of the pharmacists thought it was important to talk to patients receiving a first prescription of antidepressants. Not all did so, again usually as a result of insufficient time but also because of concerns about encroaching onto a GP's territory. These concerns were also evident when patients asked questions about the purpose of the prescribed medication. Having no access to a patient's record pharmacists first needed to ascertain if the antidepressants had indeed been prescribed for depression, and that the patient was aware of this. If after questioning, depression was considered to be the likely reason for the prescription, and finding the patient apparently ignorant of the diagnosis, pharmacists were confronted with an ethical dilemma. They did not know whether or not the GP deliberately wished the diagnosis to be withheld and so were faced with the difficulty of what to say to the patient about the purpose of the medication. In these

circumstances the pharmacist tended to refer patients back to their GP. The possibilities for a concordant relationship with patients are constrained if pharmacists are reluctant to engage openly with patients for fear of risking conflict with other health professionals. Neither is it helpful for patients who seek help from the pharmacist to simply be routed back to their doctor. However where patients were self diagnosing and self treating depression pharmacists were more willing to become involved in discussion about over the counter treatments such as St Johns Wort. In these circumstances the pharmacists' approach appeared to be more compatible with a concordant way of working.

The interviews raised further questions about interprofessional relationships. There appeared to be little interaction between pharmacists and other health professionals. Many pharmacists seemed to work in isolation from other members of the primary health care team and the views they had about the prescribing of antidepressants often conflicted with local prescribing practices. Fourteen pharmacists were critical of the current high levels of antidepressant prescribing. They felt that antidepressants were being over prescribed for a number of different reasons. These included inaccurate diagnosis of depression, lack of medication review of patients on long term antidepressants and prescribing expediently in a busy surgery in acceding to their (unchecked) assumptions that patients expected or wanted to receive such a prescription. More than half of the pharmacists felt that counselling would be more effective than drug treatment in mild to moderate depression. However few pharmacists said they raised such issues with GPs. The reasons they gave for this included a lack of confidence in questioning the perceived authority of the GP. Thus, issues of interprofessional relationships and the orientation of pharmacists as subordinate members within the clinical hierarchy were shown to constrain the patients' opportunities for concordant consultations with both the pharmacist and the GP.

5. Issues arising from phase 1 to take forward

The depression studies showed that good information is a necessary but not sufficient condition for concordance. They also demonstrated that patients' dissatisfaction of medication information is bound up with and expressive of other issues. When patients are evaluating the role and benefit of information about illness and treatment, the content of information is inseparable from the *context* in which communication occurs and the *quality* of the relationship between patient and professional.

Early on in our research we had become aware that the concept of concordance needed to be extended to the complex relationship between the patient and more than one health professional. In other words it should encompass the complex network of interactions between

doctors, other health professionals and carers/relatives as well as the patient. We questioned how discordant judgements between these different parties were dealt with and the implications for illness behaviour and health care outcomes. Mary Landers' work highlighted some of these issues in relation to pharmacists and GPs.

The use and usefulness of information for patients, both verbal and written, emerged from the depression research as an important topic in exploring concordance. Patient dissatisfaction with health information is a widespread complaint in all sectors, not just the mental health service (Campbell 1996;Campbell, Cobb, & Darton 1998;Cobb, Darton, & Kiran 2001;Coulter, Entwistle, & Gilbert 1998;Faulkener 1997;Kendall 2001;Rogers, Pilgrim, & Lacey 1993). Despite more than a decade of policy initiatives setting a more patient centred agenda for the NHS (Department of Health 1996;Department of Health 1998;Department of Health 1999c;Department of Health 2000;Department of Health 2001a;Department of Health 2001b), it is clear that inroads into *practice* have been neither substantial nor widespread (Coulter 2002). There are two issues: quality of information and ease of access. These point to different processes of production and distribution. Problems of accessing good quality information and at an appropriate time have been frequently reported in the patient survey literature. In addition, and despite the development of a considerable production industry for leaflets and information materials, few of these have been considered adequate, far less good, quality (Coulter, Entwistle, & Gilbert 1998;Dixon-Woods 2001).

MEDICATION INFORMATION PROJECT - MEETING THE TREATMENT INFORMATION NEEDS OF PSYCHIATRIC INPATIENTS AT SHELTON HOSPITAL: STAFF AND PATIENT PERSPECTIVES
JULY 2002 – JUNE 2003

Background

It had been our intention from the outset to extend our research from the primary to the secondary care sector in order to explore concordance between patients and professionals both within the setting of a psychiatric hospital and community mental health services. The potential gains of concordance are at least as applicable and relevant within secondary care. It is likely that they are also even more difficult to realise. Patients admitted to psychiatric hospitals confront high stakes in relation to treatment and recovery outcomes at a time when they are experiencing acute distress. Difficult trade offs need to be made between severely incapacitating symptoms and severely incapacitating and powerful drugs, and the unpleasant and irreversible side effects which frequently arise from their use (Day, Kinderman, & Benthall 1998;Hogman & Sandamas 2000;Petit-Zeman, Sandamas, & Hogman 2001;Rogers et al. 1998). Institutional psychiatry continues to be characterised by an unprecedented degree of professional dominance and control which are underpinned by the powers of involuntary detention and compulsory treatment conferred by the Mental Health Act (Kmietowicz 2004). It is also the source of frequently voiced dissatisfaction among service users and their advocates who call for a much greater participation by patients in their own treatment (Campbell 1996;Crossley & Crossley 2001;Gray, Wykes, & Gournay 2002;Kilian et al. 2003).

Psychiatric inpatients are less likely than other patients to have access to external or independent sources of information. The length of hospital stay tends to be longer, and the likelihood of being prescribed powerful drugs is high. Such patients are relatively dependent on hospital staff and resources to provide information, so it is imperative that this should be high quality, independent and readily accessible. However complaints about widespread inadequacies of such provision are recurrent themes throughout the literature (Billcliff, McCabe, & Brown 2001;Cobb, Darton, & Kiran 2001;Corry, Hogman, & Sandamas 2002;Kelstrup et al. 1993; Perkins & Repper 1999;Rogers, Pilgrim, & Lacey 1993;Rose 2001;Smith 2002;Smith & Henderson 2000). For example in a Sainsbury Centre Report medicines information was highlighted as a cause for concern, and the biggest area of disagreement between staff and patients (Sainsbury Centre for Mental Health 1998). Nearly half (45%) the 215 patients interviewed in the Sainsbury Centre survey said that they had not had enough information about their illness or treatment. In contrast, staff considered this to be a problem for only 9% of these cases . Rose et al (Rose 2001) also found that half of the users they surveyed felt they were inadequately informed about

their treatment. A third felt that they were being overmedicated with a consequently damaging effect on their quality of life. This report indicated that staff rarely consulted users in discussing medication.   As a consequence, users remained uninvolved in decisions about care and treatment.

Nevertheless, there was a significant relationship between reported involvement and receipt of treatment information by patients and their expressed satisfaction with care. The degree to which patients feel positive about their treatment while in hospital, and also comfortable with the medication prescribed, is an important component of the quality of their experience and their overall evaluation of care. It is also likely to be an important determinant of their subsequent decisions about medicine taking following discharge into the community. Our initial study in primary care suggested that information availability and exchange would be affected by the quality of communication and relationships - both between different professionals as well as between patients and professionals - and the organisational and cultural conventions which govern these.

An opportunity to investigate the reasons behind the inadequacies in information provision arose in a local psychiatric hospital. Repeated user surveys over the years at the hospital had produced the same complaint of lack of information about medicines despite numerous attempts to address the problem. We joined a project working group made up of service users and health professionals to try and uncover the reason why the issue of meeting patient information needs was proving to be an intractable problem. From early discussions within in the group it was apparent that members had different perspectives on the purpose and use of information. It seemed likely that these differences were central to the problem of patients being able to get medicines' information. The group therefore decided the best way forward was to explore the views of service users, carers and hospital staff about medication, in order to look at the functions of information provision and exchange within the hospital organisation and hierarchy as well as the nature of information available. From this we would be able to assess the implications for concordance. The study came to be called the Medication Information Project (Pollock, Grime, Baker, & Mantala 2004).

Method

Fourteen focus groups were held comprising a total of 90 respondents. These were made up of five groups of patients, one of carers, two of psychiatrists, three of nurses, one of occupational therapists, one of psychologists and one of managers.

Findings

Patients, carers and all groups of staff agreed that the provision of medication information in the hospital needed to be improved, although patients and carers awarded this a higher priority than most of the professionals. It was not easy for patients to access information about their treatment, or discuss this with members of staff. There was a tendency for professionals, especially nurses, to present information selectively and conservatively and in accordance with what they judged to be appropriate and relevant to patients' needs. This parsimonious disclosure of information was used more or less deliberately as a strategy of patient management. We identified a number of other factors relating to hospital organisation and interprofessional working which further restricted patient access to information. These have to do with the complexity of a service provided by a range of separate agencies, and the consequences of professional hierarchy.

Both on the wards and in supporting patients 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 professional conflict with the consultant psychiatrist in charge of the patient's care. This made it easy for staff members to 'pass the buck' in responding to patient queries about treatment by referring these on to other members of staff such as the patient's key worker or psychiatrist. In practice this would often effectively block the enquiry since it then became difficult for patients to find the resolve and practical opportunity to pursue their quest for information successfully. A number of the professional 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 known 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. Another source of tension arose from the different models of mental illness held within, and especially between, different professional groups. These evaluated the contribution of medication to recovery differently. This was a source of frustration where staff felt constrained in what they could discuss 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.

In the absence of a clear system or responsibility for providing information to patients during their stay in hospital, patients were likely to be told – or not – different things by different professionals, and often little or nothing at all. Even patients who are regularly readmitted for periods of hospitalisation live most of their lives in a community setting (Sainsbury Centre for Mental Health 1998). Outside the hospital, patients potentially have a much greater access to information and advice about their illness from a number of sources, including primary care health professionals, friends and family and electronic and written media. A number of the professional respondents in the MIP – especially from the nurses' groups – were critical of the treatment interventions of primary care professionals, especially the GPs. They perceived their lack of skill in treating users of mental health services to contribute to the common cycle of relapse and readmission among their patients. There appeared to be very little effective communication and liaison between hospital and primary care staff concerning the treatment and ongoing support of patients discharged back into the community.

The Internet

Each ward had recently been provided with internet access but neither patients nor staff appeared to be making much use of this. Patients complained of boredom and a couple of younger patients had taken up smoking again in order to fill the day. In these circumstances it might have been expected that a computer would be a well-used resource. However, not all patients or staff had the technological know how to access the Internet. 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.

Conclusion

As a result of undertaking this project we that to understand the possibility of concordant relations between health professionals and patients as well as between different kinds of health professionals it is necessary to go beyond the dyad of patient and health professional, and look at concordance within the context of wider organisational structures. This approach has been taken with clinical errors where the question that is asked is not which individual is to blame but how does the system promote or reduce the likelihood of mistakes being made? Thus

organisational factors in the hospital could either facilitate or act as a barrier to the provision of information. For example a lack of resources impacted on information provision. There was only one pharmacist available for the whole hospital and thus a pharmacist was not readily accessible to patients or carers. There were no psychological therapies provided to inpatients. With no alternatives or adjuncts to medication nurses placed a high value on getting patient compliance since drug treatment was the main therapy to potentially bring about recovery and enable patients to be discharged. 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. Information for example about side effects might be withheld where it was considered it could lead to a patient deciding not to take their medicines.

There was some discord between health professionals working with different models of mental illness for example between psychologists and psychiatrists. This inhibited the development of an inpatient team and was exacerbated by the psychologists being located at some distance from the hospital. Providing computers on the wards provided an opportunity for patients to access high quality information. However, a lack of technical IT input to set up computers so that patients were unable to get into unsuitable sites, no one having specific responsibility for managing this new resource and lack of staff training meant the computers were rarely used.

Questions to investigate further

The Medication Information Project gave rise to a number of questions that we wished to explore further in order to understand how concordance can be applied, not just within single consultations, but throughout a complex system of health care. For the final study in year five of the Concordance Fellowship we proposed to investigate how patients construct meaning from diverse professional contacts and information sources, and carry this through an extended series of consultations with professionals. We wanted to throw light on how patients deal with perceived discrepancies in what they are told by different staff, and how their experience of interprofessional working shapes their participation in consultations with practitioners from different specialities. This in turn would show if it is possible for understanding to be transferred and a consensus to be sustained across a complex therapeutic network as well as the consequences for patients when it is not.

Part Two

Mental Health Service Users' Experience of Complexity in Health Care

Introduction

The existing literature relating to shared decision making and concordance issues has focused on the dyadic relationship between patient and health professional. However, the reality of care for many patients, especially those suffering from multiple and chronic health problems, involves the orchestration of a complex network of relationships with different services and specialist staff. Each consultation is shaped by the cumulative experiences and emergent understandings developed through all previous encounters between the patient and his professional contacts. Such understandings will also be formed by information gleaned from many other sources, particularly the media and the vicarious knowledge obtained from observation and discussion of what has happened to others within the patient's social circle. The question as to how patients resolve perceived conflicts and inconsistencies in professional advice, and how this affects their communication with staff in subsequent consultations has not yet been taken up for investigation.

Despite the high policy profile of patient centred medicine, it is evident that concordance is rarely achieved (Barry et al. 2000;Bissell, May, & Noyce 2004;Coulter 2002;Coulter 1997;Cox et al. 2004;Henwood et al. 2003;Jones 2003;Kilian, Lindenbach, Lobig, Uhle, Petscheleit, & Angermayer 2003;Makoul, Arntson, & Schofield 1995;Marvel et al. 1999;McKinley & Middleton 1999;Roter 2000;Rycroft-Malone et al. 2001;Stevenson et al. 2000;ten Have 1991). Moreover, there is little indication it is making much headway into mainstream medical culture and practice. In an analysis of over 28,000 videotaped consultations submitted by 4,000 candidates for the MRCGP examinations, less than 10% of GP candidates demonstrated a genuine involvement with their patients on a regular basis. A shared understanding was even rarer: fewer than 5% of candidates achieved this in three out of five selected (and presumably what they considered to be their 'best') consultations (Tate 2003). It is clear that successful strategies to realise concordance must go much deeper than merely improving professional and patient education and the development of effective mechanisms and processes of information transfer. Our depression research made a contribution to a growing body of literature that testifies to the substantial endurance of the traditional form of the medical consultation and the implicit rules governing interaction between participants as a barrier to concordance (Kettunen et al. 2001;Li 2003;Maynard 1991;Stimson & Webb 1975;Strong 1979;ten Have 1991). The second stage of our research revealed some of the systemic and organisational barriers restricting the flow of

information and the realisation of concordance between psychiatric patients and hospital staff. For example, the professional hierarchy made staff wary of being candid in their discussion of diagnosis and treatment, because they were uncertain what other colleagues might already have said to patients, and did not want to encroach on their professional territory. This study also highlighted the gulf in communication and interaction between Hospital and community staff and consequent disconnectedness of patients' experience of care as they moved from one sector to another. Hospital staff were aware that patients frequently did not continue to take their prescribed medication once they left hospital, and attributed readmissions in large part to such non-compliance and the lack of expertise of community based health professionals in dealing with serious mental illness. However, they reported that there was rarely any effective liaison between hospital and community staff and patients which could have worked to prevent these occurring (Pollock, Grime, Baker, & Mantala 2004).

Occupational specialisms have proliferated in recent decades. Individual patient care may involve a bewildering array of different professionals and agencies across both health and social services, and primary and secondary care, particularly for those suffering from multiple or chronic conditions. The ideal of multidisciplinary working is that the patient will benefit from a range of expert input specially tailored to his individual needs. In reality, however, the delivery of such a 'seamless' service is fraught with problems, notably inter-professional tension and poor communication between agencies. The experience of care for patients and carers is often fragmented and confusing (Buszewicz 1998;Caldicott, Dunn, & Frankel 2004;Cott 1998;Jones 2002;Launer 2002;Pearson & Jones 1994;Rose 2003;Shepherd & Murray 1995;Stark, Stronach, & Warne 2002;Wagner 2000;Stark, Stronach, & Warne 2002). The sheer logistics of managing successful coordination and effective communication across a complex network are formidable. An NNCSDO report on continuity of care for patients suffering from serious mental illness warned that the effort required for staff to maintain effective communication with many different agencies was likely to detract from their ability to focus on the needs of individual service users. The authors recommended that clients should be allocated to as few professionals as possible (NCCSDO 2003). Complex systems of multi-agency working can be confusing for staff, as well as patients, where they are unclear about the precise roles, responsibilities and expertise of different professional groupings (Buszewicz 1998;Launer 2002;Stark, Stronach, & Warne 2002). In practice, both inter- and intra-professional conflict and tension have been commonly reported (Cott 1998;Launer 2002;Stark, Stronach, & Warne 2002). The difficulties in providing a coordinated and coherent service to users are compounded by the different- and sometimes conflicting - explanatory models of illness and treatment employed within specific disciplines (Cott 1998;Gabbay et al. 2003;Pollock, Grime, Baker, & Mantala 2004). Inter-agency working is

widely assumed to benefit patients, and taken as a marker of quality care, but has not yet been subject to critical or systematic review (Cott 1998). Little is known about the patient experience of multi-agency working, though concerns have been raised that the involvement of large professional teams may impact adversely on patient experience of quality and continuity of care (Buszewicz 1998;Launer 2002). The Care Programme Approach was intended to overcome the problems inherent in coordinating care across a network of agencies involved in meeting the needs of patients with complex health problems. This was introduced in the NHS and Community Care Act in 1990, and has remained a key feature of mental health policy (Department of Health 1999b). However, Rose is critical of the incongruity between the CPA and another high profile policy priority: patient centred medicine (Rose 2003). CPA generally involves the coordination of care at a structural and managerial level, rather than direct user involvement: in practice, the patient is rarely part of the team. In a large survey of multi-agency teamworking Stark and colleagues reached a similar conclusion: far from being actively involved in formulating their care plan, users were often unaware of its existence. Despite the rhetoric of partnership and patient centred medicine, mental health care continues to be predominantly service, rather than user, led (Stark, Stronach, & Warne 2002).

In the final stage of the Fellowship research, we have chosen to investigate the issue of complexity further: what is it like to experience care from a plurality of different agencies and health service personnel? How is information about treatment gleaned from diverse sources conveyed and assimilated, and what are the implications for communication about medicines in medical encounters? How is meaning carried forward and shared between participants throughout a series of consultations? What are the implications of complexity for the realisation of concordance in medical consultations? To what extent does this depend on the achievement of concordance between health professionals and occupational groupings? Is this a realisable aim or merely a utopian ideal? In short, if concordance is difficult to achieve, and rarely encountered, in individual consultations between a patient and single health professional, what is the scope for its realisation across a series of consultations involving many different agencies and lay and professional participants, and often over an extended period of time?

The following report presents the findings of a qualitative investigation of professional and mental health service user perspectives and experiences of care within a complex health system.

Method

The research aimed to investigate issues and concerns that arise over information access and exchange where several different types of professional are involved in a patient's care. We wanted to explore whether and how concordance could be realised as a property of the wider health service system, rather than be confined to individual consultations and the dyadic relationship between patient and professional. A qualitative methodology was appropriate for this purpose. The study was based in the community and involved two series of qualitative interviews with 16 patients who had experience of referral to secondary care mental health services and 13 professionals from both primary and secondary care *. Four focus groups involving 19 members of local mental health user groups and voluntary organizations provided a further comparative dimension. The research was approved by the Local Research Ethics Committee.

Qualitative research aims to present an understanding of how participants make sense of their world rather than deliver an 'objective' account of how this operates. It is concerned with the construction and interpretation of meanings, and how people use these in making sense of their situation and negotiating social interaction (Bowling 1997;Bryman 2001;Miles & Huberman 1994;Murphy et al. 1998;Rubin & Rubin 1995;Silverman 2000;Strauss & Corbin 1998). Its purpose is to interpret and illuminate rather than to measure social phenomena. In contrast to quantitative research the frequency of occurrence is not necessarily equated with the social significance of a theme or topic. Consequently, we aimed to involve respondents with a wide range of perspectives and different experiences of illness and giving and receiving health care, rather than recruit a representative sample. Although our results cannot be generalised to the wider population, we expect that what we learned from our respondents about the experience of giving and receiving care in a complex health system will have a wider applicability in other health service contexts.

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* User and patient accounts incorporate references to a wide range of health professionals, not just the 13 professional respondents who took part in this study. Some of these professionals had been involved with some of our lay respondents; others had not. Consequently, patient descriptions and evaluations of their professional contacts should not be taken to apply directly to the professional respondents in the study.

Recruitment

Patients

Persons suffering from serious mental illness are a hard to reach group, and as could be expected, the process of recruitment was challenging and protracted. The partners of a health centre in a small town in Staffordshire agreed to participate in the study by taking part in a research interview and helping us recruit our original target of 20 patients. An audit was carried out of all practice patients aged 18 or over, currently living in the community but who had had an in- or out- patient referral to at least one specialist psychiatric service within the last three years. Individuals who had been treated for addiction were excluded. Seventy six names remained after the GPs had screened the list to remove patients they felt it was inappropriate to contact. Each of these was sent a letter of invitation, signed by their GP, and an information leaflet about the study. Those who wished to participate were requested to return a slip giving their contact details in the prepaid envelope supplied. We then phoned the respondent to discuss the research and arrange a suitable time and place to meet for an interview. This method of contact ensured that we had no access to respondents' personal details prior to their decision to take part in the study. The practice audit clerk mailed a single reminder to all the patients who did not respond to the original invitation. All clerical and secretarial costs incurred by the practice were reimbursed, and an honorarium was offered to the GPs and other health professionals taking part in the study. Patient recruitment took place between October 2003 and April 2004. The response rate was very low: only six patients agreed to participate. Three others expressed an interest in the research, but did not feel able to participate at that time.

Focus Groups

Our original aim was to carry out up to five focus groups with members of local voluntary agencies. We received a very positive response from the three agencies we asked to collaborate with the study. Mind and Rethink are national organisations campaigning on behalf of mental health service users as well as being service providers. The third agency, the NSUG, was a local, well established user group with a large membership and paid workers. The intention was to invite members attending regular meetings and drop in sessions to join a focus group which would take place during their normal session hours. Two focus groups with NSUG members and one with Mind took place according to this plan, although the latter involved only two services users. Although held at different venues, the two NSUG groups were attended by substantially the same people. This was a large group, however, so the second meeting provided an opportunity for further contributions from individual members, and also the development and extension of the discussion of topics raised in the first session.

Two other scheduled focus groups at drop in sessions of Mind and Rethink did not materialise on the day. There were several problems. The first difficulty was that the nature of drop in is informal and fluid in relation to those attending. Agency workers (and ourselves) were rightly concerned that the real purpose of the drop in and the normal activities of those who did not want to participate should not be unduly disrupted. Research ethic requirements ask that potential respondents receive written information about the research and then are given time to decide whether or not to participate. This resulted in service users who were present at an information session a week or two prior to the event not necessarily being the same members attending on the day of the focus group. Secondly there were some administrative problems for example where drop in workers and staff were unaware of the research project and the arrangements that had been made. Lastly it became apparent that some service users were not comfortable with taking part in a group discussion but were happy to be interviewed in connection with the research. Seven interviews were subsequently arranged with these individuals.

The fourth focus group was specially arranged for us by the NSUG and recruited from a subset of its members who had indicated their willingness to take part in consultation work and registered medication as a special interest. Seven members volunteered, of whom four were able to take part in a focus group. Individual interviews were arranged with the other three.

The process of patient and user recruitment was challenging: it must be recognised that this is the reality of working with hard to reach groups. However, a strength of qualitative methodology is the flexibility to adapt to situations as they arise on the ground, and also to respond to opportunities and discoveries which materialise in the course of carrying out the research. We did succeed in realising our aim of recruiting respondents with a wide range of perspectives and differing experiences and responses to serious mental and physical health problems, professional health care, and voluntary sector support. These were drawn from two distinct populations; general practice and user groups. The six recruited from general practice on the whole had less experience of complexity in psychiatric care. None had been inpatients on a psychiatric ward. Two were also affected by serious physical illnesses which were more of a day to day issue for them than their mental health concerns. None had addiction problems or very long term use of psychiatric medicines. There was considerable overlap between the two groups. However, it was the population of service users who had joined voluntary groups or attended drop ins that turned out to have the extensive experience of mental and physical health problems and wide range of professional inputs that was the particular focus for our research.

Professional Respondents

At the outset it was intended to interview 12 professionals from a range of different occupational groupings and settings within the locality. None of the individuals we approached directly refused to participate, though we did not succeed in recruiting a community pharmacist, or arranging interviews with two community psychiatric nurses (CPNs) working in primary care before the period of recruitment came to an end. Interviews were carried out with the four GP partners from the collaborating practice, two consultant psychiatrists, one psychologist, two CPNs in the secondary sector and one senior social worker. As the user interviews progressed, it became apparent that staff from a diverse range of agencies outside the health and social services also had an important role in providing help and support. Consequently, we included interviews with a community officer from the police force, and a psychotherapist working for an independent charity outside the NHS. We also included a paid worker from one of the user groups collaborating in the study, making a total of 13 professional interviews in all.

Research Interviews

Interviews with patients and users

Interviews were semi structured to ensure the discussion of a number of core topics, whilst allowing a considerable degree of flexibility and freedom for respondents to shape the agenda and raise and expand on issues of particular salience or concern to them. Respondents were asked initially to recount the history of their consultations and referral to different agencies and the treatments they had been prescribed and used. The subsequent discussion picked up on respondents' experience of dealing with a range of different health professionals and service agencies and their expectations and approach in dealing with each of these. It included an account of what respondents had learned about their illness and its treatment, and from what source, as well as a consideration of any problems that had been encountered regarding the consistency of information provided by different sources, and the ways in which people respond to these. We were interested in establishing to what extent service users were aware of the differences and possible tensions between different professional contacts in terms of their occupational and personal ideologies and how such awareness impacts on patients' confidence in professional care and how they approach medical consultations with different staff. Finally the interview explored respondents' perceptions of the accessibility and responsiveness of different agencies within the health care system as they had encountered it and whether they found having to deal with a range of different services and health professionals problematic or supportive. A particular focus of the interviews was how freely respondents felt that they could share information and concerns with all the professionals involved in their care, and their

perceptions of the adequacy of the information exchanged between professionals about their particular case.

Interviews with service users took place in different locations. Three chose to be interviewed in the Department of Medicines Management at Keele University. Seven were interviewed at drop in sessions, five took place in respondents' own homes and one at their place of work. Interviews at Keele and in respondents' homes/place of work lasted for about one and a half hours, with a range from one to three hours. Interviews at the drop in were shorter, being about 30 minutes on average with a range of 20 to 90 minutes.

Professional interviews

Interviews with professionals focused on respondents' general perspectives and experience of interprofessional working and service complexity, and how they felt this impacted on their relationships with clients. It did not relate to specific patients. The interview topics were similar to those covered in the patient interview, but considered from the professional perspective. All the professional interviews took place in respondents' offices, with the exception of one which was held at Keele.   These were booked for an hour, though some extended beyond this. Professionals received an honorarium of £100 in recognition of the time the contributed to the interview and service user recruitment.

Written consent was obtained at the start of each interview and reaffirmed at the end. All but three of the patient and service user interviews were taped and fully transcribed. In addition to the interview transcripts detailed field notes giving a 'profile' of each interview, and descriptions of other relevant contacts and meetings were also made and included in the analysis.

Focus groups

Focus groups provide an efficient means of collecting data from a relatively large number of respondents representing a wide range of interest groups and perspectives. The defining characteristic of a focus group is that it generates data through the interaction of group members and uses the dynamics of a group discussion to stimulate the disclosure, formulation and comparison of participants' views. One of the aims of focus groups is to reveal the underlying hierarchy of participants' priorities, rather than to impose the researchers' predetermined structure of questioning (Barbour & Kitzinger 1999;Kitzinger 1994;Kitzinger 1995;Kitzinger 2000;Krueger & Casey 2000).

Each group was led by a research facilitator who introduced and guided the discussion. In addition a scribe took notes and organised the recording of the discussion where permission to tape had been agreed by all members of the group. Signed consent was obtained from all participants at the start of focus group discussion. Travel expenses were reimbursed for the user group participants. Three focus groups were held at the normal venue for the drop in/branch meeting. The specifically convened group met at the user group headquarters. This latter group differed from the previous three in another way in that two workers from the user group sat in as observers for the duration of the discussion. It is difficult to assess what difference their presence may have made to the contributions from members.

Two focus groups were taped and two were not. One of the recordings was quite poor due to the noisy venue. Permission to tape was not sought from one group as the discussion took place at one end of the main room of the drop in with a fair amount of background noise and activity going on. A consensus to tape was not obtained from one other group. The untaped discussions were typed up from extensive notes made during and immediately after the event. For all four focus groups both scribe and facilitator wrote up field notes on their perspective of the discussion, which were included in the analysis.

The research transcripts and fieldwork notes were read repeatedly to identify recurring themes and compare these within and between cases. Our analysis considers themes anticipated at the start of the research, and which relate to its initial aims and objectives (e.g. the communication of information about treatment) as well as a number of key issues which emerged during the course of the research (e.g. knowledge about the *process* of care).

Patient and user experience of complexity

Introduction

Sixteen patients and service users were interviewed (the interview respondents). Six respondents were recruited through the GP practice collaborating with the research, and ten from three voluntary user support organisations (the North Staffs User Group (NSUG), MIND and Rethink) working in the area. Four respondents were currently employed. Three of these had continued in education beyond the age of sixteen. Of the remainder, one had retired and eleven were unable to work. Only two of these had stayed on at school after the minimum leaving age. All the interview respondents who took part in the study had experienced problems that were sufficiently severe to warrant referral to specialist mental health services. Respondents varied widely in terms of their personal characteristics and circumstances, as well as the duration and severity of their illness, and the extent and intensity of contact with both professional and

voluntary sectors. Interviews were conducted with nine men and seven women. The age range stretched from under 20 to over 60. All reported their mental health problems to have originated at least three years previously, and in five cases to extend over at least two decades. Details of respondents' age and sex, and the reported duration of their illness are given in Tables 1 and 2. Respondents were not always very clear or precise about the nature of their psychiatric diagnosis. These were sometimes complex, and subject to change over time and between different health professionals. Depression and anxiety were most commonly mentioned, alone, or in combination with other problems, such as self harm, or anorexia. Several respondents had been diagnosed as suffering from schizophrenia and/or personality disorder. A few described addiction to alcohol or drugs as their primary problem. Ten of the sixteen interview respondents had experienced at least one inpatient admission to a psychiatric hospital. Several also suffered from severe physical illness, such as diabetes, asthma or chronic pain.

Four focus groups were held with a total of 21 service users (some of whom attended two groups (Table 3). We were unable to collect systematic information about the focus group participants. However, it was evident that although a wide range of experience and severity of mental illness was represented in the groups, these were oriented towards the more enduring and serious end of the spectrum. Many of the focus group respondents reported very extensive experience of care from a wide range of social, health and voluntary services. In reporting our findings interview respondents have been allocated a fictitious first name and members of the focus groups and the GPS have been given a fictitious surname.

Experiencing a complex system of health care

Interview and focus group respondents described a very wide range of contact with health professionals and service agencies. The simplest consisted of only three strands (GP, psychiatrist and psychologist), contained within a relatively short time frame. At the other extreme, some respondents had dealt with literally dozens of different staff from many agencies across the health, social and voluntary sectors and over an extended period of time, stretching in some cases to several decades. Respondents confronted complexity in the range of different agencies they interacted with as well as the number of different personnel and the turnover of staff within individual organisations and services. They did not seem to experience what seemed to the researchers to be a bewildering sequence of referrals and contacts as particularly problematic, at least in relation to the health services. Dealing with the complications of the social services, especially in relation to entitlement to benefits, was a source of frustration and anxiety for some people. In relation to health care, respondents seemed to regard the input of specialist services as a valuable resource, even if the resulting complexity could cause some confusion.

It' s a bit complicated, because there's so many of them, the different...you've got your carer, care support. Oh, there's loads of them, the user group, Disability Solutions, and you know, the list goes on, and they all have different roles and sometimes it gets confusing who to actually get in touch with.

Q: How could that be improved on, do you think?

Well, I don't know, because they're all sort of different roles. You can't have one person with all that sort of qualifications, you know. You need people to specialise in different things, and once it gets a bit complicated when you need to get in touch with somebody.

Q: So, you're happy to have specialisation?

Oh, yes, yes, yes.

(Harry)

It was apparent, however, that users' perceptions of the professional hierarchy affected their experience and evaluation of treatment. It was also evident that patients often had no idea of the identity or function of individual health workers they were in contact with through the process of referral. We take up these issues further in the following account of respondents' interactions with the professional groups with which they had most significant and frequent contact.

GPs

The GP was usually the first port of call for respondents experiencing mental health problems and the agent of referral to specialist services, generally the CPN or psychiatrist. Some respondents described having good relationships with individual GPs, who remained involved with their mental health problems following referral to specialist psychiatric services. The ongoing support shown by some GPs was highly valued by their patients.

I think I've a better doctor (GP) than if I were a Royal, because she's time *for you. No matter how late she is in the surgery, she's got the time. She doesn't rush you out, and you don't sit down, prescription writ and out. I can be in that room for twenty minutes, and the allocated time for each patient is ten.*

(Cynthia)

Giving time in this way was a tangible expression of the GP's interest and concern. It was taken as a marker of the quality of care he provided, and also of the value he accorded to the patient as a person. The pursuit of such respect and personal acknowledgement is a major objective in

patients' quest for therapy. As the accounts of patients throughout the entire research literature amply testify, it is rarely realised in practice.

More often, however, referral brought about a change in patients' interaction with their doctors. Once specialist expertise had been accessed, some respondents regarded their GPs as no longer involved in dealing with their mental health issues, using them subsequently only for 'normal illnesses' or strategically as a source of further referral or access to services. Indeed, in acknowledging the higher level of professional expertise involved in their case, respondents quite commonly doubted that their GPs were sufficiently knowledgeable or competent about mental illnesses and their treatments to deal with them appropriately.

> *If you need someone, you really need to say, 'Well, I want to see a consultant'. You know, a specialist, whatever. Uh, because I don't think the doctor's (GP) got the time, the expertise, to do everything with you.*
> (Mr Neal)

> *The GP was not equipped to do that (understand the nature of mental health problems). It was, ""We'll try this drug"….It was that type of talking we were doing. We weren't going into what was in my head. …. GPs don't know enough about mental health. Probably because when they go through their time at medical school, it's not a popular area, is it? Not a lot of people want to get involved in all that. So they know very little about it.*
> (Edward)

In the last case, the patient had valued the help received from an earlier referral to a psychotherapist, and was looking for a similar input when he experienced a recurrence of his illness. In relation to this past experience, his GP was found wanting. Unfortunately, further access to therapy was blocked by a long waiting list, so he was left feeling thwarted and dissatisfied with his care. More generally, respondents commonly expressed disappointment with the GP's focus on drugs as the dominant or only modality of treatment, when what they had expected, or hoped for, was an exploration and explanation, and most importantly, an *understanding* of the way they were feeling.

> *A: Yes, the tranquillisers and the beta blockers, after the Prozac the tranquillisers came in about August time last year, didn't they? I kept working. I don't know how I did it, you know, I really don't. What a state I was in.*

Q: What sort of things were happening when you were going to the GP? You were sort of telling him how you were and….?

A: Yes, I was telling them, and they'd say I'll be alright. I'll be fine. You know. It was just a bit of an upset, you know, and I'd get over it.

(Denise)

Some respondents considered that it was appropriate for their GP to bow out of active involvement in their treatment following specialist referral. However, others described how they felt rebuffed by their GP's disinclination to deal with any aspect of their health – mental or physical - which had been devolved to specialist attention. They resented the partitioning of their problems in this way, and the GP's division of certain problems as legitimate topics for discussion in the consultation, and others not.

Once they've referred you to your specialist – they just do referrals, the GPs. So they didn't help – they'd referred me: it was no longer their problem.

(Joan)

My doctor, if I ask him about any other problem – If I talk about arthritis – he'll say, 'See the hospital'. And if I mention me mental health problems, he'll say, 'Ring the senior psychiatrist'. He cuts me off abruptly as soon as I mention it. So now, when he asks how I am, I know that he doesn't mean anything about my arthritis, that he doesn't mean anything to do with mental health….But you should be able to go to your doctor (GP) and tell him how you're feeling. The whole of you. Not just sort of saying, 'Well, this part of me is like this, but I'm not going to mention that. Because it's all part of you.

(Mrs Gordon)

These respondents suspected that their GPs were using the availability of specialist care as an opportunity to disengage from personal involvement in their mental health problems. As what they sought was to receive holistic care from their GP, and to establish a strong and enduring relationship based on his recognition of their complex problems and associated needs, they found this response very unsatisfactory.

Particularly in the focus group discussions, respondents revealed their sensitivity to the constraints of the professional hierarchy and the GP's intermediary position between patient and psychiatrist. They acknowledged that it could be difficult for GPs who might be wary of getting

involved in mental health issues in case they encroached on the specialists' professional territory, and especially where they felt lacking in confidence and expertise in treating psychiatric disorder.

> *This is a really important issue, and many of your members have told us this, that their GP has almost literally put their hands up and said 'Stop! I don't want to hear about your mental health. Go and see the consultant about that'. (murmoured agreement).....I think sometimes perhaps GPs are ....very nervous about doing anything within that speciality in case the consultant is cross with them (agreement) or undermines them.*
> (Mrs Simon)

Some respondents seemed willing to use their GPs as a means of modifying the treatment regime prescribed by their psychiatrist. Others were worried when their GP altered this, and regarded it as inappropriate. Most often, it seemed that GPs did not directly intervene in changing the regimen established by the patient's psychiatrist. However, it is difficult to see how patients could engage in meaningful discussions about medicines with their GP when their doctors are not directly involved or responsible for initiating their prescription. A recommendation to consult their psychiatrist with any queries about treatment is problematic when routine outpatient visits occur only at four or six monthly intervals. In this respect, the organisation of specialist referral can act as a barrier to effective and accessible care.

Psychiatrists

All our respondents had received a psychiatric referral at some point – in some cases, a number of different specialists had been consulted over many years. Although a few positive evaluations were expressed, the most common responses concerning psychiatrists were rather guarded, if not overtly negative. As with the GPs, respondents valued the ability to develop strong and enduring relationships with individual practitioners, and the feeling that they were recognised as individuals by professionals who understood and were interested in their problems.

> *She (psychiatrist) says to me, 'Well, how do you feel Cynthia, today? How do you feel? When I go in, you know, and I tell her and I just talk to her like I'm talking to you or anybody else, like. I forget she's a doctor and just talk to her woman to woman.*
> (Cynthia)

The most common complaint by service users who did not feel that they had a good relationship with their psychiatrist was that it was difficult to talk to them, or that they did not listen to what the patient wanted to say, and that they were not very understanding. The psychiatrist's role was

seen as primarily involving assessment and diagnosis, the calibration of medication as the dominant mode of treatment, and to a lesser extent, forward referral to other services and agencies, such as the CPN, or various therapy groups (e.g. assertiveness, relaxation). There was much less reported exchange of information about other issues, particularly relating to patients' thoughts and feelings about their illness and current life circumstances.

> *I came out of hospital. I used to have to go to the psychiatrist….the way the session would go was, 'What have you been up to since I saw you last?', and usually (it was) not very much. And then she might have made the odd suggestion, not very many that I can remember, about what I should be doing. And then she'd say, 'I think we'll put it up another couple of milligram……*
> (Edward)

> *Just ask me how I was getting on….what care I was having at the time, …..if the medication had been changed. They'd (psychiatrist) ask me what medication I was on, and that was it, basically.*
> (Denise)

Appointments with psychiatrists were generally experienced as clinical, rather than therapeutic encounters, contrary to patients' prior hopes and initial expectations. However, given the importance of medication to their quality of life, establishing contact with a psychiatrist who was perceived as competent and trustworthy was highly valued, and of great significance.

> *I think it's half the battle when somebody gets, whose got a psychiatrist that they really like and they get on with, and who will spend time with them. I mean, that guy that my son used to have, years ago, he was – you know, he never really got anything much out of him that was helpful. But the guy he has now – he only sees a psychiatrist once every six months now – and this psychiatrist, he's great, he is. Spends a lot of time with people.*
> (Mr King)

> *I'll give you my view, for what it's worth, about the psychiatrist. I think she's probably a clever woman….mmm….she's qualified as a psychiatrist, but she was never born to be one. She has no idea how to talk to people, how to enthuse them, how to give them confidence. She is just a psychiatrist and she knows about the medicine. She knows the rest, but she doesn't know how to put it over. Now, the two who were below her, that I*

say – the one's gone back to India now – they were completely different. Their approach was entirely different when you spoke to them, and they did give you some sort of feeling of confidence, and....mmmm.....what would I say – that they were on the same wave length as you. That they really understood your problems.
(Edward)

As the preceding extracts suggest, the outcome of change and contact with a plurality of doctors could be beneficial, as well as negative. Indeed, one respondent described how his partner, who also suffered from mental health problems, had been locked in a very unsatisfactory relationship with a psychiatrist neither of them liked for over fifteen years. An opportunity for change had finally presented itself, through a chance encounter with another doctor, when the usual psychiatrist was on holiday.

Discontinuity in relationships with psychiatrists was an important issue for a number of respondents.

The biggest drawback with the profession is that they change so much. You're never with one for very long. That's a criticism I would make. But they've got their careers to think about as well, I suppose (laughing). They move up, move on, but it doesn't help the patient much. You have to keep dragging up your history, then.
(Harry)

Harry had established a good relationship with his psychiatrist over an extended period of time. However, when this doctor retired, rather than accept appointments to see the locum who was filling in for this post, he elected to wait until a permanent replacement was appointed. He did not see the point in establishing superficial and short term contact with the locum in the interim.

I haven't seen the new one, no. Well, what he said was...he (usual psychiatrist) left I think in about September, and a locum was taking over until they could set on a permanent one. I said, 'Well, I don't want' – when a new psychiatrist starts with you, you have to go through your history, and you don't want to drag all that up. So I'd rather wait until I get a permanent psychiatrist. '
(Harry)

Finding a specialist with whom one could establish a good relationship was largely a matter of chance, and could take a considerable period of time. The difficulty of staff turnover was not

simply the need to retell one's story in the course of establishing a new relationship, but also about being powerless to maintain this over time. Since it was the professional who defined the patient's needs and also evaluated the benefit from service input, the patient usually had very little input or control over who he saw, how often, or for how long. The process of referral was often experienced as arbitrary and impersonal.

> *Particularly on the second one (appointment) she (psychiatrist) was sort of....mmmm...whether I was never meant to be her case. I get the feeling I was never meant to be her case from the beginning, and certainly she made a note two or three times in the second interview that I was then to be referred to someone else.*
> (Adrian)

The sense of depersonalisation and exclusion from being involved in the management of their own case was described by a number of respondents, and exemplified in several accounts of ward rounds and case conferences.

> A. *Mmm....when I had my psychotic episodes I was on Diazepam, and all sorts, and they started to reduce it. I sat in a room with a load of consultants and there was me. The psychiatrist said to ....the general one that's for the area...'Shall we reduce it? Or shall we not?', and I am thinking, 'Well, it's me that's taking the tablets. Have I got any say in the matter?' . I need this to help me sleep. I need this because my brain's going overwind. It's like nobody's ever asked me what I thought, like they're discussing me, but they're over there, and I'm here.*
> **Q: What was this, this was some kind of case conference?**
> A: *Yes, sort of like that, every month. And I'm thinking, 'I'm the person here you're discussing, so why don't you ask me what I want, or how I feel, instead of writing notes down and saying, "She's this. She's that."' I'm thinking, 'Hold on a minute'.*
> (Natalie)

Discontinuity in professional care, and the patient's lack of involvement in their own case management could have particularly pernicious effects in relation to medication. A general wariness and resistance to taking medicines on the part of the public has been widely reported throughout the literature. However, the respondents in this study generally accepted their need for medication, and seemed to be fairly compliant in taking the drugs their doctors prescribed for them. This was so, even though they were accustomed to experiencing serious and troublesome side effects, especially in the weeks immediately following the start of a new drug.

Mr Andrews seemed to have extensive experience of psychiatric drugs. Accepted the trade off between therapeutic effects – which he appreciated – and the unwanted side effects which came with them. Did not seem to have any input or even curiosity re what was prescribed by whom, and why his drugs were periodically changed, though he anticipated feeling bad for at least two weeks after starting a new drug, until his system got used to it and made appropriate adjustments.

(Notes from Focus Group)

The effectiveness and tolerability of their medication was a very significant issue for respondents. Changes to their regime could have a critical impact on their quality of life, and so patients were understandably wary when these were broached by their doctors. This was particularly likely to happen where patients experienced care from several different prescribers, or there was a rapid turnover of staff, each of whom might have their own views on how best to treat the patient.

Just recently, I've seen different locum psychiatrists. I've seen different ones, and every one's changed my tablets, and..um...I'm, I don't know whether it's the medication I'm taking, the side effects, whether it's the withdrawal of the tablets they've taken me off, or whether it's the illness itself.

(Mrs Gordon)

Although subject to an apparently arbitrary process of treatment and treatment change, patients usually passively accepted treatment prescribed by their doctors. Indeed, the etiquette of the consultation dictated that they must do this. Only after accepting and trying their doctor's prescribed treatment could they have any input and potential scope for involvement in their regime, by providing feedback on their experience of taking a new drug. Some respondents could actually articulate the covert rules governing the conduct of such interactions.

Ian is prepared to be quite focused in getting what he wants. He still does not seem able to take issue with doctors or voice his concerns actively. It might be appropriate to suggest an alternative, i.e. by stating a dispreference for one(drug) initially offered, but it was inappropriate as a patient to make specific suggestions re specific drugs. I.e. patient had some capacity to accept or reject drugs, but not to nominate them: that was the doctor's prerogative.

(Taken from notes of interview with Ian)

Respondents were concerned to avoid being labelled as difficult or uncooperative patients. This made them likely to accept medication they did not intend to take in order to appear co-operative. The following extract is from one the very few accounts of patients taking a stand in relation to professional prescribing decisions.

> *But one particular tablet I did make a decision about, because I went to see a locum, and he said, 'Well, this particular one', he said, 'is rubbish. I've got something far better than that I can give you.' He says, 'But with this new one you can expect to put on some weight. Considerable weight.' And I said, 'Well, I don't think that's wise'. And he said, 'Why not?', And I said, 'Well, since Christmas I've started with angina and high blood pressure and cholesterol, and I'm having breathing problems, and the doctor has told me that I need to lose weight. And if I'm going to take these tablets – and my physical health at the moment is really concerning me so much - and I don't feel happy about that, knowing what it could do.' He did say, 'We'll have to find an alternative'.*
>
> **Q: So, when you explained your concerns, he took them on board?**
>
> *That's the very first time it's happened.*
>
> (Mrs Gordon)

It is notable that this unusual example of resistance was supported with reference to the GP as an external medical authority. It was clear that service users did not usually expect professionals to take their views on board without some kind of external validation. One of the roles of the NSUG was to provide this kind of support for members who had concerns about medication. Respondents were also more likely to intervene in questioning or resisting medical judgement when they were acting as agent for a relative or partner, rather than on their own behalf. Generally, however, respondents indicated that they were likely to accept their doctors' prescriptions without question. This was so, even in cases where there was a clear difference of opinion between professionals about the appropriateness of treatment.

> **Q: Have you ever asked the pharmacist (about her medicines)?**
>
> *Well, all that they say to me is that you shouldn't be taking this because you're asthmatic. Yes (laughing), because I'm on the blue one and the brown one, so: 'Do you realise you shouldn't be taking this?', and I'm thinking, 'Well, it's been prescribed'.*
>
> **Q: So, have you mentioned that to the pharmacist? Have you mentioned that to the GP?**
>
> *No, because I think – I just do as I'm told (laughing). Yes, I know it sounds silly, but....it's like a habit.*

Q: So, does it worry you when the pharmacist says that?

Yes, it does really.

Q: But…that wouldn't cause you to stop taking it off your own bat, or –

Oh, no. If they've given it me they're doing it for a reason.

(Natalie)

Not all respondents accepted professional judgements – even when these conflicted - with the same degree of resignation as Natalie. Outside the consultation, of course, there was a considerable degree of freedom about whether and when they followed their doctors' instructions. However, respondents found it difficult to engineer change in the medication prescribed for them or to get their doctors to take on board and respond to their concerns and preferences relating to medicines. They felt that decisions about treatment remained largely within the professional domain, and most accepted this.

> *I would think, you know, obviously the professionals would assess the situation and (I would) go with whatever he thought was necessary and then treat. I would feel that we (patients) would generally know when it was working and when it wasn't.*
> (Adrian)

> *But that is entirely up to the doctor (stopping medication which the patient would prefer to carry on taking). I can't tell a doctor what's her job, tell her what she must do and what she mustn't do. I mean, she could turn round and say, 'Well, who's the doctor, you or I?'*
> (Cynthia)

> *My doctor's – I've always done what he's told me.*
> (Mr Neal)

Respondents deferred to their doctors taking charge of their treatment decisions – and were generally content to do so – for a number of reasons. They had faith in the generic expertise of professionals, even if some of their encounters with individual practitioners were unsatisfactory. They were also very aware of their own lack of knowledge and understanding of mental illness. Particularly during periods of acute distress they recognised that they were not capable of remaining in charge of their lives, and depended on professional intervention to help them restore control. Making the transition from mental patient back to person was difficult, however. Respondents were aware of the negative stereotypes attached to psychiatric disorders, and that

even professionals often regarded a mental illness diagnosis as a master identity designating enduring incapacity and 'lack of insight' among service users. Service users' tacit acceptance of professional judgement often masked a considerable amount of tension and ambivalence. A number of our respondents acknowledged that at times their illness could cause them to be difficult people to deal with, and unattractive cases for professionals to encounter.

> *Because at the time I was drinking. I was going up there (GP surgery) with drink in me system, and I was missing appointments. I'm not saying I was a model patient, but I was the person with the problem. I was the person seeing the doctors. They threatened to strike me off at that particular stage .....I've lost confidence with these particular doctors now, because I felt they didn't help me. Because basically it is...anybody that is.....days come and go and you're mixed up and you don't know, you're missing your appointments.....OK, you're a right pain to your doctor, I know, but....*
> (Joan)

This sense of disappointment with professional failure to provide effective support at a time of great need and desperation occasionally spilled over into overt criticism. A few respondents observed that professionals were highly trained and highly paid to deal with precisely the kind of problems they presented: that was their job. Consequently, it was inappropriate for patients to be blamed or rejected for manifesting inadequacies which professionals were appointed to help them overcome.

> *You get paid to be a psychiatrist, psychologist, yet you don't want to be involved with me....If I have a problem, I don't want to be told it's not their problem.*
> (Mr Griffiths)

> *I would hope to think that you (researcher) would try and influence the people higher up to perhaps try and take more understanding look at the hopeless cases. I appreciate that can be difficult, and know they have to get up and do all these cases, and see thousands of people, but nobody forced them to do it. I'm not saying they don't work hard. They must work very hard. But they are rewarded well.*
> (Oliver)

These extracts express a sense of the relationship between health professionals (particularly GPs and psychiatrists) as exploitative: professionals were seen more or less explicitly by a number of

respondents to make a good living out of being consulted over problems that they did nothing effective to resolve.

Professional help and responsibility for recovery

The boundary between self help and professional help was problematic for a number of respondents. A few were strongly committed to the ethic of self help, and sought to minimise their contact with the professional services. This could be a positive strategy for managing their recovery.

> *She (psychologist) very much used me as the conduit for curing me. So she was there not telling me, 'You need to do this, and you need to take that.' What she was doing was getting me to do things, or think along things, and then saying, 'It's you that's got to do it'. And all the time, she emphasised, 'There's only one person in all this that can make the difference and that's you. I'm only here to listen, and maybe make the odd suggestion.'*
> (Edward)

Being authorised to take charge of recovery could be liberating, and a means of being released from drugs and professional control. However, this view was associated with respondents whose illness was at the less serious end of the spectrum, and for whom recovery was a genuine possibility. More often respondents expressed their sense of rejection and disappointment at this kind of professional response. Cultural norms relating to the appropriateness and desirability of self help were widely acknowledged. Nevertheless, respondents had often hoped for greater professional direction and ongoing support, precisely because they felt they *could not* help themselves. For example, Barry accepted, albeit reluctantly, his CPN's judgement that after two appointments they had reached a point where the there was no further benefit to be gained from additional visits. He took on board that it was subsequently up to himself to maintain his progress towards recovery. Two years further on he was anxious that had become dependent on antidepressants and sleeping tablets. Barry was caught between feeling he should stop taking them, but being uncertain about whether he could cope without them. He felt unable to give up these drugs without further professional help, for which he now felt reluctant and disinclined to ask.

> *I think that when I've been to the doctor, I've always wanted him to point me in the right direction. But certainly, in most of the discussions I've had with doctors or the nurses, it was easy options: 'What do you want to do about it', and put the onus back on*

me. Which I think is probably the correct thing, as far as I was concerned, anyway. Because I didn't imagine anybody was going to wave a magic wand and say. 'Just do this, and everything will be OK'.

Q: And were you happy with that?

Mmm....Yes, I suppose, you know, I felt – I supposed deep down I suppose that's the way it had to be. I had to help myself to get over it, and I think that's what they were trying to....the direction they were trying to push me in. I think that was right. I didn't feel unduly....as I say, they were shirking any responsibility. I felt, you know, it had got to be mainly from me. But I do feel now that perhaps coming off the tablets has got to come from the medics.

(Barry)

While Barry acknowledged the appropriateness of professionals passing on the responsibility for recovery, even if he wished it had been otherwise, other respondents viewed this approach in a much more negative light.

The last time I went, I wasn't very happy at all. ...He (psychiatrist) asked me how I was, and I said, 'Not too bad, like, I'm not brilliant, but I'm getting there.' And he said, 'Well, you mustn't rely on people all the time. You've got to do this yourself. Every time you feel something's frightening you, you can't go and rely on everybody else to sort it out......I went back, and I said to Kath (her keyworker) when I came out, 'I don't think he (psychiatrist) understands what's up with me, you know'. And she said, 'Why?', 'Well, he's told me not to rely on everybody. Does he think I like relying on people?'

(Denise)

Several respondents described incidents in which they felt health professionals had been either blaming them for their inability to recover, or even disavowing the possibility of recovery, as a means of distancing themselves from responsibility or further involvement in the case. For example, Oliver recounted a CPN's formulation of his situation in the following terms.

He said to me: 'This is the way it is, this is the way it's always going to be, and it's never going to be any different.'

(Oliver)

This was one in a very long sequence of encounters in which Oliver had sought some kind of practical and constructive help for deeply distressing problems which he, and apparently also his professional contacts, found intractable. He stated his conclusion:

> *Well, I'll tell you what I thought. Nobody sorts nothing for you. You've got to do it yourself, that's what I found. I really don't believe, if it isn't there, and you can't do it, then no one else will.*
> (Oliver)

Accounts of harsh and unsympathetic treatment from health professionals were particularly associated with, though not confined to, experience as a hospital inpatient.

Experience of hospitalisation

Many of our respondents had been admitted to hospital as a psychiatric inpatient at some point. These experiences did not feature prominently in the interview and focus group discussions, which tended to be oriented to experiences of care in the community. Most accounts, however, were negative, with a few people regarding their hospital experiences as inappropriate and actively damaging, rather than beneficial. Some people acknowledged that at times they had been so ill, and unable to look after themselves, that they needed the refuge and care that the hospital provided, and had no option but to accede to treatment that was prescribed. Several respondents had been admitted under section. However, concerns about real or threatened coercion were not often voiced, and did not seem to be regarded as a prominent issue. A common theme was the lack of information about medicines provided in hospital: these were simply 'dished' out, with no further explanation.

> *When I went into the acute ward, I was on tablets I didn't even – I'd never heard of them before, and I thought, 'What are they for?', but nobody explained to me. So I was just going for medication time, and that was it, knock them back and … It's like you're a zombie and you do what they say and that's it. You haven't got a voice of your own.*
> **Q: Ideally, how would you like it to be?**
> *I'd like a diagnosis, not just to be labelled as a personality disorder. Proper medication to be addressed and explained why it's been given to you and the side effects and everything, and really just addressing it in a whole. Because as a person you should know what's going on with you and what you're taking.*
> (Natalie)

Respondents acknowledged that, especially around the time of admission to hospital, they were often in a very distressed and confused state. However, their anxieties were intensified by the failure of staff to explain what they were doing, what medication they were having and why. As inpatients, they may not have been able to maintain charge of their lives, or even take an active part in decisions about treatment. However, they could still understand and respond positively to information and a basic kindness and consideration from staff which was frequently reported to be unforthcoming.

> *I thought that was pretty dreadful, the way I was treated in hospital. ...I went down there, and the first thing they did, they gave me an injection. No, I didn't know anything about this injection. Nobody told me I was having an injection. Mmmm I was very hyped. I mean, there's no doubt about it. I can't even imagine how bad I must have been, but they gave me an injection, and I don't remember anything else, until Goodness knows how many hours later. I was on a ward, I was in bed on a ward, in this most dreadful place, which felt like a prison.*
> (Edward)

At a time when patients were themselves not able or oriented to ask for information themselves, it was still important that staff should routinely and adequately provide this for them.

With one or two exceptions, respondents did not experience their stay as an inpatient as a positive or therapeutic experience.

> *During the day they'd administer drugs when you were supposed to have your drugs, and basically they....they sat and walked amongst you and watched the television a bit with you, but not in a way of trying to do anything for you.*
> (Edward)

There was a general disappointment about the dominance of medication as virtually the only form of treatment, when this was universally felt to be a contributory but sufficient therapy. The lack of meaningful or helpful contact with hospital staff was frequently stated.

'Talking treatments': psychologists and psychotherapists
Most respondents accepted their need for medication, but also felt that this alone was not the answer to their problems. The benefit of talk was a recurring theme, and being able to discuss problems in depth and with a sympathetic and expert listener. As indicated above, GPs and

psychiatrists were generally regarded as being too short of time and/or interest and understanding to enable such therapeutic talking, and to be oriented towards a biochemical rather than a psychotherapeutic input.

> *My doctor (GP) said to me last time I went, he was looking at his watch, and he said, 'I can give you – Do you realise I've got so many thousand patients, and only three minutes for each one?*
> (Mrs Gordon)

> *Some (psychiatrists) are not all that forthcoming. I suppose pressure of work with them, they've got that many people to see.*
> (Harry)

> *It was just like the psychiatrist was just a doctor who'd come along to decide what medication I needed, or whatever. ....this person doesn't really know what's wrong with me particularly, doesn't take enough time to find out, simply wants to administer drugs.*
> (Edward)

Ambivalence towards medication as a 'necessary evil' was a particular feature of the focus group discussions. A related idea was that drugs were often prescribed excessively and /or inappropriately, and often as a substitute for time and understanding.

> *Here is a prescription for so many paroxetine. Go away and come back in a certain time. I've got another 20 or 30 patients to see.*
> (Glenda)

> *It's a prescription culture. They expect the green form. I'd rather leave the GP with nothing than start on drugs that can't easily come off.*
> (Mr Douglas)

Several respondents emphasised the point that the need for drugs could often be forestalled if only the individual could be given time and support to talk through their problems before they became incapacitating.

> *When I think back....it's difficult. I was going to see the GP knowing that I was getting worse. I probably needed somebody to try and understand better, at that time, to have*

headed off the hiatus that brought the thing about. The doctor....the GP, was not equipped to do that. It was 'We'll try this drug', ...'Oh, we'll give you some of that'....Maybe if he'd have got something in there, that would have tried to understand what the problems were that I was struggling with, then maybe we could have headed it off.

(Edward)

Given the perceived value of 'talk' as a form of therapy, it is not surprising that the skilled input of psychologists and psychotherapists was highly valued among the relatively few interview respondents who had experienced it. Three respondents mentioned contact with psychotherapists. Three others had been referred to a psychologist, and a couple mentioned contact with counsellors. Most (12) of the interview respondents had received domiciliary visits from a CPN, often over the long term. These were also regarded as helpful, in the main, though tending to have a more 'practical' focus, and at a lower level of therapeutic intensity than the sessions with the psychotherapists and psychologists. Several respondents had also received domiciliary visits from unspecified support or care workers. Two mentioned having been referred to group therapy, while a number had attended one or more of a range of practical and skills based classes (e.g. assertiveness, relaxation, anxiety management). A list of the range of services and agencies which referred to during the interviews and focus groups is given in Table 4.

Respondents varied in their assessment of the usefulness of these different groups. However, they were positive about the benefits of psychotherapy (including psychologist). In part this was due to the scope for extended discussion and time available to build a good relationship in which clients felt confident in talking openly about themselves. The focus on thoughts and feelings, rather than medication, was also valued, as was the provision of effective and workable strategies and coping skills to implement recovery.

It was...what did he (psychotherapist) call it? ....he had to change my pattern of thinking. It was all negative. Anything I saw I was thinking of as a threat. So he explained that my smoke alarm was on ten when it should be on two, and I was too wound up to act responsibly to anything that was happening. ....And I had to go over things that had happened to me when I was a child, and I had to back-track to certain placed in my childhood, where there should be happy moments in childhood that you

remember pleasantly, but there wasn't. There was things that I told him that I've never told anyone else.
(Denise)

He (psychologist) introduced me to a particular theory, he explained in great detail, and we tried to break it down and apply the theory and try and create a different behavioural response or emotional response.
(Adrian)

(The psychologist) gradually built up a picture of me, and she could read me better than anybody else I have ever dealt with and it was just the way of taking enough time and listening. ....Because I used to talk a lot to her....she was able to get a picture of me, she was able to understand me, she knew what made me tick. The psychiatrist hadn't got a clue.
(Edward)

Where respondents were positive about their contact with psychiatrists the same critical feature was the sense conveyed that the professional had time, interest and concern for them as individuals. Respondents were very aware of professional time as a scarce and valued resource, and generally took care to avoid wasting it. As the following extract illustrates, it was not necessarily the *amount* of time they spent talking to professionals that was important, as the *quality*:

Well, he (psychiatrist) would listen. He was very good at listening and he was good at giving advice and he was never nasty. Yes, I think he was a good, very approachable person....you never felt under pressure to go. You could sit and chat with him, and he'd give you advice what to do.
Q: And do you think you actually spend longer with him, or do you think it's that you don't feel under pressure when you are talking to him?
I think it's that you don't feel under pressure. You feel like you've got plenty of time even if you haven't.
(Harry)

Extended time was one of the valued aspects of the contact respondents had with a range of other workers, such as CPNs or mental health social workers, although these tended to be viewed as more generally supportive than specifically therapeutic. Focused activities such as

anxiety management classes, art groups, relaxation and yoga were helpful as a means of learning new skills and coping strategies, and also as a means of organising time and providing structure to the day.

Contact with non-psychiatric health and social services

In addition to the professionals they dealt with in relation to their mental health problems, respondents also had contacts with a many different health and social services, particularly those who suffered from one or more serious chronic illnesses (Table 4). For a few people, the continuing round of self-care routines, referrals, appointments and procedures made up much of the business of their day. Most seemed to cope reasonably patiently with the complexity of the contacts they had with the health services. However, individuals with enduring disabilities reported greater problems and anxieties in their dealings with social services and their efforts to obtain the benefits and services to which they felt entitled.

> *At one stage the council had got me running round five different places, to get information to see if I could be given rent and council tax rebate. And the information that I got for them wasn't good enough, and I had bank statements sent to them, from Newcastle. ....They said, 'We can't accept these'. And I lost my temper. I just don't need this kind of aggravation...because I'm coming across as aggressive, but it's the only way of getting a bloody point across with them, wasn't it? They had us running about that much, and it was all for nothing, all for nothing. And the Job Centre is just the same: 'We're not qualified to sort your sickness pay out. You've got to ring up the Social in Newcastle. So I sit there, and they've had me on that phone for hours, haven't they? Just sitting there.*
> (Denise)

> *I mean, we had all his benefit's stopped last year. Not his incapacity benefit, but the DVLA benefit, and we had to go to court and we appealed twice against it. And we finally won the appeal in December.*
> (Mary : Frank's wife)

Although their GP had been helpful and supportive, Frank and Mary had felt they needed help with the complicated procedures and form filling required to mount their appeal. They had first contacted Disability Solutions who referred then to the Citizen's Advice Bureau who gave then a great deal of practical support and assistance in successful presenting their case: Frank's benefits were not only reinstated, but increased after the appeal.

These systems were experienced as bureaucratic, arbitrary, obstructive and impersonal. Two respondents expressed a wish for referral to a social worker to help them sort out practical issues relating to benefits, allowances and housing. Others expressed their dependence on the voluntary rather than the statutory sector in sorting out their entitlement to crucial services and benefits.

> *The social services ....they don't tell you. They most certainly don't help you out in any way. The only other places are the Citizen's Advice Bureau. And Disability Solutions.....I think it was they that got me my Carers' Allowance, the severe disability allowance. I didn't know about those. .....Yes, people don't know. There's nowhere, it's more a word of mouth because you can't just go to the DSS and there it is, and there they'll tell you. They don't do that. It doesn't work that way, and there's a lot of organisations, even the official bodies don't know these other places. ..Even within the system people don't know. Whereas this Disability Solutions, they...it's mainly done over the phone, you just phone....and it's all sorted out for you. ...If it wasn't for the voluntary gps, God knows what people would do, people like CAB and Disability Solutions. If it wasn't for them, I don't know what people would do.*
> (Harry)

For these individuals and a number of others, the help and support they had received from different agencies in the voluntary sector, such as the Citizens Advice Bureau and Disability Solutions as well as the specialist mental health organisations had clearly been of great value.

The voluntary organisations

The study locality was very well served by the voluntary sector, in relation to mental health and other interests. Local branches of Rethink, MIND and the North Staffs User Group held regular drop in sessions and other activities throughout the week and in different sites throughout the area. Rethink also provided tenanted accommodation for a small number of users in its own premises. The voluntary agency facilities were well used by our respondents – not surprisingly since it was from these groups that most of them were recruited. Only one of the six patient interview respondents had established contact with any of these organisations. In addition to the groups specifically relating to mental health most respondents, including the patients, had also sought help from other agencies in the voluntary sector, such as the Citizen's Advice Bureau, Disability Solutions, Changes, the Richmond Fellowship or the Samaritans (Table 4).

Although very largely ignored by the professional sector, the input of the voluntary agencies was highly valued by the service users. Despite continually struggling with resources, these groups provided an accessible and supportive environment for members to meet, share experiences, and get practical help with issues such as information about medicines, services and benefit entitlements and allowances. The regular sessions and drop ins were a forum for social and recreational activities, and also provided meals and other activities, such as gardening, cooking, IT and woodworking classes. Member respondents valued these resources very highly

Because it's (the drop in) entirely voluntary. I wasn't forced to come here and …mmm…I perhaps see people like yourself, perhaps more trying to help rather than put me in a position which I don't like.
(Frank)

Q: In overall terms, what has been the most important in getting to feel better?

Here (the drop in)….cooking. I got a voluntary based cooking, and it's an incentive to get you out of the house. I haven't been solitary. …I can go to various staff and say, 'Can you help me with this?', or, 'I want to talk to you'. And they are there and they will sit and listen to you.
(Natalie)

The thing I did find is I didn't get enough help…When I went in first, into the treatment centre …I was in just four and a half weeks, and I've been quite a bad alcoholic. I did find I didn't get any after care when I got out, so I did find it very, very difficult. But since I've been coming here (drop in centre) now, I'm finding this very useful because I'm with people all day, the staff….there's some of the others have got the same problem as myself, understand my problem and they understand the difficulty with being on my own at home, where I'm not going to make it, and being here amongst other people who understand. They understand that if I'm weakened they're going to help me look after myself. You know, they're giving me support. I'm mixing in, like I say, I'm volunteering. So it's very good, useful.
(Joan)

I mean, I can come places like this because I'm with people who are more understanding. But outside, they just see you as an idiot, really.
(Mr Neal)

In particular, the opportunity to relax in a welcoming and non-judgemental environment, in a context of shared experience and understanding could be a very positive experience. The ability of individual members to select and control the amount and level of their involvement was also important, and the contrast with the professional sector sometimes sharply stated. In particular, the involvement of users as volunteers and help givers within the organisations, as well as receivers, was an effective means of bolstering confidence and self esteem. The relatively flat hierarchy within the voluntary sector stood in sharp contrast to the structured asymmetry of professional consultations which was reinforced by the particular dependency and vulnerability of persons allocated the status of mental patient.

Medicines

Most respondents accepted that medicines were necessary and deferred to their doctors' judgement about the medicines to be prescribed. At the same time, many respondents expressed their disappointment with the the 'culture of prescribing' and the dominance of drugs as a principal – and often only - treatment offered for mental disorders. Drugs were acknowledged to have an important role, but not to be the complete answer. Medicines had a profound effect on respondents' quality of life, and were often the source of considerable distress and discomfort.

> *One of the problems with medication, we've heard from so many friends here today that, the IMPORTANCE of medicines in people's lives and how, when it's wrong, it really mucks your whole life up.*
> (Mrs Simon)

Side effects were accepted as an inevitable and necessary trade off for the benefits medicines could confer in alleviating the experience of mental distress. In practice, it often proved difficult to establish a good balance between therapeutic and adverse effects, and medication was the source of a great deal of trouble for many people.

> *With the medication as well, I can remember, quite a number of years ago, my husband and myself were put on a particular tablet – the side effects were horrific. And the doctor's answer was, when we questioned it, he said, 'Well, …you know how ill you've been. You were suicidal,' he said, 'it was the lesser of two evils. Do you want to feel how you were then, or do you want to take the tablets? You've got two choices.' He said his decision to give us that medication was the lesser of two evils at that time. A lot of*

medication does have side effects, but is it.... Are the side effects worse than what you're
going through?
(Mrs Gordon)

Respondents recognised that the process of finding the most effective and appropriate drugs involved trial and error, given the great variability of individual response to particular medicines.

> *I think it's, again, trial and error, uh, the medication. I think I'm right in saying this. I*
> *feel we're all guinea pigs and I think – I wish we weren't, but I think it has to be like*
> *that. ....and I think what actually happens is, if we didn't take this medication, where*
> *would we be, any road?*
> (Mr Neal)

What suited some people would not suit others, and drugs sometimes had to be changed for a variety of reasons, including the progression of illness and the availability of new products. Respondents were well aware, also, that individual professionals prescribed differently, according to their preferences for particular drugs. Where additional drugs were prescribed to ameliorate the side effects of primary medicines it could be hard to establish the effects of specific drugs and trace the source of unpleasant symptoms to illness or treatment.

Especially during periods of acute distress and confusion, respondents recognised that they had little option but to put themselves in the hands of their doctors and accept the treatment that was given to them. At this point, patients were often too ill to be interested in the details of the medicines being prescribed: they just wanted to be helped and cared for. However, even in more normal circumstances respondents found it difficult even to discuss medication issues with their doctors, far less challenge them. A strong theme within the focus group discussions was the dislike that most doctors had of patients appearing to challenge their authority by raising issues about medication based on externally sourced information.

> *My doctor, if I say, 'I've heard that from......or someone's told me, of 'Do you think?'*
> *......And he seems to think that I am telling him his job, and he'll say, 'I do what I think.*
> (Mrs Gordon)

> *That's something we've heard many times, where a doctor's been very shirty with patients who say, 'I've read this, or heard this or got it off the internet', and his comment is, you know, 'Are you trying to teach me my job? Whose the doctor here?, you know.*
> (Mrs Simon)

Accounts of respondents making direct requests for specific treatments, or overtly resisting the treatment that was offered were rare, and tended to be made on behalf of another, rather than oneself, or to be supported by third party expert opinion of some kind, such as a pharmacist or another doctor. Almost all respondents described feeling effectively powerless to intervene or play an active part in discussions with their doctors concerning their treatment.

> **Q: And do you feel that you were able to say what your preferences for treatment are, or is it up to the doctors to decide?**
> *Well, they really decide. Because I don't know what medicines are out there, there's that many.*
> **Q: So you kind of leave it to them?**
> *Yes.*
> **Q: If something didn't suit you, would you…?**
> *I would tell them, yes.*
> **Q: Would you expect them to kind of change them, or would you feel you had to …?**
> *Well, sometimes what they'll say is, especially if you've only just started on it, it's got to get into your system, your body's got to get used to it, so give it a while longer. So that's what I do.*
> (Harry)

In conforming to the compliant role ascribed to them, respondents depended on the skill of their doctors to recognise the impact of the drugs they prescribed, and modify them when necessary and appropriate. Unfortunately, such sensitivity was far from routine, and securing the necessary help or concern from professionals could be difficult. Mrs Gordon described the miserable existence her husband had endured over more than three years when a medicine prescribed for his mental health problem caused severe nausea and anorexia. A chance encounter with a new practice nurse at the GP's surgery resulted in a solution which transformed her husband's quality of life. The nurse persuaded the GP to prescribe a different form of the drug which was coated for gastric protection.

And he had this new tablet. Just one she (nurse) changed. And within four days most of that nausea went. And he, my husband, sat and cried (with joy) because he ate for the first time in years….My husband was in misery for about three and a half years. Why didn't the doctor just – if it was only for a fortnight to see what happened? He was aware of it, the doctor was. All he needed to do was write a prescription for a different tablet. And he didn't. He wouldn't. But the nurse got him to do it. The nurse was excellent. But she didn't stay.

(Mrs Gordon)

The effect of inter-professional working and relationships on the nature of their communication with patients is considered in the next section. Mrs Gordon clearly had a rather difficult – though longstanding – relationship with her GP. However, even when respondents felt very positive and comfortable in talking to their GPs, they did not necessarily feel they could raise issues relating to drugs they had been prescribed.

We discuss everything with the doctor (GP) like on a level.
Q: But you're not able to say to him, 'Look, the pharmacist says that perhaps I shouldn't have it (incompatible drug)?
No, because I would feel out of order then…..It's like, I think it's a communication barrier. You feel like they're above you, and you do as you are told, and that's that.
(Natalie)

I would absorb it. I wouldn't go back to the GP. I would think, 'I wonder why he's saying that, and somebody else is saying the other'. I think I'd probably try to rationalise it myself, rather than confronting somebody with it. I'm almost sure I would. I'd feel as if …..ifyou confront somebody about it you would be challenging their capability, almost, I suppose. Something like that. I don't think I would.
(Barry)

Respondents deferred to professional judgements in the consultation for a variety of reasons. Courtesy was an important consideration. In addition, they were very aware of the competence gap, and their lack of specialist knowledge: the expert knowledge of professionals was awarded great respect. As we have seen, also, they anticipated that their doctors were likely to react negatively to their attempts to discuss issues about treatment, and bring in knowledge gleaned from elsewhere. Respondents generally aspired to present themselves as 'good' and cooperative

patients and to avoid antagonising their doctors. To this end, also, they usually judged it prudent to accept, and certainly not to reject, the treatment they were offered.

Medicines, as they were prescribed and experienced, were of great significance for respondents. However, although there was a range of responses, getting information about treatment was not usually felt to be such a big issue. The nature of mental illness itself, especially when acute or severe, tended to sap curiosity about medication, as did deference to professional expertise and authority. However, lack of interest in medication information was not necessarily associated with a passive orientation to illness management. Some people were happy to delegate decisions about the selection and monitoring of their doctors, while taking a proactive stance to other areas of their lives and illness management.

There was widespread agreement that professionals tended to be evasive about treatment, and that it was often hard to talk to them about it. Most information about medicines was acquired by respondents, who had to find out for themselves from a range of sources: the patient information leaflet, the user groups, the internet, books, magazines and the media are examples. At the same time, several respondents expressed the idea that information was not always welcome or helpful. Barry found the chance to discuss his problems at length with a CPN very helpful. However, he was taken aback to be given a batch of leaflets to read about depression and it treatment.

> *When I came away with these leaflets I thought back to my learning days, and thinking: this is like getting homework.*
> (Barry)

As discussed above, Barry accepted the cultural prescription for self help espoused by his doctors. He acknowledged that it was appropriate that health professionals should seek to delegate some of the responsibility for his recovery. Nevertheless, he had sought help in the hope of being given support and *direction* from an expert, rather than a self help kit which encouraged him to identify and fix the problem for himself.

Information could also have a negative effect when it was conflicting, confusing, or threatening. A number of respondents had taken, or were taking, Seroxat at the time of the study, and were aware of the media controversy surrounding the safety of this drug. This posed problems for people who felt they benefited from the drug and did not want to stop taking it, while nevertheless being concerned about the occurrence of adverse effects as a result of this.

The difficulty is that I can scare myself if I go into too much depth with information. At the time I started (on Seroxat) there was a lot of media coverage of the drug. I went and read up on it in the library. I found it frightening with regard to side effects, for example. Sensationalising a drug when you are taking it can make you very anxious. You wonder, 'What is it doing to me?'. I try to set the information in context. I get other opinions. I ask others who have been taking it. But individual reactions to drugs vary, so side effects may not be a problem for me.

(Mr Peters)

Now, there's been a lot of controversy over Seroxat, hasn't there? A while ago I read an article in my wife's magazine. Two persons that were on it. One said if they hadn't packed it in they would have been dead. And this other one said their life's been great ever since they've been on it. And....my son's like that. Ever since he's been put on Seroxat his quality of life's gone up leaps and bounds. And, eh, I was just wondering what the conclusions are about it? How it's all been worked out. The good and the bad of it type thing.

Q: And did you follow it up by trying to get information elsewhere to check-

No, we haven't actually followed it up. Because like I say, like when I made my first point about somebody getting put on something that finally suits them. You know, I mean, he's been overjoyed since he's been on this, over against all the other things previous to that that never, never user to seem to do anything. No.

(Mr King)

In this case, although troubled by his knowledge of controversy surrounding Seroxat, Mr King – and his son – decided to stay with the treatment that is conferring such obvious benefit. There is an understandable tendency to develop a commitment to a position that supports one's natural inclinations or perceived interests. Unease about conflicting or negative information would be much harder to subdue, however, where there were no clear benefits to be derived from a particular treatment.

Several other respondents were in a similar position in relation to Seroxat: it was not comfortable to feel that a drug that carried great personal benefit was considered harmful and damaging: some information might be better not known. This case illustrates the potentially double edged nature of knowledge about treatment, and a justification for the strategy which some respondents adopted of delegating decisions about drugs to their doctors.

And I think one's got to feel some sympathy with the medical staff, if they know that a medicine's likely to do you good, or believe sincerely it will help you, but it has some troublesome side effects. Should they emphasise more the good that it can do you (murmured agreement)*? Or should they give you full information about the pros and cons and let you make your own mind up? Some people would say, 'I'd rather put confidence in my doctor. He or she knows me best.' Other people would say, 'I'd rather just be given the straight facts and be able to make my own choice about it* (murmured agreement)*.' It's a very individual thing.*

(Mrs Simon)

For those who did want to find out about their medicines, however, locating a source of accurate and impartial information could be difficult. Professionals were not often found to be a good source of this. Respondents referred to patient information leaflets (rather dismissively), the media, books and the internet as resources in this context. The voluntary organisations were particularly useful, however. They provided a conduit for the exchange of information and experience among service users, and also a service in supplying individual users with quite specialist information tailored to their needs.

Respondents distinguished between verbal and written information about medicines. The latter could be useful for reference, but the former was valued as an expression of the (therapeutic) relationship between patient and professional. The personalisation possible in face to face communication with professionals was highly valued. The giving of information by professionals during face to face encounters was valued as a mechanism for building a relationship irrespective of whether or not a patient used that information to help make decisions about treatment. Exchange of information about medicines provided a useful conduit for interpersonal contact. There was also a sense that assuming such responsibility for medicines was part of the prescriber's accountability.

It's not down to the pharmacist. It's down to the doctor or the person that gives you the medication (to give information about the drug). They should actually explain. I don't believe in giving somebody a pill and say, 'Right, take it'. And that's it. They should tell you what's involved.

(Natalie)

The significance of discussions about medicines as a marker of the quality of relationships respondents had with their doctors may account in part for the relatively little use made of

pharmacists as a source of information. Once again, there was a range of opinion and experience.

> *I think – purely on medication – the pharmacist is as good, if not a better source of information than anybody else. Because it is their whole job.*
> (Mrs Simon)

However, it was evident that some people who were happy to consult a pharmacist about physical illness and treatments did not consider they were an appropriate source of information and support about mental disorders.

> *I've never asked a pharmacist about anything to do with mental health problems. Never even thought about it. Because I didn't think it was one of their, a thing they would deal with.*
> (Mrs Gordon)

Perceived advantages of pharmacists included their accessibility, impartiality and specialist knowledge of medicines. However, Mr Neal had encountered the same problem of evasiveness among pharmacists that was a more general attribute of respondents' dealings with health professionals.

> *I think it's a good idea about the pharmacist. But I had an experience about nine years ago, when I was on steroids. I asked the pharmacists the side effects, and they wouldn't tell me. 'Go and see your consultant'* (murmured agreement). *And I thought, well, I could get this information. So I went to another place: nothing* (agreement). *And that started me thinking: 'What are they giving me?'. And then the next thing that came on the television……and right or wrong, they should have put my mind at rest to say……*
> (Mr Neal)

Mr Neal's account of his consultations with the pharmacists illustrates the reluctance of professionals to provide patients with information about medicines that might be considered problematic or *troubling*. It also points to the effects of the professional hierarchy as another obstacle for patients seeking to access impartial information and open relationships with their health professionals.

Professional hierarchy

Respondents expressed an awareness of the professional hierarchy – and their place at the bottom of it. As the preceding extracts from Natalie's account illustrate, patients not only deferred to professional judgement, they also tended to evaluate information according to the authority of its source. The GP was perceived to occupy higher status than the pharmacist. Consequently, where there was a conflict between the two, the views of the GP were held sway. CPNs, practice nurses, counsellors and other community support workers deferred to the GPs. GPs, in turn, were recognised to defer to psychiatrists, who were generally regarded as being at the top of the tree. The professional dominance of the psychiatrists is well illustrated in the following experience of how ward rounds were conducted.

> *I mean, this ward round that they do. ..That was always a sore point with me, that ward round. I used to think it was a waste of time. You used to go in, and there used to be about twelve people sitting around, and the consultant used to be the only chap that said anything. All these others looked as if they were frightened to open their mouths. They never used to say a word, the others. So I used to wonder why they were there? The consultant was the only one that said anything. And it always used to seem to me to be rather a waste of time. And it used to be every Friday, every Friday morning. You knew what was going to happen, and nothing was ever different.*
> (Mr King)

In particular, other professionals seemed reluctant to encroach into the psychiatrists' particular territory – and also the source of their status – by discussing issues of diagnosis and medication with patients. Such issues tended either to be evaded, or patients were referred back to the prescriber for clarification. For example, Denise described how her key worker had helped her with practical issues like sorting out a dispute with her neighbour, and she was a good listener – but unwilling to de drawn into discussion of Denise's concerns about medication.

> *I did talk to her (key worker) about the medication, but she didn't...she thought that was something to be discussed with the GP, it wasn't her place to ....you have to be careful what you say to people with mental illness about tablets. You can put yourself in a situation where they take it literally, because we do... In the drug situation, she said that it was something that I should think about and discuss with my doctor.*
> (Denise)

Similarly, Edward describes his enthusiasm for his psychologist, and the extremely good relationship they had developed.

> *Claire (psychologist) was completely different to anybody I'd ever met before. She is one of the nicest people I have ever met, and one of the most patient... I found after seeing her a couple of times that I could open my heart to her. I could tell her everything. I didn't hold back and told her everything....I used to actually enjoy going to see her.*

Nevertheless, it was evident that the psychologist was not prepared to discuss the issue of medication.

> **Q: What were Claire's feelings about the Seroxat, did she have any particular.....?**
>
> *She didn't really want to get involved in the drugs. I made her aware and I used to tell her if I was dropping off, you know, to a lower dosage, or go up to a higher dosage, or whatever. I would let her know, but she never really commented on that, or said, 'Oh, that's not a good thing', or 'That's a bad thing'. Or whatever. She just noted it really, I think.*
>
> (Edward)

Respondents described their experiences of having their medication changed when they moved from community to hospital care, and by the different psychiatrists with whom they came in contact during the process of care. One or two respondents observed that they went to their GP to get the medication prescribed by their psychiatrist altered. Generally, however, it seemed unusual for other professionals to intervene in prescribing decisions initiated by a psychiatrist. The only account of this happening concerned a psychotherapist operating outside the NHS. He was keen for Denise to reduce and eventually stop the medication that her GP and psychiatrist felt she needed to continue taking.

> *He (psychotherapist) kept saying to me, 'Do you really need all these drugs? Can we change your mind in thinking in a positive way to take away all the bad feelings so that you don't need these drugs any more?*
>
> **Q: Did you share with (the GP and psychiatrist) what the psychotherapist had said?**
>
> *They didn't agree I was ready yet.*

Q: So, how did that leave you feeling: you'd got the psychotherapist saying one thing, and the GP…?

I thought perhaps if I could take the dosage down and see how I coped. I didn't stop, I took my dosage down.

(Denise)

In fact, although Denise eventually succeeded in her goal of coming off the tablets, this particular experiment failed, and she reverted for a time to her normal dose. She had responded to conflicting professional views by adapting the advice given by the psychotherapist who she felt understood her best, and at that point had helped her most.

Interprofessional deference and the avoidance of boundary encroachment help to avoid tension and conflict within the workforce. They also serve to reduce the risk that service users are confronted with professional dissent and inconsistency. However, the compartmentalisation of professional input in this way perpetuates the fragmentation of care that has traditionally undermined the quality of service experienced by users. Far from being the beneficiary of a seamless system of care, the patient remains the point of intersection of a range of disparate services. Each of these delivers a discrete and bounded input, with little reference or ability to respond generically or constructively to service users' most immediate and pressing concerns. The result is that instead of triggering a process of advocacy and interprofessional liaison, patient queries are likely to be met with an onward referral to another professional or agency. This not only increases the bureaucratic workload for patients already struggling with the debilitating effects of illness, it is also likely to block the chance of effective resolution of the problem. The recommendation of one professional that a patient makes a further appointment to see another – to discuss concerns about medication, for example – provides a convenient and effective of evading involvement and responsibility for the query. As has been amply documented above, patients often find it very difficult to discuss medication issues with their doctors. They described themselves as taking predominantly passive stance in medical consultations, deferring to professional judgement, and anxious to avoid seeming to challenge medical authority. It is precisely because they find it difficult to address these issues with their prescribers that patients often seek additional views and support from other professionals and care workers. In addition, where patients are referred back to discuss issues with a psychiatrist with whom they have scheduled appointments at four or six monthly intervals, they are likely to have to wait a long time before even the potential opportunity for discussion and treatment modification presents itself.

The Care Programme Approach (CPA), and the appointment of a key worker to coordinate the care and liaise with all professionals involved in an individual case was supposed to solve the problem of fragmented and inefficient delivery of psychiatric services. The ideal of team working not only encompasses the goal of achieving benefit through specialist input, but also flattening the professional hierarchy. Our findings provide no evidence that either of these has been achieved. As we have seen, not only were patients themselves sensitive to the operation of a professional hierarchy, they also recognised its influence on the individual staff involved in their care. Respondents conveyed no sense of being at the centre of a therapeutic team. Only two people referred to having a key worker. Although the input of these was valued, it was circumscribed by the limitations of their role definition. The only account of what seemed to be a team case review was given by Natalie. This was a strikingly negative experience, in which she felt the object of a discussion from which she was effectively excluded. Notwithstanding the great rhetoric and well established commitment to patient centred care and choice, our respondents' accounts describe a system in which patient needs, and also the assessment of health outcomes, are still dominated by professional judgement and evaluation. Respondents' describe, by and large, their conformity with the traditional deferential role of patient, and their acceptance of professional judgement and disposal which is very far from being comprehensible and transparent, far less collaborative. Good relationships and effective interventions were often the result of chance rather than design, and often short lived. There was no dynamic in the system building on the positive and progressive aspects of patient's experience of care which frequently fell short of therapeutic.

> So you see how this sort of comes from one word of mouth to another, and nobody's like looking at me and saying, 'What would be best for him?', and then being able to pull all the strings to make all those things happen.
> (Edward)

Respondents seemed routinely to be passive recipients of services and treatments dispensed with little or no explanation - or at least no clear understanding - of their purpose, duration or expected outcome. The professional identity of staff with whom they interacted was quite commonly unknown. Individual staff and services came and went in an unpredictable and arbitrary fashion. The process of referral and discovery was often a matter of chance. Far from being a system sensitive to patient preferences and responses, the overwhelming impression was of the passivity and powerlessness of patients to influence the direction and quality of care.

Chance and arbitrariness as a determinant of health care

Respondents accounts included many instances of services that were arbitrary and unresponsive to their needs. Long waiting times could be frustrating but were more or less an accepted feature of the health system. Sometimes, however, appointments arrived after the need for them had passed. Several respondents were surprised to receive notification of appointments with a psychiatrist. Not only did these arrive long after the consultation with the GP who had initiated referral, but they had no recollection of the referral having being made or understanding of its purpose. As a follow up to a consultation with his GP, Barry had been referred to a CPN who he had seen on two occasions, within a matter of weeks. He found these sessions very helpful, but accepted – albeit rather reluctantly - the nurse's suggestion that no further appointments were needed.

> *Then, I suppose, perhaps because.....I was surprised after that ...I don't know whether I should have been surprised or not, but I seemed surprised when I got a letter through the post saying there was an appointment to see.....mmmm.... the psychiatric doctor at the local mental health centre......it came as a bit of a surprise because I was back to work again and thinking, 'I'm getting over this'.*
> (Barry)

Barry went along with the referral, feeling that he ought to take the opportunity that was offered, but felt that, although talking about his feelings and concerns was still useful, he was just repeating what he had already said to the CPN. At this stage, there was no real therapeutic gain to be derived from his contact with the psychiatrist.

Momentous consequences could flow from chance encounters: for example, the practice nurse that persuaded Mrs Gordon's GP to change the form of her husband's medication, or the appointment of a new psychiatrist to Mr King's son. Sometimes significant information could be discovered fortuitously, for example: a social worker passing on details of one of the voluntary organisations, or a feature on the media.

> *It's like finding out that we was entitled to tax credit. Now, that's only because I was home one day, and it was on Good Morning (television programme), and this man was talking, saying: you are entitled to tax credit now if you're on a low income.....and we applied for it.*
> (Mary: Frank's wife)

Other times help came from unexpected sources, including individuals acting outside the boundaries of their normal roles.

> *The only person who we got any help from was Brian, really.....single parent advisor at the Job Centre. He was only there twice a week. And he sorted out lots for us and it wasn't really his job.*
> (Denise)

Joan described how, at a point when she was in great distress and desperate for help, it was community officers from the local police force who provided critical support.

> *Well, I had to wait. This is the difficulty. I had to wait twelve months to be admitted (to alcohol addiction unit), and during that time the Police were marvellous. I got picked up for being drunk and the Police took me home and they came out to me because I was suicidal at one stage, and they sat with me for three hours and talked me out of it. And, basically they have been very brilliant, you know. I went up to the doctors and said, 'Can you hurry me along,' like, and, 'Oh, no. You've got to wait. You're on the list and you've got to wait.' Well, I mean, really and truly speaking, when you're begging for help and you really want to stop, and you're ruining your own life, ...for somebody in that situation.....*
> (Joan)

Respondents had very little control over which professionals they were referred to, or any means of holding on to valued relationships and services. Change could be for the better, as in the case of Mr King's son, and Harry's partner when they were moved on to different psychiatrists. On the other hand, as described above, Harry himself declined appointments with a temporary locum after the psychiatrist with whom he had developed a very good and longstanding relationship retired. He felt there was no point in episodic meetings with different psychiatrists, and preferred to wait until a permanent replacement was in post.

Respondents experienced services being stopped when resources were redeployed or individual staff members left or became ill, and were not replaced.

> *I can't see my counsellor any more (service was withdrawn). I see my key worker, but all she does is listen to me. And the counsellor....I'd been seeing him for more than a year, and I built a good relationship up to where I actually trusted him. My first care*

worker I had from May until September, and then she was off. I had to get a new one:
they'd forgotten about me. You tend to be forgotten about. I've also got a psychiatrist
who doesn't seem to understand what I'm going through.
(Denise)

Edward had found visits from his CPN helpful, following discharge from hospital. However, his understanding of the reason for these being stopped was that his psychiatrist felt that he the extended distance involved in travelling to his house was an inefficient use of the nurse's time. He was also sorry that the yoga classes run by the Mental Health Centre, which he attended for over a year, ended when the teacher retired, and was not replaced.

Access to services was determined by professional, rather than user, assessment not only of need, but also of benefit. For example, Glenda's psychologist stopped her weekly sessions because he felt they had reached a point where there was nothing more he could do for her. Glenda was reluctant to delve deeper into her past and childhood experiences and negative events. The psychologist felt that these held the key to her enduring problems as an adult. Glenda held a different view: she did not want to 'go deeper', feeling that discussing distressing issues relating to her past would merely cause more upset, rather than resolve it. She valued the weekly sessions with the psychologist and the chance to discuss her problems. Nevertheless, since she was not willing to accept the service on the professional's terms, and his perception of benefit, it was terminated, apparently without the offer of any alternative. If she had been able to exercise choice, it would have been for long term weekly sessions with a CPN, or possibly a liaison psychiatrist.

Glenda was also well aware of the consequences of refusing services offered by professionals: during an acute episode of her illness she had rejected a psychiatrist's suggestion that she should be admitted for a stay in hospital. Glenda's main reason for not wanting this was that she could not bear to be admitted as a patient to an institution in which she was employed as a member of staff. Her refusal had caused some umbrage, particularly to her GP, who had asked 'Don't you want to get better?', and accused her of not wanting to be helped. She was now wary of seeing her GP again, partly because she wanted to avoid further experiences of being offered services she did not want, and thus attracting the label of being an uncooperative and difficult patient. Along with a number of other respondents, she described how she had in the past gone along with her scheduled appointments with a series of different psychiatrists, few of which she had found helpful. Again, she had not wanted to seem uncooperative of rejecting of help. However, she felt that these sessions had involved continually going over the same ground. As there was

little continuity of staff she ended up telling her story repeatedly to different people: she described herself as feeling 'like a hamster in a wheel'.

One reason for being unable to access appropriate help is not knowing that it is there. Unfamiliarity with the complexities of the system, and lack of transparency about entitlement and availability of services made if difficult for users to play an active role in assessing their own needs and how these could most effectively be met. Many respondents felt that drugs were a necessary but not sufficient treatment for their problems, but often found that they were all that was on offer. People who had accessed other services and resources – from counselling to yoga or art therapy – often found them helpful. However, there was no easy way to discover what services were available.

Some respondents found themselves receiving a service to which they had no knowledge of being referred. Others remained unclear about the role or professional identity of workers allocated to them. Consequently, they could not have any clear idea about the rationale or purpose of the referral or its supposed outcome. Other respondents knew what they wanted, but could not find a way of accessing these within a system which they experienced to be inflexible and unresponsive. For example, Denise asked for a home care worker to provide help with basic tasks such as shopping and housework, which she was struggling to cope with, but was turned down. Although some respondents had become quite expert in managing the system, it could take a long time to discover what was available re resources and entitlements, and as we have seen, these were often discovered by chance.

Respondents found out about the voluntary agencies in a variety of ways, but rarely from health professionals. This is so, even though the NSUG had an office in the local psychiatric unit, and was active in making contact with patients on the wards. Once again, it was often chance that dictated such discovery: seeing a poster, or picking up a leaflet at the surgery, a feature on the radio or in a magazine, or even passing the office in the street. Once contact was established with one agency, respondents were able to find out about others, and also had access to information and support about a wide range of issues and services. In addition, the voluntary agencies constituted a very valuable resource in providing opportunities for members to meet and socialise, as well as programmes of activities directed to both recreational and therapeutic purpose.

The feeling that there should be easier access to information and a more systematic means of distribution was widespread.

Mrs Gordon: *I think, getting the help, though. I think if initially you go to your doctor, you aren't getting the help and information that you need, then there should be a secondary place where there's a phone number* (agreement) *where you can pick up the phone and say, 'Well, look, I need some help or information'. And that particular person or organisation should have a list, and they'll say, 'Well, either come in, or we can come to see you, and we'll give you a list of where to go for that information, or where to get your help.' There should be a specific place or person that you can go to –*

Mr Neal: *- the users group!*

Mrs Gordon: *- and this is it! I think* (agreement) *– but it isn't an official one and everyone doesn't take – and there are some people who can't come here – I love it, and it's fantastic – so it's alright for us, but there should be something for everyone, not just…*

Respondents were willing to make some effort to access information and to learn how to work the system, but they felt it reasonable that they should be provided with a steer to put them in the right direction. As it was, their experience had frequently involved services that were mystifying, bureaucratic, and unresponsive to their needs, and a system from which they were largely excluded as passive recipients, rather than active agents and co-producers, of care. The voluntary agencies were highly valued for the services and resources they provided. However, there was also a feeling that they should not have to substitute, or fill in, for gaps in the statutory services. It was considered to be inappropriate and unsatisfactory that the self help groups should supply services voluntarily for which the statutory services were paid, but often failed to provide satisfactorily.

Professional Experience of Complexity

Roles and relationships of professionals interviewed

The GPs were based in one practice and referred patients to the psychiatrists, one of the CPNs, the social worker and the psychologist who were interviewed. It is likely that they had less involvement with the last professional as there was a long waiting list for psychology which deterred GP referrals to the service. They would not have referred patients to the psychotherapist or the second CPN as she worked in secondary care. The GPs appeared to be unaware of the particular user group from which the user group worker respondent came and not to have close relationship with any other mental health self help group. Their understanding of any role for the police in mental health was in relation to sectioning patients and this happened infrequently in primary care.

One of the psychiatrists worked in adult mental health services and referred patients to both CPNs, the psychologist, the social worker and possibly, though unlikely, to the psychotherapist. The psychiatrist spoke of the formal role of the police within forensic psychiatry but did not make reference to informal relationships between individual police officers and patients. There was no direct relationship between the psychiatrist and the worker from the user group or the psychotherapist. The second psychiatrist worked in old age psychiatry and had a relationship only with the GP respondents. Old age psychiatry has its own CPNs (none interviewed) and a different social work team from the social work respondent and no psychologists.

Both CPNs worked in the secondary sector. One was with an emergency team who worked with service users in a crisis with a view to trying to avoid admission to hospital. She received referrals from psychiatrists and GPs and also on occasions from the police. The other CPN worked in the community with patients with severe and enduring mental illness. There was no direct relationship between this CPN and the GPs. The CPNs supervised home support workers. Both CPNs had relationships with social workers.

Adult mental health had a dedicated social work team from which the social work respondent came. Older people with mental health problems did not have a specific social worker but were picked up by social work teams for the elderly and allocated a social worker to sort out particular issues e.g. admission to a nursing home. Integrated care was being phased in within adult but not older people's services as the interviewing period was coming to an end. Under integrated care the distinction between social workers (mental health) and primary care CPNs will be blurred. Both will work in the same location and a patient would see the first person available which could be a social worker or a CPN.

The psychotherapist, the police officer and the user group worker operate outside the NHS and local authority care. The police officer had established relationships with a local user group (not the one from whom the worker came), and with secondary care CPNs. The user group from whom the worker came had a working relationship with the health care trust for whom the psychiatrists and the CPNs worked. The role of the user group is to act as a link between service users and service providers. In one direction they act as a pressure group to improve services. They get feedback from service users via community groups and volunteer workers on the psychiatric wards. In the other direction they help users by providing information and referring them to organisations. The psychotherapist was the most distant from the other professionals interviewed in terms of his location outside the NHS, his work in adult mental health which was a side shoot of his main stream work with children, and the different model of mental illness with

which he worked. He did not have direct contact with the main stream NHS services accessed by his clients but implicitly supported their use of these.

Relationships with service users

The kind of relationship that professionals had with service users was primarily influenced by their role in relation to those with mental health problems. The police officer was likely to encounter service users when in a crisis such as a suicide attempt. He saw the police task being to defuse a situation and to avoid any intervention that could escalate an incident. The officer had organised training for himself which was run by a user group in order to understand how service users might be experiencing 'the crisis' and therefore how best to relate to them. He had learned that normal talking and listening worked best. He was unique in the effort he had taken to understand user perspectives and to recognise the value of user led training in helping police officers to deal effectively with service users in a crisis

> *But in fact he (man threatening suicide) did say to us when we were getting into the police station, "Thank you very much for being so kind to me." And I'll never forget that. But at the end of the day it's only a matter of talking to people.* (Police Officer)

The police officer had a very practical and apparently humane approach but which nevertheless deferred to medical expertise. His role involved the management of difficult situations but had absolutely nothing to do with providing treatment. This was the responsibility of the medical profession and assumed to be expert, appropriate and effective.

The psychotherapist saw his role as enabling service users to take responsibility forthemselves.

> *Part of the philosophy with the counselling I do is we get people to meet their own needs as far as possible.*
> (Psychotherapist)

He was concerned to promote service user autonomy and prevent a dependent relationship being established.

> *Always working towards a positively framed end to the therapy when the person's life is then working well enough to carry on without the counselling.*
> (Psychotherapist)

While both psychotherapist and psychologist could offer a long term relationship it was more usual for patients to be seen over a period of months rather than years. The duration of therapy was largely determined by the professional's perception of a patient's capacity to benefit and stopped when this had either been achieved, or reached a plateau from which no further progress was anticipated.

The GPs had a number of tasks in fulfilling their role as the initial point of contact for patients seeking help with a mental health problem. Initially these included gaining rapport so that patients felt able to divulge their symptoms and problems. Then, when a mental health diagnosis seemed likely, they might need to negotiate with patients to accept the diagnosis, treatment and possibly referral to psychiatric services.

> **Q: Is that something that is quite common? That people resist (a psychiatric diagnosis and referral to secondary care for it)?**
>
> *A: Yes very much so. They see it as a real failure and you know not something that people rush in and ask you to do.*
>
> (Dr Abbey)

After referral the GPs expected to remain involved in all aspects of patients' care including mental health. Indeed they felt they had an important role in preventing fragmentation of care. They were the means of integrating different parts of the service.

> *I think GPs have quite a central role, meaning they're in the middle somewhere and their advantage is that they're accessible.*
>
> (Dr Chandler)

In order to do this the GPs needed to know their patients. Although time was limited in each single consultation, with a stable population it was possible to build up such knowledge across an extended series of consultations.

The psychiatrist spoke of operating with two distinct but interrelated roles, firstly as a doctor caring for patients and secondly as a guardian of NHS resources. He considered many patients seen in primary care to have a temporary distress reaction following the experience of some adverse event rather than to be suffering from a clinical depressive disorder. Although commonly prescribed for distress reactions antidepressants were appropriate only for the latter group. As a

consequence a large number of patients were diagnosed and treated inappropriately in primary care. Once assigned, it was very difficult for him to detach an illness label.

> *It's very difficult to say, "Well hang on, really you haven't got a depressive disorder as described in the text books. What you've got is a complicated social situation and something that you've been struggling with since you really became an adult and the likelihood is that the medication isn't going to change that. But the illness model creates an ability to opt out of responsibility to get more into dependency and also secure some benefits.*
> (Psychiatrist)

Because the antidepressants were unlikely to resolve the psychological distress these patients may ultimately end up being referred to him for specialist advice as primary care had not successfully dealt with the problem. However apart from treating individual patients he also felt that he had responsibility for effective prescribing at a population level.

> *And in the early days of antipsychotic agents and antidepressants, probably producing hope to people where there was no hope. But the whole thing's gone a bit pear shaped since really and it's very, very confusing. When you look at how much medication there is in the system at the moment. I mean it's certainly our role if we can to try and rationalise medication and get it under some control and get it in the British National Formulary limits and all that sort of stuff.*
> (Psychiatrist)

Thus a patient could be treated for a depressive illness in primary care (after possibly some persuasion that he suffered from depression) which does not respond to treatment and is then referred to a mental health specialist. The psychiatrist's assessment may be that the patient does not have a depressive illness and does not require medication. This must impact on the relationship between psychiatrist and patient and perhaps explain why some service users felt they did not have a good relationship with their psychiatrist. Thus discrepancies in inter-professional models of mental illness can impact negatively on the patient's experience of care.

In old age psychiatry it is more likely that someone other than the patient has sought medical help. The psychiatrist was not always sure of the real motive for a referral.

A lot of what I do is try to work out what the agenda here is, why am I here then and if it's a nursing home for example, it may be because other residents have been hassling the nursing home staff, who've been hassling the GP and you've got to work out why you're here and what do they want you to do.
(Psychiatrist)

The psychiatrist not only has to develop a relationship with the patient but also with carers and care staff. Conflict could arise between the different agendas of patient and carers/care staff , raising the difficulty of what to say to whom. This posed less of a problem where a patient had dementia and may not have sufficient mental faculties to understand what was happening. In some circumstances the psychiatrist found herself having to be an advocate for the patient and bring in the care that she thought most appropriate.

The CPNs were not time limited and saw patients at home. Part of the CPN's role was to help service users adhere to the treatment plan agreed in the Care Co-ordination Programme (CPA). There was the opportunity to build trusting relationships necessary to get service users on board over treatment.

It's about working with the person because you know you're not going to get somebody to comply if they're not happy with the treatment that you know, you're recommending.
(CPN)

The social workers, like the CPNs, the psychiatrists and one of the doctors all saw themselves as advocates for the patient. However social workers thought that because they worked outside the NHS they were more independent than CPNs and able to question clinical decision making particularly around medication more directly. They considered that this might make them a more effective patient advocate.

I think to an extent the social workers would only see themselves as advocates because they you know wouldn't feel junior to a medic, in a sense that they're not. ---Now this again might change, once people are in a team together (integrated care), the dynamics might change, but currently social workers have an advantage – if one perceives it as that – as being employed by a different organisation and being primarily based in a different team. So therefore they have the support to perhaps challenge medics about some decisions.
(Social Worker)

As this example shows, the social worker thought that the introduction of integrated care might compromise his independence. The GP's role was also changing with the introduction of a new GMS contract for family doctors from April 1st 2004.

Q: So do you see your role as changing, I mean do you see it as inevitably changing, when you say you came into it for this kind of holistic kind of things and now things are more fragmented. I mean is that something that you've experienced in your working life?

A: Yes, it's definitely changed, I mean it's changing even more now, I mean we're ticking boxes … if somebody comes in for a … maybe not a mental health consultation, or maybe they have come in for a mental health consultation and they are fifty and I'm looking at a screen and I'm seeing that we haven't done this, that and the other on them. Then I'm trying to get that into the ten minutes because that's what I'm being paid for …mmm… where as the … well that's how it's going to be because otherwise I can't even think. Because it's all about ticking boxes and doing all these kind of government led things, in ten minutes, which is not very long.
(Dr Dawes)

The ten minutes allocated for each patient has to accommodate the government's agenda as well as the patient's.

Professionals had diverse aims and visions in respect of their role with patients. Some expressed awareness of a clinical hierarchy and how the position of a professional within or outside of the hierarchy has implications for relationships. New policy initiatives of integrated care and the GMS contract will affect the roles of those working in mental health. Integrated care will foster closer relationships between social workers and CPNs/psychiatrists which could be beneficial to patients in joining up care. However, it may also have adverse effects if service users view social workers as part of psychiatry. Opportunistic screening as part of a health prevention role for GPs in the new GMS contact may cause tension with their care role, as both compete for consultation space.

Perceptions of relations between service users and professionals

Respondents held different views about the positioning of service users and professionals. Some referred to a hierarchy. The user group worker and the psychologist saw the psychiatrist at the top of the hierarchy, GPs in the middle and nurses closest to the patient.

> *I guess the hierarchy of difficulty would go that the easiest (for service users to talk to) would be nurses, middle ground would be occupied by GPs, perhaps most difficult might be consultants.*
>
> *Because people feel those varying degrees of deference towards them and also that these people have such a wealth of experience, how can I challenge their view. You know people will say … you know I might say to them "Who's your consultant at present?" "Dr So and so, he's the head man you know, or he's the top dog you know, I've got the best in the country." People have enormous … well some people have great confidence in them …mmm… others less so, but I think patient service users do find it quite difficult to challenge the decision made by someone whom they perceive to be in immense authority, knowledge, wisdom, experience and I guess that just lends itself to a very unequal relationship in which the patient is really passive, putty, - recipient of whatever the doctor says really.*
>
> (User group worker)

This respondent felt that the distance between the user and the professionals could be a source of confidence but was also indicative of a relationship in which the patient had a passive role. In contrast one GP considered that psychiatrists were trained in interpersonal skills and therefore good at establishing relationships and communicating well with patients. Another GP felt that the traditional authoritarianism of psychiatry had changed and the profession was now more patient centred.

> *There's much less prescriptive diagnosis and paternalism in psychiatry than there used to be. I think patients used to be told, "Take this and go away and do as you're told." Without any explanation and there's a lot less of that than there used to be.*
>
> (Dr Brown)

Dr Chandler did not accept the notion of a professional hierarchy.

> *I don't see it as hierarchical …mmm… I don't really accept hierarchies. We don't really have one in the practice. People are professionals in their own sphere, so I wouldn't*

contradict a psychologist on a psychological matter ----, counsellors and psychiatrists and psychologists all have different roles and as long as they're working within their own field, there's no ... they are the expert in that field-
(Dr Chandler)

Dr Chandler felt that different professionals recognised and responded to each others particular areas of expertise. For their part the doctors considered themselves to operate in a patient centred way and that they solicited the patient perspective.

I mean in general practice as a whole you quite often get patients who are not telling you what really is bothering them and you get reasonably good at picking up there's something else there. That you know, if I can just press the right button, they'll tell me and that will apply in mental health problems as well.
(Dr Chandler)

If you see someone with depression obviously I put forward what my view is of things and then you discuss what the options are, how they would like to proceed, how I see the options. Yes, it's very much a dialogue, always the case.
(Psychiatrist)

However the other professionals had a rather different perception of the relations between service users and doctors.

Some service users find it very daunting to see a psychiatrist. (Social worker)

I would say in the secondary service, I don't feel people gain a lot from their GPs. I think they see us and the psychiatrists as the specialists really. No I would say, particularly a lot of the people I see don't even like going to see their GP.
(CPN)

A lot of people don't think to ask that (about the side effects of the medication they take), because if you go to the GP with depression or anxiety, you're run down anyway aren't you, you're preoccupied with the problem and if the doctor says "Oh you need this pill." Then off you go and take the pill. It's really hard to challenge your doctor I think.
(Psychotherapist)

While the CPN thought that patients were uncertain as to whether a GP had the necessary expertise to deal with their mental health problems, and preferred to see a psychiatrist, the social worker and psychotherapist felt that patients found it hard to talk openly to doctors.

Communication with patients could be affected by an individual's position within the professional hierarchy. Those lower down the hierarchy may feel constrained about divulging information which is at odds with an approach taken by a professional higher up. One example of this concerned diagnosis. The CPN said that some psychiatrists were reluctant to share a diagnosis of personality disorder with patients. This could make for difficulties in her relationship with patients.

> *A: I'm just trying to think of an example, I think sometimes it's more where the diagnosis of a personality disorder, I mean some doctors find that more difficult, for some reason, to say to patients and that's you know frustrating for you as the CPN who's trying to work with that person.*
>
> **Q: Would you actually be able to go and negotiate or bargain that with the psychiatrist, or do you feel that's their decision and that's the way it must stay?**
>
> *A: No I think often you can have some dialogue about that and you know, sort of work towards ways of that diagnosis being given. Because as I say if it's not it's very difficult to work with that person because you're going in different directions.* (CPN)

The CPN felt she needed to negotiate with the psychiatrist before she could give information about diagnosis to the service user. Her ability to be open and responsive in discussions with the patient was consequently constrained.

Respondents gave instances of local working that did not fit with a notion of a simple hierarchy, for example a secondary care CPN advising a GP on medication. There were also examples of hierarchical relationships being seen as counterproductive by those who occupied a higher position. For example one GP wished that primary care CPNs were not so deferential and would say directly when they disagreed with a diagnosis or treatment.

Professional models of mental illness

Respondents had different understandings of the nature of mental illness. The biomedical model referred to the extent that a mental health problem was seen as being biologically determined rather than a response to social circumstances (social model).

'Unfortunately the system –you know we are geared—we're a medical model aren't we? And mmm I think that's difficult, we do treat people in the medical model that you sort of diagnose, treat and mm you know perhaps we don't offer many other alternatives in the health service.

(Dr Abbey)

The medical model which suggests the need for a diagnosis and treatment often involving medication was associated particularly with the psychiatrist working in adult mental health, and also the GPs. CPNs and social workers who had more day to day contact with service users in the home adopted a more eclectic and pragmatic approach, which sought to integrate the two models.

Again I personally feel that as nurses we're perhaps more the middle of the road and we see the doctors as more of a medical model obviously and then social services obviously come from a totally different perspective and it's how do you get those to meet, how do you get that to work. I think as nurses we do try to encompass all those kind of … I always feel like you've got to look at the big picture and take into consideration you know, all the different aspects really.

(CPN)

So there are different perspectives, but I think that people probably realise that the reality is somewhere in the middle and that both perspectives are valid. When we are an integrated team the challenge is to have an equal consideration of the medical and the social care model of mental illness.

(Social worker)

While the CPN and the social worker suggested that they accepted a hybrid of the social and medical model nevertheless it was clear that other professionals operated with different and opposing models of patient pathology and professional practice. Compare Dr Dawes' approach with that of the psychotherapist.

Sometimes I do try, with sometimes the antidepressants I try and compare it to something very physical and very obvious. Like come in with a chest infection I'm going to give you antibiotics. Come in and I think you're depressed, this is going on, I'm going to give you an antidepressant.

(Dr Dawes)

I prefer to work with my client's definition of the problem. In a way it's the only one that counts because that's the one we're going to respond to, so whatever labels have been stuck on by other people--- I'd say "OK well tell me what's going on in your life, I'm not treating schizophrenia, I'm helping a person."

(Psychotherapist)

The GP and the psychotherapist are working with different models. The GP's medical model presumes that psychiatric disorders constitute discrete 'disease' states resulting from biochemical abnormalities for which medication is an appropriate response. The psychotherapist operates with a model of mental health problems as an expression of adversity for which the remedy is to help service users overcome or adapt to their problems through the re-establishment of stable coping mechanisms and responses. The psychologist worked with a similar model but both spoke of competing models within psychological therapies. The user group worker was critical of the medical model in which mental illness is viewed as a deficiency disease.

I suppose the sorts of things that make me and my colleagues most hot under the collar really, would be this analogy that mental illness is like diabetes.
Once it's diagnosed you're on the insulin for life, you are a diabetic till the day you die and we are seeking to challenge that, or to remonstrate with people and to talk to them about people can become poorly but they can become unpoorly, they can get well, then can move on, you don't have to be depressed all your life ----.

(User group worker)

The consequence of holding different models of mental illness is that professionals deliver different messages to service users. The user group worker was concerned that the chemical deficiency model of mental illness told service users that they had a chronic disease which implies that the illness can be controlled with medication but can not be cured. One of the GPs expressed uncertainty about the issue of recovery in mental illness.

Rehabilitation psychiatry is a bit of a grey area that I'm not totally confident that I understand fully. The concept of rehabilitating somebody after they've had a physical illness ...mmm... is somehow different to a psychiatric illness, which maybe a chronic psychosis, (is) never going to recover, but still gets this label which implies that there's going to be expected improvement.

(Dr Brown)

Dr Brown's thoughts on recovery corroborate the user group worker's viewpoint.

The psychiatrist working in adult services considered that the involvement of many disciplines and different professional perspectives was a positive thing.

> *You know with multiple stakeholders, if they're all of the same opinion, there wouldn't be any point in having them as stakeholders. It's got to be that they're coming at things with a different angle and different position, just as we're coming from our perspective too. But we're not a unified group, we vary, as do general practitioners.*
> (Psychiatrist)

This psychiatrist saw pluralism as healthy and beneficial and makes the point clearly that there is intra-professional variation as well as inter-professional difference in medical practice variation. Nevertheless, the difference between models has important consequences for the messages delivered to patients not only about the nature of their illness but also about suitable treatment options and the possibility of recovery.

Multi-professional involvement and information exchange

Despite these acknowledgements of different clinical perspectives, few professionals expressed any awareness that they might be delivering a competing message about diagnosis, treatment or recovery from a colleague, or how this might be experienced by a service user. The exception was the social worker who recognised the tension between complete openness with service users so that they know everything that professionals know and the distress such openness could cause.

> *I think fundamentally service users should have all the – should know what the debate is and what all the discussion and what the decision is and what's being discussed. The difficulty on occasions is, is that a social worker and a psychiatrist vehemently disagreed. If you aired that with the service user there, there could be some people that feel quite unsupported or concerned about that. Because it's their (service user) life isn't it. The social and medics might debate something, not on a theoretical level, but might debate something like I don't think we should be doing this, or we shouldn't be doing that and if the person's there, that can be difficult. The counter argument is people should hear what their options are and should be involved.*
> (Social worker)

The co-ordinated care meeting was seen by the CPNs as a means of integrating different perspectives, including those of the service user, and resolving differences by mutual agreement. However as shown in the quote above the social worker considered a frank exchange of ideas could be very uncomfortable for the service user in which they become an object of professional inspection. It was in any case unclear to what extent real decision making went on in that meeting or took place in other settings where the service user was not present as, for example, at team meetings. For those service users who did not know their diagnosis it is difficult to see how they could participate as partners.

Q: How is a meeting handled then, in a situation where there isn't a shared diagnosis?

A: I think---that's a difficult one really--- I'm trying to think of ways of handling. I feel sometimes where that's the issue, that probably things are skirted around. They're not actually fully discussed.

I suppose I am thinking more in terms of where it is somebody—you know, personality disorder. I do feel some of that you're kind of skirting around the issue. You're not actually saying what that person is experiencing. So it feels like you're not kind of being completely--- I don't know.

(CPN)

Although all relevant professionals are meant to attend a care review meeting it was reported to be rare for GPs to attend. Dr Brown made reference to this.

So I sometimes feel that just as the GP, my experience isn't always that important at a complex care programme review for example. Because the specialised services have a more specialised view and I'm not always as up to date with a patient's particular situation as I'd like to be.

(Dr Brown)

Dr Brown felt that his contribution to the meeting was not vital because he lacked specialist knowledge and did not have the fine detail of a service user's circumstances. Yet as we have seen the GPs all thought they were vital in bringing different aspects of the service together and ensuring holistic care.

There were other informal avenues for professional coalitions. These boiled down to whether one professional contacted another directly to join up care or whether the service user acted as a go-between. In the latter case service users may be re routed to another professional to get information or they may be the conduit for interprofessional communication.

> *What tends to happen is someone will ... a client will ask a question that is actually inappropriate for me to answer and then you open up the discussion about who they should refer to with that question and why and that again is about their sort of acceptance of the confusion, so they're just throwing something out and hoping I'll catch the ball, but you know it's not always possible, so then you have to direct them to the person who they ought to be aiming it at and then that sort of clarifies things a little bit for them.*
> (Psychologist)

> *You can have other people undermining what you're doing. So if I go ... if somebody's got regular contact with the CPN, I'd give her (service user) some leaflets (so that) she could then take them to the CPN and she could say "This is what (my psychotherapist) is doing." And then judging from the response I get back (from the CPN via the service user.) (If the CPN says), "Well that's fine, yes great, carry on with that, you do that, that's fine, I'll just check your medication." or like "That sounds terrible, what on earth are you doing?" Then we'll know whether there's someone who's going to be working against me or not. Because you know everyone is guided by philosophies and they're not always compatible.*
> (Psychotherapist)

If a service user acts as an intermediary then professional boundaries are maintained. It helps one professional to avoid encroaching on another professional's territory and reduces the risk of interprofessional tension. It is convenient for the professional but makes more work for the patient. The psychotherapist felt it was good for service users' recovery to undertake this task as that way it reduced dependency on him. The latter view was held even though he recognised that it can be very hard for service users to challenge professionals. In contrast one GP described a patient as taking on the role of unofficial go-between herself. This GP encouraged patients to come back even if they had been referred on to the psychiatrist.

> *I've got one patient who always comes back the week after she's been to see the psychiatrist, just to tell me what's been going on, so I know what's going on. That tends*

to be the older patients that do that, they come back and want to let you know what's happening in that way.

Q: Are you happy with that, or do you think you'd rather they didn't because you'd get a letter from the psychiatrist anyway?

A: No, I quite like it I think.(GP D)

There is a contrast between a professional delegating a role to the patient that they may feel unable to fulfil and a professional creating a relationship with a patient such that they choose to take on the role. It can also provide a pretext for contact with a doctor which consolidates a relationship in a situation where a patient might need grounds or encouragement for consulting.

Patient choice - professional views and information

Most respondents accepted that service users have a right to be involved in decisions about treatment and to be given information to help them do so. This view was held with a varying degree of commitment. Sometimes this was expressed more as a right of service users to refuse treatment rather than shared decision making. One of the CPNs accepted that service users have *'got choice at the end of the day,* ' She described a case of a service user who had chosen to reject depot injections even though she felt that the drug ' *suited him very well in terms of his mental health.'*

Q: How easy is it to work with patients, such as the young man you described there, when you have a clear feeling about what the solution should be and they actually reject that?

A: It's frustrating. It's really disheartening sometimes because you see how unwell that person can get you know. How much better they can be if they'd just kind of stick to the treatment plan.

(CPN)

This does not sound like shared decision making but rather a professional very reluctantly having to accept that they cannot make a service user have treatment that they do not want. In these circumstances some respondents introduced a question of patient competency in discussing service users' capacity to make decisions.

Sometimes it's difficult to get concepts across ...mmm... because the patient doesn't have enough insight, the patient does not have enough education to understand the words that you used, or enough experience of mental health themselves to understand

how ...mmm.. how they fit into a diagnosis or a treatment regime. I don't often feel that it's difficult, I can usually find some way of relating to a patient.
(Dr Brown)

When he's well I would say that there's more insight, he recognises you know that he's not been so well at times and kind of needs this input. When he's not so well he can become a little bit argumentative at times, you know it's difficult because often he might say you know, "You've said all this to me before."
(CPN)

Another respondent felt that when acutely unwell patients may not be able to make choices or even want to do so.

Sometimes they're too ill to be able to make an important decision and you have to tell them I think. I think we do have to tell people what to do sometimes.
(Psychiatrist)

In contrast, respondents working outside the clinical sphere and who employed a social model of mental health were more likely to talk in terms of patient competency being the norm. They recognised that even at times of extreme distress service users appreciated and responded to explanations about what was happening to them, and being treated as normally as possible.

And it's the exception that somebody doesn't have the capacity to understand and doesn't have insight, because I think even people ... and I know that people, when the social workers have the function under the mental health act, of making applications when people go in, so I know some very unwell people that have been acutely psychotic and have had to be taken into hospital against their will. ie. I suppose in a sense we're saying there that they don't have the capacity to act in their best judgement, --, but I know that they've still got capacity to understand certain aspects of what's happening, because we know from what people will say to us afterwards, some people will say "You were actually quite nice to me when you did that." Or say something else, people are not entirely unaware.
(Social Worker)

This echoes the police officer's experience of being thanked for his kindness by a man distressed enough to be attempting suicide.

In order to make choices service users need a clear understanding of available services and therapies. The myriad of services that cut across health, social services, the independent and voluntary sector, primary and secondary care, and are organised differently depending on whether a person is a child/adolescent or adult or older person is very confusing. The section on roles and relationships gave a taster of this. This confusion was recognised by several respondents.

> *... so obviously there's a lot of confusion around, understandably because they haven't been told. But I suppose it's then not knowing what questions to ask really.* (Psychologist)

A certain level of understanding was needed in order for service users to know what questions to ask their doctors and other health care workers. In primary care the social worker hoped that integrated care would improve the service user experience. Other professionals appeared resigned to the way things were even though they recognised that service users might find it difficult to negotiate their way around the system and exercise choice. They were also resigned to system shortcomings, such as lack of contact with other professionals, poor exchange of information, and confused communication within the system. Clinical professionals individually dealt with the cases that were referred to them and then moved them on/out/back but seemingly often with no real feel for what they were achieving in the process. They accepted that this was all right partly because of the assumption that psychiatric patients lack insight (as an ongoing attribute) and have limited scope for getting better and partly because the system is designed around professional assessment of service users' needs, and evaluation of the therapeutic gain from service input. Each professional service does what it can, in terms of plying its trade, and then discharges the patient, or moves him on elsewhere.

Where professionals provided information at the level of individual treatments it was mainly verbal with two exceptions. The psychologist gave patients a leaflet about the psychology services. This included an explanation of the difference between a psychiatrist and a psychologist. In response to requests for information from service users the user group worker would photocopy pages from the BNF and a BMA manual on medicines This respondent reported that GPs had reacted positively when service users introduced the photocopied material into the consultation to back up their concerns or queries about medicines. She believed that the knowledge that the patient had user group backing was a factor in the positive response, as was the credibility conveyed by the logo of the BMA or BNF. Service users who merely presented

their own verbal account of information they had obtained from independent sources tended to find their knowledge was not taken seriously.

> *It's rather depressing really that one has to … I wouldn't say resort to subterfuge, only it isn't subterfuge, but a doctor won't just listen to a patient and accept what they say, but you have to kind of prove it through some third party in a way that's acceptable to a doctor.*
> (User group worker)

The user group was using high profile information sources to provide complex information for patients. In contrast, one of the psychiatrists thought that service users did not want too much or too difficult information about their medicines.

> *I think try and adapt that level of information to something that's actually worked, that the person is going to find useful and workable with. Then I suppose I would do a bit of editorial control over that, because I think it would be very difficult to give everybody everything really. I think in many ways that's a bit of a fudge anyway, because you just … a bit like you said earlier you're just throwing data at them, aren't you, without really sort of helping them how to refine it and find out what's important. And if most people, a bit like me, it's really the bottom line you're interested in and you know, you want it packaged, perhaps in an oversimplified way, but if you look at the newspapers that seems to be what most people want.*
> (Psychiatrist)

The purpose of information related in the case of the psychiatrist to a diffuse idea that it was a good thing for service users to know what they were taking. The user group was concerned to help service users to get their doctors to take the experience of side effects seriously.

When thinking about patient choice professionals were not necessarily referring to choosing one type of treatment over a different type, or even whether to accept treatment at all, but rather to choice within a type of treatment. This related particularly to medication. While there was some acceptance of patients' preference for one type of medicine over another rejection of medicine per se was often seen as an indicator of someone becoming ill rather than exercising choice. CPNs saw the education of service users and carers about mental illness and treatment as an important part of their role. While they were trained in delivering some psychological therapies

such as cognitive behaviour therapy this was as an adjunct to medication. They saw medication as crucial in effecting recovery.

Patient choice - organisational barriers

The ability to exercise choice was also affected by barriers thrown up by organisations delivering services. The long waiting list for secondary care psychologists deterred the GPs from using the service and raised the threshold of referral. A knock on effect was to reduce the interaction between psychologists and other professionals. The psychologist described how she felt somewhat marginalised from the rest of the professional team

> *Well I feel more part of the psychology team here, so I'm sort of part of mental health speciality, within psychological services far more than I am a member of the mental health resource team.*
> (Psychologist)

Another barrier was access to alternative therapies. This was not simply about the availability of services but funding them.

> *For something like yoga, Indian head massage, aromatherapy those could be purchased under direct payments. (A social services scheme to give money to a client to buy in the services they need.) But there was a debate about whether some of those needs are health needs, or social service needs and it dates back to a similar sort of thing about, you know, is a bath a health bath or a social bath, which drives me completely bonkers really. It doesn't fit in with our strategic vision for mental health services which is meant to be saying that we shouldn't be prescribing certain needs to either health or social services. We should be flexible in our approach.*
> (Social worker)

Pooled budgets could change the picture so that, for example, the cost of the alternative therapy could be offset against the savings from not prescribing a medication. As the social worker pointed out this presumes that health professionals working within an evidence based model of care would find that acceptable and also that service users themselves are allowed to define what they find helpful to the process of recovery in their own terms.

Discussion

The accounts of our respondents have illustrated the wide range of different agencies and staff involved in providing care for users of mental health services. Multi-disciplinary teams can include GPs, social workers, counsellors, community psychiatric nurses, home support and crisis team workers, occupational therapists, physiotherapists, health visitors, dieticians, psychologists and psychiatrists. Patients living in the community may also be referred to a range of outpatient clinics and support services, such as anxiety management, assertiveness training, or group therapy. In the case of mental health service users who experience physical health problems, the list of professionals and agencies involved in providing care is further extended. In addition, people with enduring and complex health needs require support with many other aspects of their lives, to do with housing, income and employment, which require them to contend with a further set of complicated and bureaucratic services. As is evident from Table 4, also, respondents were also making use of a very wide range of resources provided by the voluntary and patient support organisations.

The English National Service Framework for Mental Health (1999) states that people with mental health problems can expect continuity of care from integrated services provided by well coordinated staff and agencies. These services should be patient centred and delivered in partnership with patients. These commitments, and the principle of involving well informed users in the planning and evaluation of care, are reinforced in *The Journey to Recovery, published in 2001* (Department of Health 2001c). The Care Programme Approach (CPA) has been in operation since 1991 to provide a framework of integrated care to identify total needs and coordinate input from multiple staff and agencies (a 'seamless service' (Department of Health 1997)). This initiative was a response to recognised problems with service integration, regional inconsistencies and variation, the burden of bureaucracy and difficulties in realising the goal of orienting health care directly on the needs of users. The basic principle applies to all mental health service users, including those who require only single agency or short term support (Department of Health 1999b).

This statement of ideal practice is very far from the experiences described by our respondents. Their accounts are supported by other reports and study findings of care and teamworking in mental health (Corry, Hogman, & Sandamas 2002;Hill 2003;Jones 2002;Kilian, Lindenbach, Lobig, Uhle, Petscheleit, & Angermayer 2003;Kmietowicz 2004;Letendre 1997;Quirk & Lelliott 2001;Rose 2001;Rose 2003;Rutter et al. 2004;Sharkey 2002;Shepherd & Murray 1995;Smith 2002;Stark, Stronach, & Warne 2002). Experience of care continues to be often unsystematic and

fragmented, and delivered to patients adopting a traditionally deferential role in relation to consultation with professionals and service provision. Patients are not sufficiently informed about treatment or offered choices which would enable them to be meaningfully involved in planning and evaluating their care. Far too often access to professional input and other significant resources – in both formal and voluntary sectors – comes about through chance rather than coordinated planning. We were struck by the extent to which respondents were powerless to intervene in the management of their care, being subject to, and usually compliant with, professional disposal taken on the basis of individual, or sometimes collective ('multidisciplinary') judgements of which they had neither cognizance or involvement.

As with most of our own respondents, Rose reported that very few service users were aware of the CPA or involved in the coordination of their care (Rose 2003;Rose 2001). The CPA is central to current policy for the delivery of mental health services (Department of Health 1999a;Department of Health 1999b). However, despite the rhetoric of 'partnership' and 'patient choice', Rose concluded that often it impacted only at the organisational level, in terms of professional liaison and integration. Usually, in fact, direct involvement with users was bypassed. As a result users continued to be excluded from the system that is ostensibly set up to serve them. In a large survey of multidisciplinary working in mental health services carried out for the ENB, Stark et al found further evidence that the rhetoric of 'team working' and 'patient centred' medical practice had not been converted into practice. As in our own study, the professional hierarchy remained largely intact, and headed by clinicians and doctors. They concluded that the provision of care was still service rather than user led, and that a high level of 'user anomie and alienation' remained (Stark, Stronach, & Warne 2002). While the idea of professional specialism and integrated teams may be attractive from the vantage point of the policy maker and health worker, it is not yet clear that it necessarily confers benefits on the patient, or improves his experience of care (Launer 2002;Stark, Stronach, & Warne 2002).

It is evident that there has been depressingly little change in the quality or organisation of mental health services since the pioneering survey of users' views reported by Rogers et al, in 1993 (Rogers, Pilgrim, & Lacey 1993). Many of their findings were echoed by our respondents in the complexity study. Users experienced problems with medication, including lack of effectiveness and side effects, and were frequently frustrated by poor communication with staff and a lack of information or understanding of treatment. This was dominated by medication, with little choice or awareness of alternatives. Many people did not find the experience of hospitalisation or contact with their psychiatrists therapeutic: some considered these to be positively harmful. Rogers et al observe that

Whilst the original distress of patients may culminate, however it is treated, in prolonged disability, currently there are strong grounds to consider that some of the interventions of professionals (however well meaning) cause physical harm to patients, undermine their esteem and disable them from returning to a valued position in society. It is for this reason that users often talk of 'surviving' psychiatry, or of being 'survivors' rather than 'patients'.

(Rogers et al, 1993:172)

Lack of change persists because the system continues to be focused on the interests of professionals rather than patients. Professionals referred to changes in their roles as a result of new policy initiatives. Integrated care was introduced into NHS policy in order to facilitate joint working between health and social services. Under integrated care local health and social services can merge. The role of social workers and CPNs becomes blurred as they operate from the same base where either one may be the first point of contact for a patient referred to the community mental health team. Eventually pooled budgets and a single management structure will be brought into being (Cameron & Lart 2003).

Integrated care was only in the early stages of introduction as the fieldwork was being carried out. Not all the professionals that we interviewed and none of the service users made reference to it. Those who did, expressed support for its ideals, but also doubts as whether these would be achieved in practice. One problem is that integrated care does not apply to the mental health care of adults after the age of 65. Other uncertainties related to whether psychologists would be incorporated into integrated care, the differing ideologies of social workers and CPNs, and that integration may simply result in a further consolidation of the professional hierarchy, and the continued domination of the biomedical perspective on mental illness. One of the social workers was concerned that integrated care could work to the disadvantage of patients to the extent that it consolidated coalitions between professionals which patients would find even harder to resist. The result could be that the outcome is a more fragmented service. Stark et al found that far from eroding them, multidisciplinary team working produced a clearer demarcation of professional roles. Concern about transgressing into other workers' territories caused a retraction from the designated boundaries , causing gaps through which service users could slip, where no member of the team had assumed responsibility for a particular aspect of care (Stark, Stronach, & Warne 2002).

The advent of supplementary prescribing will modify the role of the CPN. Both CPN respondents were interested in undertaking this work and saw an advantage to service users in being able to

alter doses without having to wait for sanction from a psychiatrist. One of the CPNs also saw a possible downside in that it could affect the relationship with a service user where medication became a contentious issue and the CPN could no longer distance herself from prescribing decisions. The new GP contract has altered the role of doctors. It abolished individual lists so that patients could be seen by any doctor in the practice thus thwarting continuity of care. The study practice had responded to this by bringing in their own arrangements to try and ensure that patients with mental health problems see the same GP where possible. The new contract also sets targets for opportunistic screening during consultations. Taking time in the consultations to screen for physical health problems reduces the time available for talking about patient concerns.

Services continue to be provider rather than user led, with needs, interventions and health outcomes predominantly defined and evaluated by professionals rather than users. In effect, patients are offered the resources that health care workers have to provide, and which derive from the working practices and explanatory models underpinning professional education and culture. This is largely independent of what patients actually want, or feel they would benefit from. GPs in both the complexity and depression studies provided a telling illustration of this. They acknowledged that many of the problems – and solutions – experienced by mental health service users were social and economic, rather than clinical, in nature. Nevertheless, they continued to operate within the biomedical model of diagnosis and treatment – and were comfortable about doing so – because this was what they were trained to do, and what defined their professional comfort zone. In consequence, many issues of concern to patients remained unaddressed and potential sources of help were not identified in general practice consultations.

The perpetuation of professional dominance is oiled by patients' lack of knowledge of how the system works, and the options that are available. Patients cannot exercise choice if they remain unaware of the options available to them. Deference to professional expertise is fuelled by the vulnerability of sickness and the dependency of ignorance. Mental health service users are the subject of conversations held by a multiplicity of professionals, from which they are largely excluded. In an open society it is extraordinary that, as described by one of our respondents, a patient should have to consult her GP for feedback about what her psychiatrist had written about her, and to have to glean what she could from sneaking a look at the letter showing on the GP's computer screen, rather than have access to this directly. It is also unacceptable that in a supposedly patient centred age, she should feel unable to ask her GP directly for a copy of the letter, even though she would like to have one.

Focus group respondents in the MIP study described their frustration when staff constructed their medical record on the basis of inaccurate assumptions and judgements which they were powerless to correct. This was particularly galling when staff presumed to know more about a patient's state of mind, and the nature and cause of their problems than the patient herself. Nothing more effectively disenfranchises the patient than to be denied access to the record of information that others compile about him, and to be excluded from discussing, correcting and responding to this. Under the terms of the Access to Health Records Act (1990), all patients have theoretical access to their health records. In practice, few patients are aware of their rights of access, or have implemented these (Rose 2001). Since April 2004 patients should be sent, or at least offered, all copies of letters about them written by clinicians (http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/CopyingLettersToPatients/fs/en). Despite the retention of clauses restricting access on grounds of third party confidentiality, or risk of 'harm', this initiative is greatly to be welcomed. It is potentially an important lever for forging real change in relationships between patients and health professionals, and bringing about greater transparency in health care service and provision. The copying of letters to patients is hopefully a stage in realising the goal of providing patients with access to, and management of, their own electronic health record. In the meantime, investigating the effects of this initiative is an important area for research.

We began the complexity study with a focus on patients' information needs about treatment and medicines in particular. Dissatisfaction with information about these has been a recurring theme throughout the literature (Campbell, Cobb, & Darton 1998;Cobb, Darton, & Kiran 2001;Corry, Hogman, & Sandamas 2002;Pollock, Grime, Baker, & Mantala 2004; Rose 2001;Sainsbury Centre for Mental Health 1998). Respondents in the complexity study had concerns about medicines information but overall, this was not one of the most salient issues for them. Other aspects of care, such as relationships with staff, or access to services, tended to be more pressing issues. Medicines had an enormous impact on their quality of life, and frequently caused a great deal of trouble (NSF 2000;Rose 2001). However, many people declared themselves more or less content to trust to professional expertise – and often experimentation – in the matter of which drugs should be prescribed. Respondents also understood that the variability of individual responses made it difficult for doctors to tailor drugs precisely, and that a certain amount of trial and error was to be expected in the course of finding the best treatment. Where patients felt unable to make judgements about highly specialised matters the delegation of responsibility for treatment could be a convenient and positive decision, freeing up time and attention for other things. In accepting their initial treatment decisions, respondents nevertheless hoped that doctors would be

responsive to feedback about problems or side effects and willing to change the prescription accordingly. This was not always the case.

More than direct intervention in treatment or prescribing decisions, respondents sought to establish *good relationships* with health professionals who understood their problems and acknowledged them as individuals: they wanted to feel able to *trust* their doctors and to feel confident in looking to them for direction during times of weakness and distress. Ideally, they sought to establish relationships which were not only good, in the sense of being supportive and pleasant, but also genuinely therapeutic, in adding directly to the individual's development of insight and sense of recovery (Kai & Crossland 2001). Many respondents reported difficulties in establishing, or retaining such relationships (Letendre 1997;Rogers, Pilgrim, & Lacey 1993; Sainsbury Centre for Mental Health 1998). Good relationships with particular individuals were valued, but could not mitigate against the intransigence and insensitivity of the wider system. A striking feature of respondents' accounts was the sense of powerlessness and inability to influence the services or process of care that were meted out to them by professionals (Goodwin et al. 1999;Hill 2003). There was very little indication of CPA procedures being in place, far less effective (Rose 2001;Rose 2003;Stark, Stronach, & Warne 2002). As we have seen, respondents' contacts with agencies and individual staff often seemed to be governed by chance rather than design. Most described having no idea why particular referrals or treatments were being advocated, nor what options or additional therapies might have been available, how long they might have to wait to access a service, their likely duration of contact and what particular therapies or treatments could be expected to achieve. Knowledge and discussion of these basic issues are acknowledged to be critical for adequate patient involvement, exercising choice and meaningful evaluation of services, as well as essential aspects of quality care (Department of Health 1999b;Kelstrup, Lund, Lauritsen, & Bech 1993;Kilian, Lindenbach, Lobig, Uhle, Petscheleit, & Angermayer 2003; NICE 2002a; NICE 2002b;Rose 2001).

Direct payments have been introduced for the purchase of treatments and services, including options only available outside the NHS (http://www.dh.gov.uk/PolicyAndGuidance/PatientChoice/Choice/fs/en). In principle this is a good idea, intended to facilitate choice and autonomy for service users. In practice, both of the two respondents who mentioned this (one professional and one user) had found it to be cumbersome, restrictive and bureaucratic. In effect, it seemed that the freedom of users to choose how to spend their payments was limited by official definitions and criteria of eligibility. For example, it was reported that if a user wanted to buy a complementary therapy the local authority would question whether this should be a local authority expense. If it passed to the

health authority the evidence base of the therapy would be challenged. Frank had experienced the difficulty of keeping on the right side of the bureaucracy involved in direct payments. For example he had to discover what was defined as a 'legitimate' holiday and what was not and that he could not pay the person who came in to look after his partner to let him have a night out. In practice 'choice' can be so circumscribed the benefit is effectively negated.

Respondents' accounts indicated that it was not so much information about specific medicines but knowledge about available services, resources and entitlements and also the *process* of care that was critical in determining whether they could be involved in their own case management or were effectively excluded from this (Rose 2001). The problem is that such involvement goes directly against professional interests and deeply entrenched patterns of enculturation. The idea that patients should contribute not just to the design, but also the evaluation of services, is deeply subversive, and strikes at the heart of professional identity. This has traditionally been based on the monopoly of specialist knowledge and expertise on which the prerogatives and control of medical decision making and clinical judgement are based (Freidson 1970;Freidson 1975). Freidson argues that the effect of too many concessions towards patient participation in decision making will undermine professional status: he will, in effect, cease to *be* a professional (Freidson 1975;Silverman 1987).

A good deal of discussion has taken place about the extent to which the role and status of the doctor has been undermined by trends towards proletarianisation (loss of autonomy) and deprofessionalisation (loss of monopoly of specialist knowledge) (Armstrong 2003;Harrison & Dowsell 2002;Hunter 1994;Kelleher, Gabe, & Williams 1994;Weiss & Fitzpatrick 1997;Williams & Calnan 1996). No doubt there have been trends in both directions, though the extent to which either has yet made substantial inroads into professional roles and status remains unclear, and is certainly not substantial. Despite being challenged by the professionalisation projects of a diverse range of new specialisms within the 'multidisciplinary team' (such as supplementary prescribing), doctors still retain their place at the top of the professional hierarchy. Despite unprecedented public access to specialist medical knowledge there is plenty of evidence that the traditional etiquette of the consultation survives pretty much intact. Few patients feel comfortable appearing to challenge their doctor's expertise by raising discussion of their own expert knowledge in the consultation (Beckman & Frankel 1984;Braddock et al. 1999;Byrne & Long 1976;Cox, Stevenson, Britten, & Dundar 2004;Kettunen, Poskiparta, Liimatainen, Sjogren, & Karhila 2001;Makoul, Arntson, & Schofield 1995;Towle et al. 2003). It appears likely, also, that many patients currently have no wish to do so and, as in the complexity study, are content to collaborate in reproducing the traditional forms of interaction with health professionals that they

have come to expect and so tend to consider appropriate. As we have argued above, the critical factor perpetuating the passive subordination within the health care system is not so much lack of knowledge of the technicalities of treatment, but ignorance of their case: who is involved in making judgements about treatment and other interventions; what decisions have been made, and on what grounds, who is making and sharing the record of information about them, and the implications and consequences that flow from this (Gillespie, Florin, & Gillam 2002;Kilian, Lindenbach, Lobig, Uhle, Petscheleit, & Angermayer 2003;Sang 2004). Achieving transparency and sharing of such information between professionals and patients, so that the patient is effectively included as part of the team, rather than a passive recipient of services over which he has no control, is a prerequisite of concordance.

Enduring resistance to the idea of *patient* expertise, has been a powerful inhibitor of the development of more accountable, responsive and patient centred services (Crawford et al. 2002;Sang 2004;Williams et al. 1999). This is particularly true in the field of mental illness, where professional doubts about patient competence tend to be expressed in terms of assumed 'lack of insight' as an inevitable and persisting characteristic of psychiatric disorder (Crawford & Kessel 1999; Faulkener & Thomas 2002;Harper 1995). It is the business of professionals to deliver care, in terms of what is deemed to be the best interests of patients. However, it is apparent that – however well intentioned – professionals are usually unaware of the extent to which patients may define and evaluate 'benefit' differently from themselves: substantial discrepancies have emerged between the goals and values of lay and professional groups and sub groups (Barker & Buchanan-Smith 2003;Meddings & Perkins 2002;Pollock, Grime, Baker, & Mantala 2004;Rogers, Pilgrim, & Lacey 1993;Rogers, Day, Williams, Randall, Wood, Healy, & Benthall 1998;Rose 2001;Shepherd & Murray 1995;Williams, Cattell, Greenwood, LeFevre, Murray, & Thomas 1999). In particular, it has been noted that patients are often disappointed with the predominantly drug oriented approach to treatment within psychiatry, favouring psychological and other less invasive forms of treatment and intervention (Kilian, Lindenbach, Lobig, Uhle, Petscheleit, & Angermayer 2003;Letendre 1997;Pollock, Grime, Baker, & Mantala 2004;Rose 2001). Patients tend to be oriented towards a social, rather than biochemical, model of pathology, and to be concerned with re-establishing normal occupational and social functioning, rather than elimination of symptoms (Letendre 1997;Pollock, Grime, Baker, & Mantala 2004;Rogers, Pilgrim, & Lacey 1993;Shepherd & Murray 1995). Studies of user perspectives have consistently emphasised the importance of personal relationships and the value of shared experience, self help and peer support as aids to recovery (Barker & Buchanan-Smith 2003; Faulkener & Thomas 2002;Meddings & Perkins 2002;NSF 2000;Pollock, Grime, Baker, & Mantala 2004;Rogers, Pilgrim, & Lacey 1993;Rose 2001;Shepherd & Murray 1995).

They also emphasise the need for help in dealing with practical concerns and problems, such as housing, employment, income and benefits. Similarly, within the present study, respondents described the therapeutic benefits of simple activities such as supportive listening, relaxation or art classes which could be provided by both health and private sectors. The voluntary group drop in centres were a valuable resource in providing a place to go, and hence a means of structuring time, companionship, informal and organised activities, as well giving practical advice and help. Particularly valued features of the voluntary sector are the opportunity they offer for users to contribute help as well as receive it - a role from which they are excluded in the formal health services - and to do this in a social, rather than a clinical, environment (Gartner & Reissman 1977;Rogers & Pilgrim 1993).

It is evident that if they had a free choice in the matter, many users would opt for psychological therapies at least as well as, if not always instead of, medication (Rose 2001). A number of studies in addition to our own, have documented the very negative views of many patients towards psychiatric hospitalisation, and the often difficult relationships they have with psychiatrists. Neither aspect of care was experienced as therapeutic (Goodwin, Holmes, Newnes, & Walthi 1999;Letendre 1997; Rogers, Pilgrim, & Lacey 1993;Sainsbury Centre for Mental Health 1998;Shepherd & Murray 1995). User driven services would result in a radical redistribution of mental health service resources and a major modification of the professional hierarchy and associated roles. There would be a much reduced emphasis on drugs as the dominant modality of treatment, and contraction of the role and influence of psychiatry. Psychological therapies would be greatly extended, along with increased provision of alternative, recreational and occupational therapies. The emphasis would be on maintaining or restoring social and economic function and dealing constructively with personal and social adversity, rather than pathologising the person and medicalising his condition: nothing saps economic and occupational prospects quite as much as a psychiatric diagnosis (Rogers, Pilgrim, & Lacey 1993). The value and expertise of the voluntary sector would be acknowledged and extended. The interventions that patients want are often relatively cheap and simple to provide. Much of the demand for psychological services could be met by training a range of support workers, including CPNs, to provide effective therapies. At present the patient is largely functioning as an intermediary between different professionals and services, and absorbing the inconsistencies between these. Centring the system on the patient in this way should make it simpler, cheaper and more efficient. It would also constitute a radical reorganisation and redistribution of professional expertise and contribute to a substantial demedicalisation of the mental health services, as well as the wider society.

It is not surprising that the user perspective and the role of the voluntary organisations have been largely ignored by health professionals within the mental health services. Perhaps more accurately, they are largely unseen. Their focus and orientation lie largely outside the professional purview. Mental health professionals are trained to assess patients and provide treatment within a biomedical model of psychiatric disorder in which the patient is largely subjugated to the enduring authority of clinical judgement and professional expertise. The idea that patients not only possess a valid but different perspective, but also their own particular expertise, is deeply challenging to established professional interests. It is important to note that there is no suggestion that professionals believe themselves to be acting other than in the interests of the patient. In seeking to resist the patient perspective, however, they capitalise on established positions of professional dominance to extend and maintain their own self interest (Freidson 1970;Gillespie, Florin, & Gillam 2002;Hill 2003;Illich 1977;McNight 1977;Rogers, Pilgrim, & Lacey 1993;Sang 2004;Zola 1975). In 1977, McNight wrote that

> When the capacity to define the problem becomes a professional prerogative, citizens no longer exist. The prerogative removes the citizen as problem-definer, much less the problem-solver. It translates political functions into technical and technological functions. Once the service professional can define remedy and need, a third disabling remedial practice develops. It is the coding of the problem and the solution into languages that are incomprehensible to citizens.
> McNight, 1977:85 – 86

Nearly thirty years later, after decades of academic critique and political rhetoric in favour of patient centred medicine, shared decision making and concordant consultations, we find mental health care is still dominated by professional assessments of needs and benefit. If anything, the expansion of professional specialisation and multi-disciplinary working, alongside a massive expansion in psychotropic medication has intensified the professional dominance of mental health care (Double 2002;Medawar 1997). Professional roles and identities are demarcated by *difference* and the maintenance of a distinctive set of educational and working practices and ideological commitments. It is not surprising that these resist attempts to flatten the professional hierarchy, or blur the boundaries between occupational specialisation through the introduction of integrated care. As Stark et al have reported the operation of multi disciplinary team working has had the effect of rigidifying, rather than blurring, the distinctions between different role specialisms. This has obvious implications for patients' experience of team working and multidisciplinary care, especially where different practitioners may be operating with contrasting,

not to say, incompatible models of pathology and treatment, including different degrees of 'therapeutic optimism' about the prospects and nature of recovery (Shepherd & Murray 1995).

We have noted above that user respondents in the complexity study were placed in the role of intermediary between different professionals, absorbing the differences in professional practice and styles of treatment. Professional respondents expressed different views, not only about the nature of mental illness and its treatment, but also of the appropriateness and value of different occupational input. For example, the psychiatrist viewed GPs as often diagnosing, prescribing and referring inappropriately; the social worker viewed his profession as able to provide more effective patient advocacy than the CPNs. The complexity study reinforced the findings of the MIP research concerning the effects of the professional hierarchy in constraining relationships and communication between individual health workers and service users. For example, one of the GP respondents acknowledged the deference of CPNs to medical authority. A CPN described the difficulties she experienced when a patient had not been made aware of his diagnosis, given that it was the psychiatrist's prerogative to reveal this information. If this had not been divulged, it placed in question the value of the team discussion held at case management meetings, and the scope for patient involvement in this. This kind of constraint effectively sabotages the possibility of concordant consultations, and effectively shows up the nature of the collegiate solidarity and collusion between professional workers and the extent to which it works against patient autonomy.

Several of the professional respondents in the study commented on their awareness of the confusion caused by the complex nature of the health services – for themselves, as well as patients. Ongoing change and innovation were viewed with some trepidation. The GPs were guarded about the likely impact of the GMS contract in changing the nature and continuity of their relationships with patients through the abolition of specific lists. They were also concerned about the ways in which new patterns of remuneration would change their practice and reduce the scope for engaging directly with patients' psychosocial concerns. All the professional respondents who mentioned the subject were guarded in their anticipation of integrated care. A social worker anticipated that it might work to the disadvantage of his own specialism as well as patients, in consolidating the professional hierarchy, and consequently reinforcing the dominance of the biomedical model. The nurses and social workers in particular were aware of the discrepancies between the medical and social models of mental illness, while trying to endorse the idea of a 'bigger picture' that had room for both. Overall, the evidence from our own and other studies indicates that professional specialisation has not so far resulted in users having more choice or involvement in services and care. However, it has arguably contributed to

making the system more complex and difficult to navigate. It has strengthened the grip of professional dominance and the biomedical model at the expense of the social, which has been established over several decades as the more attractive and valued option for services users and carers.

Engineering a significant shift in practice towards a genuinely patient centred medicine which opens up the possibility of concordant consultations will require a major structural revision in health service organisation and professional practice. It is not enough to keep providing patients with information about medicines, and encouragement to seek advice from professionals, or to bombard health care workers with continuing education programmes and encouragement to adopt a concordant approach to practice. We have argued here, on the basis of our own findings and those of other studies, that significant change will only come about when mental health service users have access to the means to reorient the system from being provider led to user driven (Hill 2003;Rogers, Pilgrim, & Lacey 1993; Rose 2001;Rose 2003;Shepherd & Murray 1995;Williams, Cattell, Greenwood, LeFevre, Murray, & Thomas 1999). A primary lever for such change is transparency in information provision and enabling users to have full access to their own health record as a prerequisite for genuine participation in their own health management and the capacity to enter into a (concordant) dialogue about how individual needs may be identified and met.

Conclusion

Concordance has developed from a concern with high rates of non-compliance in medicine-taking among patients. Nevertheless, from the outset concordance was viewed as an integral aspect of care, rather than a discrete or narrow component (RPSGB 1997). Our exploration of concordance through the series of research projects we have undertaken throughout the Fellowship has reinforced this point. Each of these has contributed to empirical knowledge as well as having implications for health service policy and practice. As with all qualitative studies the concordance research is specific to the relatively limited number of respondents involved. However, the findings draw strength from the range and depth of perspectives incorporated from a wide range of professional as well as lay respondents and their consistency, not just between the different stages of the fellowship research, but also in relation to many other published studies. It is from the situation of findings in relation to existing research, rather than the capacity to generalise results from a representative sample, that qualitative studies derive much of their value.

The depression study started from an interest in how doctors and patients communicate about depression and its treatment in general practice consultations. Depression was felt to be a particularly appropriate area for concordance research because it is constituted primarily through communication and interpretation rather than physiological indicators or signs. The research revealed a considerable distance between the lay and professional perspectives on depression and particularly its treatment with antidepressants. The doctors were unaware of the extent to which these proved problematic for patients over the long term, rather than at the point of prescribing. Patients were concerned about psychological dependence, rather than physiological addiction, as their doctors tended to suppose. For many respondents, the decision to continue antidepressant medication was an ongoing, iterative process, rather than an event occurring at a discrete point in time. Particular issues for patients concerned their continuing need for antidepressants, and a sense of uncertainty about their ability to cope unaided with the experience of future difficulties. This, in turn, had negative implications for their conceptions of self and personal integrity. Patients' evaluation of treatment was carried out with reference to their knowledge of prevailing norms and stereotypes about depression and antidepressants and reassessed in relation to new knowledge and ongoing experience. The research sheds light on the personal significance of taking antidepressants, but also flags up wider issues around the social significance of medicines and their acceptance as a form of personal technology.

In the Medication Information Project, we moved to the secondary health sector to investigate the processes of information provision and exchange between staff and inpatients on acute psychiatric wards. The research involved a wide range of different stakeholder views. Once again we discovered a heterogeneity of explanatory models, not just between service users and professionals, but also within different professional groupings. The research also pointed to the importance of organisational factors, as well as cultural, in determining patients' access to information about medicines and from whom they were likely to receive this. For example, junior staff deferred to their superiors' policy on divulging information to patients. In addition, staff were wary of conveying inconsistent or conflicting information to patients. As they had no way of knowing what had already been told, they were inclined to avoid discussion. Thus the nature of the communication in one consultation between a patient and professional could be constrained by external factors including the norms of interprofessional working and relationships. This widened the focus from a consideration of concordance as an accomplishment of dyadic relations between individual patients and professionals, to being a property of wider communicative networks and systems. The operation of a professional hierarchy pointed to organisational complexity as in important feature blocking concordance in consultations involving patients and hospital staff.

In the last phase of our research, we widened the empirical and analytical scope of concordance in an investigation of how mental health service users' experience complexity in health care, and how this compares with professional accounts of inter-agency working. Our findings are congruent with a long line of research which finds the traditional role of passive, deferential patient continues to be the norm. Medication had a tremendous impact on respondents' quality of life. However, they had very little influence on decisions about treatment or opportunity to discuss their concerns about medication. As in the MIP study, non-prescribing professionals were reluctant to engage directly in conversations about medicines. In general, respondents deferred to medical expertise regarding the management of their medication. They rarely described concordant encounters, although clearly were disappointed in the impersonal, brief and transient relationships that often characterised their contacts with a range of different health professionals. Although medicines information was a concern for our respondents, it was not a major issue. Frustration over unsatisfactory relationships with health workers and lack of knowledge about the process of care were considered to be greater problems. Patients were largely on the receiving end of professional assessments of their needs and benefits. As long as this is the case, they cannot effectively be involved as partners in their care. Their dependency is reinforced by their lack of access to information concerning judgements and decisions which professionals make about their care, and their exclusion from the discussion of their case which goes on between professionals. We identified greater transparency of information about the *process* of care as the major issue in meeting the information needs of the respondents in this study. It is also a prerequisite for the realisation of concordant consultations. The recent initiative to send patients copies of all letters and other information exchanged between health professionals is greatly to be welcomed, and potentially an important lever in realising a real increase in professional accountability and patient participation in care. It should contribute to greater involvement of patients in the assessment of their individual needs, and evaluating the benefits and outcomes of care.

Over the five years that we have held the Fellowship, concordance has acquired a profile within the spheres of policy and academic research. Indeed, the concept has developed to the point of attracting a critique (Heath 2003). A major problem has been the misunderstanding and misapplication of the term as a pseudonym or euphemism for 'compliance'. Heath is critical of concordance being used by professionals (as is widely the case) to rebrand compliance, perhaps to engineer a more 'informed' compliance. This difficulty persists because of a professional mind set which finds it very difficult to accept the reality of patient expertise and choice. This, in turn, results from traditional organisational structures which delimit the contact patients have with

professionals and a deeply entrenched etiquette about how such contact should be conducted. Prevailing conventions of the consultation make it difficult for patients to express their concerns and engage in decisions about their care. Consequently, it is difficult for professionals to develop an awareness of patient perspectives and responses to treatment. Our research has made a contribution to an understanding of the different perspectives of mental health service users and different professional groups. It highlights the negative consequences which follow from the lack of mutual awareness and shared understanding of explanatory models underpinning lay experience and the professional response to illness (Kleinman 1980;Tuckett et al. 1985). Openness to such different perspectives – among diverse members of the multidisciplinary health care team, as well as between patients and professionals – is a prerequisite for concordance.

An important objection to the value and viability of the concordance concept has focused on the extent to which patients are excluded from decision making by the inevitability of professional framing of the choices available to them and the presentation of risk (Elwyn et al. 1999a;Elwyn et al. 1999b;Elwyn, Edwards, & Kinnersley 1999;Elwyn et al. 2001). All stages of our research have revealed the extent to which mental health service users felt constrained by lack of therapeutic choice, and their ignorance of available options. Greater knowledge of these, and, as we have argued, transparency about the processes of care through the sharing of clinical records with patients, would strengthen patient's capacity to resist the effects of professional framing, and establish their entitlement to treatments and interventions which accord with personal values and health outcome goals.

The difficulty in meeting patient information needs is intensified by the great variation in individual preferences for knowledge and participation in making decisions about treatment. Patients' desire for information and involvement may vary within single illness episodes, and also according to the nature and severity of disease. There is increasing evidence that patients may value information, and in particular wish to be fully informed about the full range treatment options, but prefer to delegate responsibility for decision making to their doctors. Desire for information may be common, but the desire for direct involvement in decision making is variable. Edwards et al discuss the ideas of 'appropriate involvement' and 'enough information' which emerged from focus group discussions with patients (Edwards, Elwyn, Smith, Williams, & Thornton 2001). Acceptance of treatment decisions, and the feeling that the best choice had been made, was important to their respondents. However, the sense or *feeling* of having been involved in such decisions was held to be more important than actually having done so. The critical factor here is the quality of the relationship patients manage to establish with their doctors, and that they feel they have been treated with courtesy and respect.

The concern with shared decision making, extending patient choice, and realising concordance has been stimulated by many factors. These include a desire to increase professional accountability, improve the quality and experience of patient care, and realise the intrinsically valued goals of patient autonomy and choice. A focus on the quality and accessibility of patient information has been a particular preoccupation of such initiatives. There is no doubt that unprecedented public access to specialist information is both a response and a spur to lay interest and demand. However, the research findings concerning patient preferences for information and involvement in health care are varied and, to some extent, equivocal. It is becoming clear, however, that information gathering is not necessarily a reflex response to the experience of illness or involvement in health care. Information may be reassuring, adaptive and empowering. Equally, it may be unwelcome, threatening, or irrelevant. We found this in our complexity research, where some service users did not feel competent to participate in medication choices, or had no desire to do so. They preferred to delegate the responsibility for such decisions to their doctors. Monitoring and feeding back the effects of medication, on the basis of their lived experience of taking this, was another matter, however. Many respondents described the difficulty they experienced in making themselves heard and frustration caused by the insensitivity of their doctors to their problems with medication.

Patient centred medicine, shared decision making and concordance, are relatively recent policy developments. It is to be expected that it will take time for them to be taken up and applied – by patients and professionals – in medical consultations as new skills are acquired (Say & Thomson 2003;Williams, Cattell, Greenwood, LeFevre, Murray, & Thomas 1999). Mental health care may lag behind other specialities (Lammers & Happell 2003). Participants may feel more secure in conforming to roles that they feel comfortable with and have come to expect. However, it is also pertinent to ask about the salience of the concept of concordance for patients, and the extent to which, like 'shared decision making' and 'the expert patient' these are professional, rather than lay, constructions. A bewildering array of research evidence has produced complex and varied results about the patient response to greater information and involvement in illness management, and the desire to share decisions with their doctors. Findings about the effects of patient participation on 'satisfaction' with services and health care outcomes are also varied. However, if we review the evidence in relation to the question what do patients themselves say about what they most want from health care, the answer is quite clear. Over and over again, it emerges that what patients search for in the quest for therapy are good relationships with professionals, reassurance, the feeling that their problems have been understood and acknowledged, that they have been dealt with and valued as a person rather than a case

(Barker, Lavender, & Morant 2001;Bissell, May, & Noyce 2004;Burkitt Wright, Holcombe, & Salmon 2004;Coyle 1999;Edwards, Elwyn, Smith, Williams, & Thornton 2001;Gask et al. 2003;Goodwin, Holmes, Newnes, & Walthi 1999;Kai & Crossland 2001;Kelstrup, Lund, Lauritsen, & Bech 1993;Kleinman 1988;Letendre 1997;Mechanic & Meyer 2000;Rose 2001;Shapiro, Mosqueda, & Botros 2003;Shepherd & Murray 1995;Werner, Widding Isaksen, & Malterud 2004;Williams, Cattell, Greenwood, LeFevre, Murray, & Thomas 1999).

In addition, there is evidence – including the results of the complexity study – that patients may prefer to trust their doctors, and delegate decisions about treatment: The responsibility of decision making may be considered onerous and burdensome. Lupton (Lupton 1997;Lupton 2003) has commented on the tension between trust and autonomy for modern patients, caught between the desire to accept the dependency of the traditional patient role, and the drive to assert themselves in the role of independent 'consumer' of health services. She suggests that the current preoccupation with choice and self-determination may do a disservice to patients in undermining the trust and faith in professional expertise which patients have traditionally valued in medical encounters. When people feel weak, distressed and vulnerable, they may actively *want* to be taken care of. Other concerns have been voiced about the extent to which extending patient involvement and responsibility in illness management may provide a convenient foil for professional abrogation of responsibility (Dowrick 1999;Salmon & Hall 2003;Salmon & Hall 2004).

The increase in personal responsibility for matters relating to health and illness is clearly expressed in the enthusiastic espousal of 'self management' programmes, and a more general commitment to the 'expert patient' (Department of Health 2001b;Donaldson 2003;Lorig et al. 1994;Lorig 2000). Ziebland et al (Ziebland et al. 2004) have identified a tendency for the acquisition of expert knowledge to be developing as a marker of patient 'competence'. It remains an empirical question – and an important topic for investigation – to what extent patients are comfortable with the extended responsibilities of the 'expert patient' role. However, increasing the burden of accountability for their health to patients without also achieving greater choice and responsiveness in health care would be particularly invidious.

The prize offered by concordance is that patients and professionals engage in more open and productive consultations. Patients will be committed to treatment options they have played a part in selecting, and so the prescribing of inappropriate and wasted drugs and unwanted treatment should be substantially reduced. A great advantage of concordance over models of shared decision making is that it accommodates a wide range of patient preferences and emphasises the diversity of negotiated outcomes. It also acknowledges the reality of conflict and

dissent between patients and professionals, and that it may not be possible to achieve consensus. However, the real goal of concordant encounters is that all parties *exchange* information, and share different perspectives as the basis of an increased understanding. Concordance is not without risks and costs, however. It increases the demands of all participants within a social encounter that is always complex and challenging, and often potentially fraught. An important reason for the intransigent durability of the traditional doctor- centred consultation is that it provides a mechanism for the containment of disagreement and the consequent protection of the ongoing relationship which both patients and professionals are highly motivated to maintain (Ehrich 2003;Strong 1979;Tuckett, Boulton, Olson, & Williams 1985). Concordance invites the exposure of differences and increases the likelihood of conflict and disagreement in the consultation, which may not always or easily be resolved (Dowell, Jones, & Snadden 2002). Patients may value getting information from their doctors as a way of building relationships and extending communication. However, it is apparent, once again, that the relationship between trust and information is problematic and asymmetrical. Neither party is generally yet comfortable with the patient's disclosure of expert information within the consultation. This is often regarded by patients as well as professionals as inappropriate and constituting a challenge to professional competence and authority.

Throughout our research we have been struck by the deference which patients describe in their dealings with professionals and their low sense of entitlement to health care resources. This is despite three decades of research and critique relating to professional dominance within the health care system, and an established policy commitment to the development of truly patient centred medical practice. We find it extraordinary that so little change has occurred in this time. The accounts of our respondents throughout the different stages of our research are echoed by many others throughout an extensive research literature, stretching back to the pioneering work of Tuckett et al, Byrne and Long and Stimson and Webb in the 1970s and 1980s (Byrne & Long 1976;Stimson & Webb 1975;Tuckett, Boulton, Olson, & Williams 1985). Medical consultations are still generally characterised by patient deference and taciturnity, and acceptance of professional judgement about matters of the utmost significance to their health and wellbeing. A sense of vulnerability and concern to avoid antagonising their doctors are critical factors governing patient behaviour, along with the comfort of adhering to established roles and routines. There is very little sign that concordance has made significant inroads into practice. The ideals of concordance may be exemplary, but it is not yet clear to what extent they are resonant with patient goals and concerns, and the desire to avoid rather than engage with conflict in the consultation. One of the great strengths of concordance is its concern with understanding and sharing the detailed perspectives of the patient. The Fellowship research has revealed something of mental health

service users' perspectives about illness and experience of treatment, and the divergence between these and professional views. It has identified the provision of information about treatment options and the processes of care as a prerequisite for increasing patient involvement in decisions about care and moving towards more concordant relationships with professionals. We feel that the next direction for future research is to undertake detailed qualitative studies of the *patient perspective* on concordance and how this relates to what patients most value in health care and their consultations with doctors.

Appendix A

Table 1 Age/sex of patient respondents

Age/sex	Under 20	20 –39	40 – 59	60 plus	Total
Men	0	3	5	1	9
Women	1	2	3	1	7
Total	1	5	8	2	16

Table 2: Duration of patients' mental health problem

Duration of illness (years)	3 <5	5>10	10>20	20+
No of Rs	4	4	3	5

Table 3: Focus group composition

Focus Group	Type of meeting	Number of participants
1 NSUG	Regular drop in meeting at branch HQ	14
2 NSUG	Regular drop in at branch location	11
3 MIND	Regular drop in meeting at branch location	2
4 NSUG	Special interest group convened for research	4 (+ 2 NSUG support worker observers)

Table 4: List of contacts referred to by respondents*

Primary Care GP Counsellor Practice nurse	**Social Services** Social Worker Day Centre Mediation officer

Secondary Care
Psychiatrist
Psychologist
Psychotherapist
Community Psychiatric Nurse
Hospital nurse
Key worker
Care Support worker
Pain Clinic
Rehabilitation Clinic
Sex therapist
Alcohol Advice Centre
	The voluntary sector
	North Staffs User Group
	Rethink
	    • Gardening
	    • Woodwork
	MIND
	Relate
	Richmond Fellowship
	Samaritans
	Citizen's Advice Bureau
	Narcotics Anonymous
	Lymebrook Centre
	American Clubhouse
	Drug Link
	Disability Solutions
	NSPCC
	Request
	Changes
	Alchoholics Anonymous

Mental Health Resource Centre • Men's group • Relaxation therapy • Social skills group • Assertiveness training • Anxiety management • Art therapy • Yoga • Theatre classes	**General/ unspecified/other** Police Local Council Employment scheme IT training Pharmacist Prayer meeting/church Lunch club Job Centre Amateur Dramatic Society Ramblers Association Access course Gym

*This is a list of the organisations and agencies mentioned by respondents in the interviews and focus groups: the actual range of contacts would be greater. It relates only to mental health issues and problems, not physical illnesses, and includes all references to organisations or activities that respondents regarded as having a therapeutic consequence, and/or being beneficial to their recovery.

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