Shared care arrangements for specialist drugs in the UK: the challenges facing GP adherence

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ABSTRACT
Objective To explore the challenges facing GPs’ adherence to shared care arrangements for specialist drugs.

Design A qualitative study using semistructured interviews; data analysed using the ‘framework’ approach aided by QSR N-Vivo 2.0.

Setting Three Primary Care Trusts (PCTs) within one Strategic Health Authority (SHA) in the North West of England.

Participants 47 semistructured interviews were conducted with a range of Practice, PCT and SHA staff and other relevant stakeholders.

Results GPs faced multiple challenges in adhering to shared care arrangements for specialist drugs. Psychiatric patients were given as an example where such arrangements were perceived as particularly difficult to maintain, with patient non-compliance a contributory factor. GP uncertainty and confusion surrounded the sharing of test results between primary and secondary care, and was felt to give rise to test duplication and omission. Of particular concern to GPs was the lack of compliance of practice and hospital colleagues with these arrangements, and the dependence they placed on specialists’ responses to requests for advice.

Conclusion This study provides evidence of the numerous challenges facing GP adherence to shared care arrangements. Such challenges need to be overcome if the issues of test duplication and omission are to be addressed, and GPs’ future acceptance of shared care arrangements encouraged.

INTRODUCTION
In 2007, the Royal College of General Practitioners produced an information sheet detailing the concept of ‘Shared Care’. 1 Shared care has been defined as ‘the joint participation of hospital consultants and general practitioners in the planned delivery of care for patients with a chronic condition, informed by an enhanced information exchange over and above routine discharge and referral letters’. 2 Such integration and regular liaison have long been advocated in UK guidelines for the management of asthma 3 and dementia. 4

Integrated care schemes for chronic conditions such as diabetes have been shown to be as effective as conventional outpatient clinic attendance in clinical and economic terms. 5, 6 Patients found this type of care convenient and possibly cost-saving, 5 and were more likely to select integrated care in the future. 6 In 2008, Cheung et al 7 went further by suggesting that the majority of patients with diabetes receiving routine GP management for their condition did not need to regularly attend a specialist clinic. Nurse-led shared care programmes have also been shown to be effective, with McHugh and colleagues reporting how an educational intervention led to an improvement in patient care for those awaiting coronary artery bypass grafting (CABG). 8

Primary–secondary integration, via shared care, has promoted the prescribing of specialist drugs in the community for the treatment of certain chronic conditions. Specialist medicines have been defined as ‘medicines, usually of high-cost, that are initiated only by a hospital doctor and require complex prescribing and/or therapeutic monitoring arrangements not normally undertaken in general practice’. 9 GPs have been found to be generally dissatisfied with shared care arrangements for prescribing specialist medicines, especially around issues of clinical responsibility associated with prescribing and often monitoring. 9 With enhanced services and practice-based commissioning (PbC) aiding a shift in healthcare from secondary to primary care for some specialist services in the UK, 10 GPs’ ability and willingness to adhere to shared care arrangements has gained prominence. This study explores the challenges faced by GPs attempting to adhere to shared care arrangements for specialist drugs.

METHODS
Study design
This study was a three-stage sequential design. Stage 1 aimed to seek the perspectives of a wide range of practice staff within three Primary Care Trusts (PCTs) in one Strategic Health Authority (SHA) which was chosen for its convenience in the North West of England. Stage 2 sought additional information and further explanation in a similar way (as discussed below) from the pharmaceutical adviser/prescribing lead in each PCT (July to August 2005, n=3) as well as from stakeholders with a vested interest in the primary secondary care interface (Stage 3, October 2005 to January 2006, n=8). These individuals included the local hospital’s chief pharmacist and medical director, and members of interface groups including the SHA Interface Prescribing Group (a group specifically set up to address prescribing issues which occur at the interface), for example.

For Stage 1, 342 letters were distributed to staff in 26 general practices (via their practice managers), inviting them to participate in a face-to-face semi-structured interview on how primary–secondary care interface issues were perceived to have impacted on GP prescribing. Of the 73 staff who responded, 36 were purposively selected to include a GP(s) (n=14) and one or more other staff members per practice (see...
table 1). Ethical approval was obtained, with individual and institutional confidentiality assured.

Qualitative interviews, lasting 25–150 min, were conducted by the first author at a location of the interviewee’s choice during January–July 2005, audiotaped with permission and transcribed verbatim. The topic guide for practice staff was prepared in sections to accommodate participants’ varying degrees of knowledge on the subject area. For Stage 3, separate topic guides were developed for each of the varying groups’ members in line with Local Research Ethics Committee (LREC) recommendations. All topic guides (available on request) were informed by an extensive review of the literature and questions continually refined as understanding emerged. No particular patient groups were enquired about by the interviewer; interviewees raised those groups that concerned them most. This process was iterative; issues raised by participants (Stage 1) were fed into subsequent interviews (Stages 2 and 3) thus providing further knowledge and increased understanding about emerging themes. No new themes emerged during later interviews, indicating that thematic saturation had been achieved.

Analysis
Detailed and repeated reading of transcripts was conducted to identify recurrent themes common to interviewees working in practices (practice managers, doctors, receptionists and nurses). PCT staff and stakeholders’ perspectives were used to provide further understanding on these emerging themes. Main and subthemes were developed as part of the five-stage ‘framework’ approach,11 using constant comparison. Themes were continually refined and applied systematically to the whole dataset using computerised software QSR N-Vivo version 2.0. Consistencies and differences were identified, apparent ‘negative cases’ examined, and evolving explanations further refined and tested. In the quotes presented below, words in parenthesis and ellipses (…) were added by the authors; the former to clarify meaning, the latter to indicate the removal of unrelated text. Participants’ occupations or roles were identified: DR, doctor; PM, practice manager; NU, nurses; AD, administrative staff; PA, pharmaceutical adviser; PL, prescribing lead; ST, stakeholder. An identification code was assigned to all participants to reflect the order of interviews.

RESULTS
Four inter-related themes central to understanding the challenges facing GPs’ adherence to shared care arrangements for specialist drugs emerged: GPs’ ambivalence surrounding the management of psychiatric patients; the sharing of test results; complying with the shared care arrangement; and dependence on specialist advice.

GPs’ ambivalence around the management of psychiatric patients
The patient group most commonly referred to by interviewees was psychiatric patients. Shared care arrangements for these patients were perceived by GPs, PCT staff and stakeholders as being particularly difficult to maintain. Patient non-adherence was reported with therapeutic drug monitoring attendance at GP practices. This was believed to contribute to a deterioration of the patient’s condition and the consequent takeover of their care by the hospital (DR11, box 1). One stakeholder, who reflected on her role as chief pharmacist of the acute mental health trust, felt that psychiatric patients often required more consultation time than other patient groups, and ‘some individual GPs’ did not have a good understanding of mental health issues (ST1, box 1).

Sharing of test results
The sharing of test results was illustrated as problematic, most commonly by discussing lithium and disease-modifying anti-rheumatic drugs (DMARDs). One GP expressed difficulty in altering the lithium dosage without the latest hospital results (DR12, box 2). A colleague who shared his view explained how she was often unaware that such tests had been completed by the hospital and relied solely on the patient to inform her. She felt the hospital’s inability to inform the practice contributed to test duplication (DR11, box 2). Such duplication also occurred in other practices, where the electronic link between the hospital’s and practice’s computer systems was not sufficiently advanced to allow the transfer of lithium results. Although the capabilities of such systems were outside the scope of this study, staff in another practice in a different PCT appeared to only have access to test results which they had requested themselves. One GP regarded their behaviour as appropriate, explaining how she made the assumption that tests had not been conducted if not reliably informed by the hospital (DR15, box 2). Supporting both views, one stakeholder felt the aforementioned technical inabilities, together with the lack of a shared care protocol for lithium, had exacerbated the current situation thus potentially giving rise to both test duplication and omission (ST1, box 2). Practice and PCT staff supported this view: ‘there must be occasions where you’re assuming the other one (hospital) is doing it, and they are assuming you (GP) are doing it, and no one is actually doing it’ (DR12). With patients perceived as ‘falling between primary and secondary care,’ local PCT initiatives (which financially rewarded practices that sought hospital test results) were felt to have brought about ‘pretty good improvements … even with that patient set (psychiatric)’ (PA5). However, GPs appeared reluctant to contact secondary care directly, highlighting the perceived time and effort required: ‘You have got to weigh up in a busy day how much work you want to put into following this up’ (DR29). This lack of results sharing was acknowledged to have possible future implications for secondary care prescribers, with ‘some practices refusing to take on patients who, maybe in the past, they would have been willing to take on’ (PA5).

GP uncertainty and confusion also surrounded the sharing of test results in relation to DMARD monitoring and prescribing. One GP, who had recently completed his training in hospital, expressed doubts about whether secondary care monitoring had
been carried out in accordance with the agreed shared care arrangement and explained how such uncertainty had given rise to some prescribing concerns (DR12, box 2). The importance of accurate monitoring and initial patient stability was illustrated in many quotes, with appreciation shown for any advice and guidance offered (DR15, box 2).

**Box 1 Patient group**

‘It can be difficult because those patients quite often you don’t necessarily see them and if they are quite bad they tend to be just seen at the hospital so trying to keep on top of their monitoring can be quite difficult’ (DR11)

‘We do struggle with our clients… I mean they (psychiatric patients) do take a lot of time up with physical health, complaints and long consultations and I think some GPs who aren’t skilled in mental health obviously would like to send them all back to us but that goes against community care so there is that sort of issue’ (ST1)

**Box 2 Sharing of test results**

‘they (psychiatric patients) often have their levels done I think at the hospital before their appointment but then you don’t get those levels back and then it is hard for you to manage it yourself… say if they have had a relapse or were really suffering and you think … has the lithium worked, you know? … it is hard then to change that without having no real information of the latest tests’ (DR12)

‘And of course, one of the problems is that if they had their blood test done by the hospital it would never come up on our computer system because they would never send us the results… You would only know about it, if say, you called the patient in… we need to check your lithium levels and they said ‘well, I’ve had them done last week at the hospital’… you can end up duplicating things because they never send them over’ (DR11)

‘We can only look at the tests we have generated ourselves so that is where your monitoring of drugs issues comes in and that’s why things get duplicated because if we haven’t done it, and we haven’t had a letter to say that someone else has done it, we can only assume that it has not been done. Yet it might have been done but we don’t know about it’ (DR15)

‘this was a massive issue … We have no shared care protocol. We (acute mental health trust) have loads of different organisations that we liaise with. Everybody does different … even the teams within one patch don’t do it the same way. I mean we need to do a shared care protocol then it will be clear but … the biggest area of dispute I think is who is going to do the monitoring… obviously both sides need access to the results. We need to see the results and there is no way of electronically transferring that information … because the system is not electronic then if there is confusion about who is doing the test then I imagine that some patients have no test and some have two’ (ST1)

‘there are some very toxic drugs used in the rheumatology where they need accurate monitoring in the first few weeks of starting it … basically whoever prescribes it is responsible but when you have got shared care you are not always sure who is doing the tests and you don’t want to duplicate tests either … Sometimes like, they will have them all done up if they have been seen at the outpatient clinic or if they are having their blood tests done regularly but occasionally not … it is not always entirely clear’ (DR12)

‘the rheumatology Specialist Nurse will follow the protocols to the letter and will ask for certain blood tests to be sent to her and she will either phone you or write back to say ‘That’s ok. They can carry on with that medicine’ and that’s great. But then they are other departments where it doesn’t happen like that … you are left in a void and you don’t quite know whether the test is been done elsewhere … things get duplicated’ (DR15)

**Complying with the shared care arrangement**

Both practice and hospital compliance with agreed shared care arrangements were questioned by GPs. One GP hesitated to accept such arrangements, explaining how responsibility would then be transferred to him for the entire practice staff monitoring and prescribing of the specialist drug. As patients were entitled to see any GP in his practice, he could not guarantee that other GPs would adhere to such an arrangement for a number of reasons (DR23, box 3). These included infrequent GP use of specialist drugs and his inability to highlight potentially dangerous situations to fellow GPs in the future. According to him, a practice computer system which could ‘automatically flag up an error message or a warning message to say “Look out, this patient is on this drug, they shouldn’t be”’ (DR23) would help eliminate this problem and potentially ensure GP compliance with shared care arrangements. GPs in other practices did not appear to consider this a problem, explaining how GP communication was ‘usually (done) through the notes or on the computer’ (DR29) within the practice. One GP explained how ‘reminders’ or ‘little messages’ could be put on to the ‘prescribing screen’ (DR30) to facilitate compliance with shared care arrangements. Despite this, he acknowledged how little he had used the computer as a means of communication, showing dependence on other practice staff to recognise and report abnormal levels that required immediate GP action (DR30, box 3).

In relation to hospital compliance with shared care arrangements, one GP expressed her belief that a higher number of tests had been carried out than had previously been agreed. She recalled how the shared care arrangement was ‘not working at the moment’ because consultants were ‘unnecessarily’ repeating blood tests recently conducted by her practice (DR19, box 5). Another GP, who also shared this view, took reassurance from the fact that she had kept her side of the agreement: ‘as long as you know you have done your part of it then you can be as happy as you can be I think’ (DR15). However, for others, the hospital’s non-compliance impinged on their prescribing responsibility and raised feelings of insecurity: ‘whoever signs the prescription is whose responsibility it is’ (DR12).

**Dependence on specialist advice**

Much dependence was placed on the response of specialists to GP requests for advice. One GP illustrated this by highlighting the effort required in addressing methotrexate irregularities, in terms of referring to supporting information, and seeking specialist advice (DR25, box 4). Similar evidence was provided by a nurse in a different practice, who explained how reliance had been placed on hospital staff to inform them about what they should ‘do in the meantime, while they are waiting’ for specialists to see three patients who had suffered adverse effects from a specialist drug (NU32, box 4).

**DISCUSSION**

Shared care arrangements for specialist drugs have many far-reaching benefits for patients and throughout the National Health Service (NHS). In this study, GPs faced multiple challenges
Box 3 Complying with the shared care arrangement

‘the worry I’ve got is they will send a letter that says ‘Will you please continue this drug, this is the monitoring you need, and these are the indications for why you should stop that’ … We have got seven doctors here. That information lands on my desk as a letter and I’m sitting there thinking right, so how do I make it safe so that I know that if these conditions are met, somebody in the practice will know to stop the tablets knowing full well that it is not a tablet we use regularly … it was a problem that we pose in the practice’ (DR23)

‘I mean if they were on gold injections and their neutrophils dropped below such and such you are going to stop it … It wouldn’t come up on the computer but things like that would be followed up say by the nurse’ (DR30)

‘if we have been doing the monitoring every two months say … and then they go to the clinic on month four, the consultant will always do the bloods even if they don’t need doing … we have done them the week before’ (DR19)

in adhering to these shared care arrangements, the most important being their ambivalence around the management of psychiatric patients, the sharing of test results, compliance with the shared care arrangement and their dependence on specialist advice. Drawing comparisons with existing literature, one of the core issues for GPs was the sharing of tests results. Confusion over the monitoring and treatment of patients with mental illness was particularly apparent. A joint report from the Royal Colleges of Physicians and Psychiatrists notes how patient non-adherence to treatment or health advice necessitates referral to a mental health team. This leaves the stakeholder’s view of how some GPs are not skilled in mental health and would like to refer all patients back to hospital vulnerable to criticism. In addition to the technical limitations of both hospital’s and practice’s computer systems mentioned in this study, specialists were portrayed as failing to meet their perceived obligations to disseminate the results of tests conducted. Crucially, such breaches brought issues of test duplication and patient inconvenience to the fore and raise important concerns over patient safety, and cost to both the patient and the NHS, of this test repetition or more significantly from its acknowledged absence. This study also shows how the introduction of a PCT initiative potentially encouraged test duplication.

The National Programme for Information Technology (NPfIT) being delivered by the agency Connecting for Health in the UK supports the provision of better, safer care, by enabling clinical information to be securely shared between different parts of the local NHS. However, with implementation of the NHS Care Record Service (CRS) still at an early stage and concerns voiced at Connecting for Health’s unrealistic timetable, the risk to patients’ safety continues to grow. There also appears to be a need for an improved approach to communication that connects frontline staff with each other and with patients. In this way, more support could be offered to GPs addressing specialist drug irregularities, psychiatric patients’ non-compliance, and ensuring colleague compliance with shared care arrangements. While computerised support might be necessary, this study also shows how it may not be sufficient to obtain commitment from relevant parties to making the process work. GP involvement in the development of shared care arrangements from the onset is likely to be beneficial. Both GPs’ and stakeholders’ accounts gave the impression that such issues had the potential to influence future acceptance of shared care arrangements by primary care. This is an important finding, with Lord Darzi’s report High Quality Care For All reinforcing the message that more care could, and should, be provided closer to people’s homes. With many UK regions planning to make this vision a reality, it is clear from this study that better communication between primary and secondary care is essential.

This study had inherent limitations, one being self-selection; it is possible that primary—secondary interface issues interested participants more than non-volunteers. This, together with the fact that the study was undertaken within a single SHA in England, limited the generalisability of findings. However, common themes did emerge, and thematic saturation was satisfactorily achieved. This study would also have benefited from complementary interviews with patients, hospital clinicians and discharge liaison nurses, increasing the number of alternative viewpoints and strengthening the conclusions drawn. One of the main strengths of this study was the breadth of participants interviewed, some of whom had recent or current experience in secondary care. Different perspectives from both within and between practices, PCTs and different primary—secondary interface groups helped ensure the credibility and trustworthiness of study findings. The sequential approach also enhanced the entire study by allowing initial data analysis to guide efficient sample choice.

CONCLUSION

We recommend that policy makers take into account the complex picture presented here, and the multiple challenges facing GP adherence to shared care arrangements for specialist drugs. The core issue of ‘results sharing’ needs to be acknowledged and addressed if future problems relating to test duplication for both patients and hospitals are to be avoided. Such a finding gains increasing emphasis with the Departments of Health’s Creating a patient-led NHS and subsequent Commissioning a patient-led NHS documents highlighting how the patient’s experience is paramount and their choice integral to the way services are delivered. With the Care Quality Commission supporting the referral of patients to primary-care-based specialist monitoring clinics, we suggest that PCTs review their shared care arrangements for specialist drugs between primary and secondary care in light of our findings.
Acknowledgements We would like to thank all participants who generously gave up their time for this study.

Funding This study was funded by the University of Manchester as part of a PhD programme.

Competing interests None.

Ethics approval Ethics approval was provided by the North Manchester Research Ethics Committee (Ref no D14/406/99).

Provenance and peer review Not commissioned; externally peer reviewed.

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