

Patient and carer participation in old age psychiatry in England 2: models of participation

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ABSTRACT

Background: There are a number of models of patient and carer participation. Their usefulness and applicability to old age psychiatry is considered.

Methods: Models of participation are reviewed and related to examples of participation initiatives drawn from the author's work in the context of the National Health Service in the United Kingdom.

Results: Models of participation which emphasise collaboration and partnership are found to be useful. Simple interventions such as copying letters to patients and/ or carers can lead to change in the balance of power between staff and patients/ carers. Initiatives which draw on the experiences of patients and carers can facilitate organisational learning and development. Involving patients and carers in education offers a way to influence services and the staff working in them.

Conclusions: Participation is better understood as a spectrum rather than a hierarchy. Old age psychiatry services would benefit from developing greater patient and carer participation at all levels.

Keywords

Collaboration; consultation; consumer group; copying letters to patients; patient journey mapping; workforce education and training.

Introduction

Arnstein's ladder of citizen participation describes participation on an axis from non-participation (patients and carers as passive recipients of treatment/ education) to citizen control (citizen power). Applying this model to healthcare the aim would be patient/ carer control – it imposes a hierarchy of participation with a rigid dichotomy: either patients have power or professionals have power. Similarly Hickey and Kipping (1998) saw participation as a continuum from information/ explanation to patient control, passing through partnership (Figure 1). Glasby (2007) cites the work of Hoggett (1992) in setting out a model which includes the issue of whether participation is enacted as an individual or through collective action but again the aim is control and the model hierarchical.

These models fail to take account of the expertise of health and social care staff and the importance of the interactions and relationships between patients, carers and health and social care practitioners. Tritter and McCallum (2006) commented on the emphasis on power in participation, stating that it ignores the existence of different forms of knowledge and expertise. They argued that, to reflect the diverse ways that patients participate, Arnstein's ladder would need to have multiple ladders, some with more rungs than others, and with bridges between the ladders, resulting in a scaffold structure.

Alternatively we could envisage participation as a balance between patient/ carer control/ power and health care professional control/ power. In the early days of the National Health Service (NHS) in the United Kingdom, professionals controlled decision-making. There has been a shift towards more patient and carer control, but,

if we take seriously the need for flexibility, inclusiveness and respect in participation activities (as described by Restall and Strutt (2008) in their 'conceptual framework' for participation), then genuine partnership/ collaboration becomes the pinnacle of participation, valuing and respecting the contribution made by all parties to the decision. Tritter and McCallum (2006) describe this as:

“not a hierarchy of knowledge ... but rather a complementarity between forms of knowing ...”. (Tritter and McCallum, 2006, p. 164)

Old age psychiatry can learn from work on participation and models of participation in children's services (Wright *et al.*, 2006) which can be extrapolated with modifications to adult settings: these avoid the hierarchical approach. Young children are often excluded from consultations or decision-making by parents and health/ social care practitioners making decisions on their behalf (Wright *et al.*, 2006): there are interesting parallels with old age psychiatry where adult children/ relatives and practitioners may disempower and exclude older adults and make decisions for them. Shier (2001 and 2006) devised a model with five levels of participation and three stages of commitment (a modified version of this to make it applicable to an older adult context is set out in Table 1). At each level of participation an opening may occur (first stage of commitment) and an opportunity might allow this to operate (second stage of commitment). At the third stage of commitment it becomes an obligation, ie it is incorporated within the organisation as agreed policy/ procedure. Shier's model is designed as a planning/ assessment tool and to use it one starts at the bottom (indicated in Table 1 by Start Here). It is not a hierarchy where higher is necessarily better, instead Shier argues that different levels of participation are appropriate to different situations. Similarly Treseder (Fajerman and Treseder,

1997) incorporated the idea of child and adult initiated participation into a circular model, used in younger people's settings: this described five degrees of participation, regarded as five different but equally good practice options applicable to different situations. The five options are: patient/ carer initiated – shared decisions with staff; patient/ carer initiated and directed; staff initiated – shared decisions with patients/ carers; consulted and informed; assigned but informed.

This paper describes four initiatives drawn from the author's work and discusses them in the context of models of participation. All are set within the context of the UK NHS but the themes they raise and models of practice are of broader interest and applicability.

Participation example 1: Copying letters to patients and carers

In 2009 the British Medical Association (BMA) issued guidance for consultants on best practice for copying letters to patients (BMA, 2009). The guidance states that copying letters to patients is 'beneficial on the whole' and that one potential benefit is to maximise the person's understanding of their illness. In a section on potential pitfalls it suggests that it may be inadvisable to copy letters to people with significant cognitive impairment/ dementia, and that there might be safeguarding issues which could place a child at risk when information is copied to parents.

There is no doubt that most patients are positive about their experience of receiving copy letters (Lloyd, 2004; Nandhra *et al.*, 2004; Marzanski *et al.*, 2005; Treloar and Adamis, 2005; Mason and Rice, 2008). The position of carers in respect of the practice of copying letters is less clear. Dale *et al.* (2004) reported that older adults

wanted to share information with their carers: 54% of old age psychiatry out-patient patients said that they would like their carer to receive a copy of the letter about their care. Carers in the same study overwhelmingly wanted to receive a copy letter (95%). Mason and Rice (2008) also looked at copying letters in an old age psychiatry service in a community mental health team context: they write that the decision to send the letter to the patient or carer was based on discussion with the doctor “and common sense”. If the patient had established significant cognitive impairment they were asked for consent to send the letter to their carer, and if cognitive decline was advanced the letter was offered to the carer. The response to letters was positive: they were regarded as useful and clear. They note that all the respondents spoke English as their first language. Treloar and Adamis (2005) also investigated the practice of copying letters to patients and carers in an old age psychiatry out-patient context. They found improved knowledge of medical recommendations amongst patient and carers together with better knowledge of who to contact. They commented on confidentiality: ‘concerns about confidentiality did not arise.’ In old age psychiatry services where patients and carers are seen together letters will hold no surprises for either party.

Sending letters about their care to patients or (with the patient’s permission) to their carers is a way of involving patients and/ or carers by informing them. If patients or carers are asked to feedback about the experience, the exercise moves from information to consultation on Hickey & Kipping’s continuum. However for consultation to have meaning, it needs to feed back into and influence services.

Clark *et al.* (2008) describe two older people's mental health projects which involved copying letters, referring to the practice of copying letters to patients as:

“offering transparency and confirming respect for equality in the relationship between patient and clinician.” (Clark *et al.*, 2008, p. 31)

Table 2 lists potential benefits and drawbacks of the practice – taken from the Department of Health Good practice guidelines (Department of Health, 2003) with additions - and evidence for them. The benefits and drawbacks are written from the viewpoint of the professional. The Clark *et al.* paper moves towards considering the practice of copying letters from the perspective of patients and their families. The column in Table 2 headed 'conclusions' attempts to refocus the benefits and drawbacks from a patient/ family perspective. The practice of copying letters can move a health/social care encounter towards partnership with patients and carers: for example, patients or carers who receive copy letters know when they receive their copy that the professionals have received theirs and can then actively pursue any actions or outcomes which should follow.

A simple intervention (in this case copying letters to patients and/ or carers) may be symbolic and more powerful than might have been anticipated. It involves a move away from expert language and secrecy. When the people receiving letters are empowered to use the letters to actively take a lead in their own (or their relative's) care and also consulted about their experience so that learning is used to inform the development of individual care and of the service itself, the balance of power shifts further. This leaves the BMA (2009) guidance for consultants looking rather patronising in its assessment of the practice of copying letters, particularly as Clark *et al.*'s (2008) initiative included people with cognitive impairment, dementia and

other mental health problems of later life. To classify this initiative as a way of informing patients and carers about services/ care is to make an assumption that the initiative involves information flow in one direction: when information flows in both directions, the level of participation and power sharing is greater and change may ensue from the interchange.

Participation initiative 2: Patient journey mapping

On Hickey and Kipping's continuum (Figure 1) consultation is the next step after information/ explanation. Consultation is the act or process of consulting and one definition of 'to consult' is 'to exchange views'. Exchanging views in itself could be a sterile exercise; the purpose of consultation is to influence and ideally to improve decision-making. Restall and Strutt (2008) referred to this bluntly, in writing:

“participation activities which consisted solely of information exchange were, at best, a waste of time and, at worst, exploitation. People did not want to participate for the sake of legitimizing what health planners had already decided, but rather to make a real impact on decisions that improve services.” (Restall and Strutt, 2008, p. 236)

Crawford *et al.* (2002) point out, from the perspective of patients' participation in planning/ developing health care, that participation may be intended to legitimise the decisions of administrators and managers rather than to devolve power. SCIE (Carr, 2004, p. 18) calls this a 'technology of legitimation' which aims only to support the predetermined organisation position/ plan, rather than to look for ways to improve and develop plans/ proposals:

“exercises to approve of service planning and policy proposals, rather than enabling service patients to be key players or partners in their formulation”
(Carr, 2004, p. 17).

Patients and carers can work with health and/or social care professionals to map their journey and review their experiences of care with a view to improving and developing services. An account of some of the work of the West Midlands Older People’s Mental Health Collaborative (Doherty *et al.*, 2009) describes two carers’ journeys with dementia and some of the learning which was derived from mapping them, plus how this led to action points for the organisation concerned. The authors comment that the process:

“may even have wider benefits in altering the relationship between patients, carers and those professionals working with them ...” (Doherty *et al.*, 2009, p. 510)

and may bring about:

“changes in culture for the individuals and services involved.” (ibid, p. 501)

This is an example of sharing power in collaboration, of deriving mutual benefit from the exercise, and of co-creating new ideas in conversation.

One of the main criticisms of this initiative is that no patient or carer journey will be typical or representative. Those patients/ carers who volunteer to become involved may be people who have particular reasons to become involved eg they may have strong views arising from difficult or unsatisfactory experiences. In employing journeys as a service improvement tool the issue of representativeness is largely irrelevant, since learning will grow out of the collaboration between staff and patients/

carers whatever experiences the patients and carers involved describe. It is important, however, that healthcare staff members approach these initiatives with a view to learning from the patients and carers involved, respecting their stories, experiences and ideas, and valuing the time and effort patients and carers are prepared to give. From the perspectives of all those concerned it is necessary that learning from patient journey mapping exercises influences services in order that the time and effort is well spent, particularly as some of the learning points may not fit with how services are operating at the time and may carry costs. If necessary changes to service operations are identified and do not influence the organisation, the mapping experience can be frustrating and demoralising for staff and patient/carers.

The staff members who were involved in Doherty *et al.*'s (2008) project were working both in management and care. This allowed the project to influence relationships between individual patients, carers and a range of staff members within the organisation involved. At the same time practical benefits were developed with the potential to change practice at the level of families using the service and at the level of organisational policies, procedures and plans. It would have been helpful to get feedback from the patients/ carers whose journeys were mapped about how they perceived the exercise and its effects, both on their journeys and on their relationships with professionals and organisations involved: this is an action point for future work. It is important that staff involved in projects like this are in positions where they are able to influence organisational operation in response to learning, and that these initiatives are properly resourced and supported by organisations involved.

Participation example 3: the Consumer Group

A second initiative which illustrates consultation is the Consumer Group, set up by the Faculty of Old Age Psychiatry, Royal College of Psychiatrists, in partnership with the Alzheimer's Society and Age Concern, to develop the relationship between patients, carers and old age psychiatrists nationally, and to establish a way in which all could work together on matters of mutual interest. The group acted as a forum for collecting and reflecting on written narratives produced by those carers of people with dementia who chose to do so (Benbow *et al.*, 2009). As with the patient journey mapping, those patients and carers who became involved in this project cannot be regarded as typical or representative but that does not detract from the experiences they bring. The Consumer Group narratives were subjected to a qualitative thematic analysis and the analysis was presented to the patient/ carer forum for discussion and consideration of how the themes could be addressed in the work of the group. This methodology constituted 'consultation' between the professionals and carers involved, and actions were developed in partnership. Table 3 sets out the identified themes from the narratives paper and from a related paper written by the same group (Ong *et al.*, 2007), together with the ensuing actions. It is evident that, although the Consumer Group was established in response to a professional initiative and with professional interests in mind, it led on to actions which were co-created by the interaction between Consumer Group members and the professionals involved:

“(the) patients and carers ... at times were challenging, refreshingly politically incorrect and unafraid to raise any issue that concerned them ...” and

“the group was valuable in ways that had not been anticipated.” (Ong et al., 2007, p. 48)

Furthermore:

“the group did not want to work to the faculty’s agenda, and instead saw this as their opportunity to get the faculty to take the actions they think are needed.” (ibid, p. 48)

The Consumer Group (and the patient journey mapping work) illustrates teaching and learning as collaborative and relational practices (McNamee, 2007). The members (users, carers and professionals) all learned from each other and taught one another. That learning was carried into the work of all the organisations involved. Although the Consumer Group work started as an exercise to involve patients and carers in consultation, it allowed patients and carers to exert more control and start to influence the agenda and strategy of the organisation they were working with, to the benefit of all concerned. This joint endeavour subverted the expected power structure and the Consumer Group is a process model which is potentially applicable to other settings.

Participation example 4: patients/ carers in education

It is apparent from the preceding examples that information giving, consultation and partnership working are not separate discrete entities. Instead their boundaries merge to form a spectrum of participation. Consultation may be about ‘ticking boxes’ at times, but at its best it carries the underlying assumption that actions will result from that consultation. This introduces the possibility of the people running the consultation sharing power with those they consult, so that the outcome is not

necessarily that intended by either group but instead a co-construction (or partnership) which grows out of the dialogue between the two. The outcome then becomes, not the outcome of one party imposed on another, but a different outcome to which both groups are signed up. This fits well with theories of systemic therapy.

The Consumer Group initiative (Ong *et al.*, 2007; Benbow *et al.*, 2009) crossed the boundary from consultation to control by giving the patients and carers involved the space to influence the focus and activity of the professionals they were working with. The work described in Benbow *et al.*, (2008), which was taken further in Benbow and Boyce (2008) and Benbow *et al.* (2011), moves from consulting with patients and carers to working in partnership with them. Furthermore it involves work in developing and delivering education rather than in service provision, management or planning.

Education offers an opportunity to influence the health and social care system by influencing those working within it. Tew *et al.* (2004) describe how the involvement of patients and carers in education at all levels is essential if health and social care professionals are to develop partnership working with the people using their services. They listed a series of areas for involvement: direct delivery of learning and teaching, course / module planning, programme management, recruitment and selection of students, practice learning, student assessment, course evaluation and as course participants. The involvement of patients and carers in non-passive roles in the education of health and social care professionals is a relatively recent development. Previously, patients may have been involved as 'teaching aids' (Repper and Breeze, 2007), for example in the bedside teaching of medical

students. Wykurz and Kelly (2002) reviewed the involvement of patients in medical education, describing their active (as opposed to passive) involvement as new. Forrest *et al.* (2000) describe drawing on patients' views to influence design of a pre-registration nursing curriculum. Ikkos (2003) describes patients as teachers of interview skills, teaching doctors to understand the 'point of view' of 'patients' with mental illnesses. Livingston and Cooper (2004) went further: they described patients and carers as active educators in professional training, arguing that their different perspective gives them a unique role in teaching. A project and toolkit to investigate the needs of patients involved in planning and delivering mental health services and education has been reported by Lloyd *et al.* (2007). Anderson *et al.* (2008) have described involving people with communication needs in developing and delivering education.

Wykurz and Kelly (2002) acknowledge that they found the emphasis to be on the value (rather than potential negatives) of patients as teachers and state that this might be due to publication bias. Other writers allude to possible negative effects (for example Walters *et al.*, 2003). It is likely that the mechanism by which patients and carers are involved is important in ensuring a positive experience for all involved. Indeed, although the involvement of patients and carers has become embedded in education recently, a range of models has been described; one to one conversations (Elliott *et al.*, 2005); long term following of a person living with a dementia (Skog *et al.*, 2000); working with service patient (or carer) groups (Humphreys, 2005); involvement in developing, delivering and evaluating education (Barnes *et al.*, 2000); workshop based teaching (Waterson and Morris, 2005); a 'facilitated dialogue' (Scheyett and Diehl, 2004).

Benbow *et al.* (2008) describe the involvement of patients and carers in teaching on an MSc module for health and social care professionals. The stated aim was to give the students a different perspective of assessment and care planning. As with the Consumer Group initiative, this innovation had consequences beyond those expected. Student ratings and feedback were overwhelmingly positive. The work led on to a Higher Education Academy funded mini-project (Benbow and Boyce, 2008; Benbow *et al.*, 2011). A dedicated module (In our Shoes) was planned and designed in partnership with patients and carers using focus groups, and a recruitment workshop was held at which Morgan (co-author and an honorary lecturer at Staffordshire University) spoke about her experience of teaching.

In keeping with the shift in emphasis, Benbow and Boyce (2008) includes forewords written by a patient (Morgan, 2008, p. 3) and a carer (Hughes, 2008, p. 4). The project involved patients and carers in the direct delivery of learning and teaching, in module planning, in student assessment and course evaluation, and the authors write:

“Involving patients and carers at all levels of education sends a powerful message to the professionals they train about the value and importance of hearing and attending to the voices of those using their services.” (Benbow and Boyce, 2008, p. 6)

One of the concerns expressed about involving patients and/ or carers in teaching is that those people who have the confidence and motivation to teach may not be representative of the majority of patients and carers: Repper and Breeze (2007)

reported that some mental health lecturers had expressed this view. Whilst this may be true in some settings, the authors argue that learning will grow out of the relationships established and the conversations that take place, whether or not people's experiences are regarded as 'typical':

"The teaching team came to the view that the individual material brought by patients and carers, whilst clearly important and influential, is only part of the learning experience and the process of the sessions is equally powerful, ie learning from patients and carers, having the opportunity to talk, question and debate with them in an educational environment." (Benbow and Boyce, 2008, p. 13)

The 'In our Shoes' project *shared* power between educators, practitioners, students, patients and carers, and all parties *collaborated* in the design, delivery and assessment of the module. The project involved a shift in power dynamics, but giving power to patient/ carer teachers did not involve the facilitators in sacrificing their own roles and authority as some have feared (Felton and Stickley, 2004). The project evolved from the interaction between patients, carers, educational staff, practitioners and the third sector. The acknowledgements (Benbow and Boyce, 2008, p. 18) credit the Phoenix Centre, the Alzheimer's Society and Approach, a third sector organisation led by Boyce who co-authored the report.

Conclusions

Participation is better understood as a spectrum rather than a hierarchy. Patients' and carers' voices can be heard in a variety of ways, some of which have been described here, but, in order to participate, irrespective of organisational and health

service structure, what patients and carers say must carry the potential to influence and change, and the aim of participation is better conceptualised as partnership/ collaboration rather than control/ power. Partnership implies similar status, shared power and some equality of influence over agenda, implementation and outcomes. Old age psychiatry services would benefit greatly from a focus on patient and carer participation throughout service delivery, management, planning, and improvement, together with workforce education and training.

Conflict of interest declaration

None.

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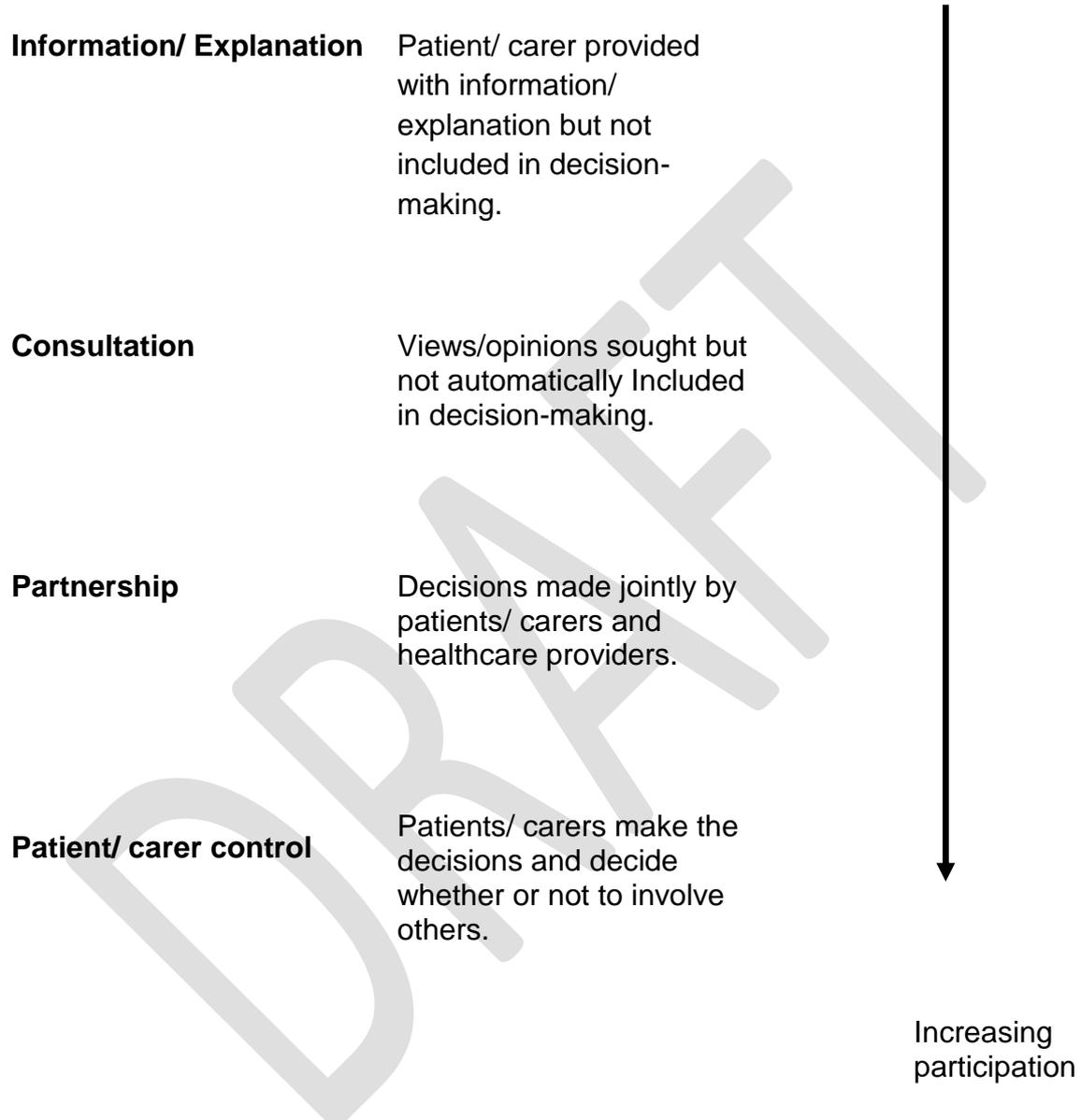
Figure 1: Participation continuum (modified from Hickey & Kipping, 1998)

Table 1: Shier's model with modifications to make it applicable to an adult context (from Shier, 2001 and Shier, 2006)

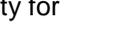
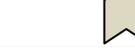
Levels of participation	Openings	Levels of commitment	
		Opportunities	Obligations
5. Patients/ carers share power and responsibility for decision-making 	Are workers/ organisation ready to share power with patients/ carers? 	Is there a procedure to enable patients/ carers to share power and responsibility for decisions? 	Is it a policy requirement that patients/ carers share power and responsibility for decisions? 
			
4. Patients/ carers are involved in decision-making processes 	Are workers/ organisation ready to let patients/ carers join in decision-making processes? 	Is there a procedure to enable patients/ carers to join in decision-making processes? 	Is it a policy requirement that patients/ carers must be involved in decision-making processes? 
			
3. Patients'/ carers' views are taken into account 	Is the worker/ organisation ready to take patients'/ carers' views into account? 	Does the decision-making process enable the worker/ organisation to take patients'/ carers' views into account? 	Is it a policy requirement that patients'/ carers' views must be given due weight in decision-making? 
			
2. Patients/ carers are supported to express their views 	Is the worker/ organisation ready to support patients/ carers in expressing their views? 	Does the worker/ organisation have a range of processes to help patients/ carers express their views? 	Is it a policy requirement that patients/ carers must be supported in expressing their views? 
			
1. Patients/ carers are listened to Start here 	Is the worker/ organisation ready to listen to patients/ carers? 	Does the worker/ organisation work in a way that enables listening? 	Is it a policy requirement to listen to patients/ carers? 

Table 2: Potential benefits and drawbacks of copying letters to patients and/ or their carers

Potential benefits of copying letters to service patients from Department of Health (2003)		Evidence for this statement	Conclusions with reference to the contribution of Clark <i>et al.</i> (2008)
More trust between service patients and professionals	Increased openness leads to greater trust between professionals and service patients.		Increased openness <i>should lead</i> to greater trust between professionals and service patients.
Better informed service patients	Service patients and carers have a better understanding of the condition and how they can help themselves.	O'Driscoll <i>et al.</i> (2003) found that letters helped patients understand their diagnosis and treatment. Nandhra <i>et al.</i> (2004) reported that patients said receiving letters helped them "gain perspective" on their condition. O'Driscoll <i>et al.</i> (2003) reported that patients found that letters helped them understand their diagnosis and treatment.	Service patients and carers have a better understanding of <i>the professionals' views about or assessment of the</i> condition and how they can help themselves.

Better decisions	Service patients are more informed and better able to make decisions about treatment options.	Treloar and Adamis (2005) found that patients who received letters had a better knowledge of their care plan and who to contact.	Copying letters “ establishes a culture of openness, inclusiveness and partnership between professionals and families, and improves the appropriateness of service responses. ” (Clark <i>et al.</i> , 2008, p. 37).
Better compliance	Service patients who understand the reasons for taking medication or treatment are more likely to follow advice.		Professionals who discuss matters fully and communicate openly with service patients will give better advice and it is likely that compliance with it will be greater.
More accurate records	Errors can be spotted and corrected by the service patient.	O’Driscoll <i>et al.</i> (2003) and Mason and Rice (2008) reported some errors in letters which were corrected by patients.	Errors can be spotted and corrected by the service patient.
Better consultations	Professionals confirm that patients understand what is said during the consultation. Patients are better prepared and less anxious.		Where professionals understand the requirement to communicate openly with service patients they are likely to make more effort to do so which should lead to more satisfactory consultations from everyone’s perspective.
Health promotion	The letters can be used to reinforce advice on self-care and life styles.		Letters could be used to set out the views of service patients and carers about the illness.

Clearer letters between professionals	Letters written between professionals are clear and understandable to both professional and lay people.		Letters which are clear to patients are likely to be clear to the professionals who receive them.
Ensuring all aspects of care plan progressed as planned (Mason and Rice, 2008).			<i>“It enables patients and carers to play an active part in interpreting findings and making and evaluating plans for care and treatment.”</i> (Clark <i>et al.</i> , 2008, p. 37)
When letters should not be copied from Department of Health, 2003 - drawbacks		Evidence for this drawback	
Where the patient does not want a copy	People may have problems with privacy at home, may be in situations of domestic violence, may not accept the diagnosis or may feel they criticise the professional by asking for a letter.	Most studies in this area have found that a minority of patients do not want a copy letter (Dale <i>et al.</i> , 2004; Marzanski <i>et al.</i> , 2005; Mason and Rice, 2008).	Sending a letter to a person’s home could in theory lead to a breach of confidentiality, increase the risk of domestic violence or elder abuse, or compromise the relationship between the person and the professional.
Where the clinician feels that it may cause harm to the patient or for other reasons	Sometimes “health professionals are anxious to protect patients” (page 7); concern about reactions to bad news, sensitive areas such as child protection and mental health.	Some psychiatrists express concerns over patients’ distress (Murray <i>et al.</i> , 2003; Nandhra <i>et al.</i> , 2004). Some patients express concerns about possible distress (Marzanski <i>et al.</i> , 2005). Information was found to be omitted from almost one quarter of letters in	A letter could cause distress or put a person at risk in some way eg if it is seen by a person for whom it is not intended.

		<p>Nandhra <i>et al.</i>'s (2004) work.</p> <p>Mason and Rice (2008) reported that one service patient was distressed by the letter.</p> <p>Some authors have expressed concern about the potential effect on the therapeutic relationship (eg Lloyd, 2004).</p>	
<p>Where the letter includes information about a third party who has not given consent</p>	<p>This could lead to a potential breach of confidentiality and there may be additional concern that harm might result either to the patient or the third party.</p>	<p>Third party information was removed from one letter in Mason and Rice's (2008) study.</p> <p>Two instances of omitting third party information were reported by Murray <i>et al.</i> (2003).</p>	<p>Letters between professionals may include third party information with possible consequences if this information is revealed. In addition patients may share letters with other family members/ carers thus further disseminating information.</p>
<p>Where special safeguards (eg) for confidentiality may be needed.</p>	<p>Sexually Transmitted Diseases clinics are given as an example.</p>	<p>Some patients express concerns about confidentiality (Marzanski <i>et al.</i>, 2005).</p>	<p>Older people living in care homes may be at risk of compromised confidentiality.</p> <p>People with impaired capacity may need special consideration.</p>

<p><i>The letters themselves change as a result of the practice</i></p>		<p>Psychiatrists omitted information from letters (Murray <i>et al.</i>, 2003; Nandhra <i>et al.</i>, 2004) Psychiatrists alter their usual letter writing practice (Nandhra <i>et al.</i>, 2004).</p>	<p>Changes to letters could be regarded as a positive or a negative outcome of the practice.</p>
<p><i>Increase in workload (and costs) for the NHS</i></p>		<p>Small increase in secretarial workload was reported by Nandhra <i>et al.</i> (2004). This has been a concern in other areas of medicine (eg rheumatology; Payne and Jobanputra, 2006). Pilgrim and Waldron (1998) drew attention to the economic constraints on participation and this is relevant even with a simple intervention. Young-Min <i>et al.</i> (2004) commented on the need for large print letters and audiotapes as an alternative for some patients. Jelley, van Zwanenberg and Walker (2002) highlighted the potential difficulties for those with educational disabilities and inadequate reading skills in English.</p>	<p>There are additional costs involved in copying letters to patients. As yet there is no study of the cost-effectiveness of the practice. Translation into black and minority ethnic (BME) languages is helpful but is not regarded as essential (Clark <i>et al.</i>, 2008).</p>

Table 3: Themes identified in Consumer Group and ensuing actions, taken from Ong, Benbow, Black *et al.* (2007) and Benbow, Ong, Black *et al.*, (2009)

Carers themes	Actions arising from Group
Difficulties in obtaining a diagnosis	One day conference organised with primary care.
Bridging private and public worlds	Involvement of carers in the Consumer Group.
Stressors associated with caring for a person with dementia	Involvement of carers in the Consumer Group.
Difficulties with services offered by social services	Raised awareness amongst professionals attending the group, and in the Faculty generally.
Emotions experienced by carers	Addressed by the exercise of producing and sharing the narratives. Feeding the themes into the work of the Consumer Group and of the organisations involved (the Faculty of Old Age Psychiatry, the Alzheimer's Society and Age Concern). Writing a paper in order to make the learning more widely available to others.
Other themes	Example of actions arising from Group

<p>Commenting on Faculty and College documents and proposals</p>	<p>Eg when the Faculty considered updating their report on ethnic elders, the Consumer Group organised a meeting to which elders from minority ethnic communities were invited through one of the organisations involved in the Group. This led on to joint working on a document later published as a College Report (CR156 obtainable from http://www.rcpsych.ac.uk).</p>
<p>Discussing and planning work proposed by Faculty</p>	<p>eg one member of the Consumer Group becoming involved in work on transitions between working age adult and older adult services and others became involved in a one day meeting which contributed to the work. The end result was a document called Links not Boundaries (College Report CR153).</p>
<p>Responding to issues raised by patients and carers at the Group. Note: Patients and carers could add anything they wished to the agenda and raise non-agenda items at the meeting for discussion and</p>	<p>Eg members of the Consumer Group raised concerns about the interface between primary care and old age psychiatry. This linked with the carer theme of delay in diagnosis and led on to a joint seminar looking at the issue.</p>

debate.	
Sharing frustrations and concerns.	eg the Consumer Group debated the issue of using anti-psychotic drugs to treat people with dementia and the discussions contributed to the Faculty advice produced on the use of atypical antipsychotics.
Forum to discuss future strategy of all those involved in the Group.	Future strategy was discussed at the Group, allowing all three organisations to contribute, alongside individual patients and carers.