Positive and Inclusive?
Effective ways for professionals to involve carers in information sharing

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Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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prepared by

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Acknowledgements

This study is a collaborative project between Rethink severe mental illness (the largest mental health charity in England providing support to 7000 people daily through 380 services and 135 support groups) and the Health Services Research Department at the Institute of Psychiatry. In carrying out the research, the project team has drawn on the support and expertise of an extensive group of people contacted through networks such as Mental Health Alliance, organisations such as Age Concern, Mind and the South London and Maudsley NHS Trust and from individual contacts. This short project would not have been possible without the support of these stakeholders.

In addition to developing a network of contacts, the project team formed an expert panel, a virtual network and a virtual panel. The expert panel met on three occasions. It has steered and shaped the project, and been involved in writing this final report. Members of the panel are listed in Appendix 1 and we are grateful for the time, support and encouragement that they provided. The virtual network helped to publicise the study and have also commented on the final report. Again we thank all the virtual network members for their enthusiasm and support.

The research data collected for the study has been provided by mental health service users, professionals working in mental health, carers supporting a person with mental health problems and carer support workers. People accessed our surveys online, were interviewed over the telephone, attended workshops or groups hosted by the research team, and sent in policy documents supporting the sharing of information between mental health professionals and carers. We are grateful to everyone who has participated in this national study.

Finally the research team would like to recognise the support provided by colleagues in Rethink and at the Institute of Psychiatry. This project has been a team effort – thank you to everyone who has played a part.

Preface

This research project addresses good practice within mental health for the sharing of information between mental health professionals and carers. Within mental health, the sharing of information between professionals and carers is only one information sharing context. Others include information shared between professionals, and between service users and professionals. There are some common principles governing the sharing of information, and these will be outlined in the report, but there are also distinct practices or strategies that are particularly relevant to information sharing between mental health professionals and carers, the specific focus in this report.

It is important from the outset to acknowledge the practical difficulties that can arise when using the term ‘carer’. There is no single definition of a carer (Clements, 1996). This report defines a mental health ‘carer’ as a relative, friend or neighbour who provides practical and emotional support to someone with a mental health problem. A carer may or may not live with the person they support. However, the term carer is controversial. Some carers dislike it because it implies they did not ‘care’ before the person they support became unwell or because it unhelpfully professionalises the relationships. Others do not recognise that the ‘regular and substantial’ support they provide entitles them to specific ‘carer’s rights’ such as carer assessments. When does the role of a mother, father, wife, husband, partner, neighbour or friend end and the role of ‘carer’ begin? Equally there are service users who do not recognise their carers as such and who do not want them involved with their mental health care. The term carer thus encompasses a variety of relationships and caring contexts compounded by legal complexities, such as the criterion for the ‘nearest relative’ (see Section 2.2.3). The context of care is something we will return to throughout the report as a central consideration when professionals decide how to share information with ‘carers’.

The government’s commitment to carers includes three strategic elements: the provision of information, support and direct care. In this study we considered the different types of ‘information’ that carers require at times, and share when appropriate, to help them support a person with mental health problems. We also address where information should not be shared with carers, and highlight the central role of service user consent. We have used three different terms to distinguish between different information types:

1. *General information* for example information in the public domain on mental health problems, available treatments or resource directories for local services

2. *Personal information* for example specific information relating to the care of the person with mental health problems such as diagnosis, medication types or content of their care plan
3. *Sensitive personal information* for example information that is of a highly personal nature such as HIV status, history of sexual and emotional abuse or views on relationships with family members.

These terms can be broadly defined but how they apply to individual cases may vary because what counts as sensitive information in one scenario, will be considered in another as personal information. Personal and sensitive information is often regarded as confidential information. In Western societies confidentiality in healthcare is of crucial importance because it underpins the development of the therapeutic alliance between the service user and professional. Confidential information is central to this study because the principle of 'patient confidentiality' governs how and to what extent professionals share information with carers in mental health.

The focus of this study is on examples of good practice in information sharing between mental health professionals and carers. This research investigated good practice by acquiring positive and inclusive examples of how carers are being supported by professionals across England, and also by identifying information sharing problems. The project targeted several specific groups of carers including young carers, carers of adults of working age and carers of people with dementia. The experiences of carer support workers (CSWs), service users and professionals were also sought. The study was undertaken alongside other initiatives addressing the problems of poor communication with carers, for example the Partners in Care Programme (Royal College of Psychiatrists and Princess Royal Trust for Carers), care forums (for example The London Carer Charter), carer groups (for example the Suffolk carer strategy) and reviews of professional codes (for example the British Medical Association). These initiatives have or will all be developing good practice recommendations. The implementation of these recommendations should help to improve the support provided to carers.

Note on the research objective

This research focuses upon identifying models of good practice in information sharing between professionals and carers. However, it was considered necessary to include negative as well as positive experiences in the study for the following reasons:

1. To help stakeholders to progress from negative to positive situations and compare their good and poor experiences of information sharing in mental health.
2. To establish recommendations for good practice based on lessons from poor experiences.

The empirical research in the study relates to England. International perspectives were sought for comparative purposes through the policy and literature review process. The main stakeholders in the study were service users, mental health professionals, mental health carers and CSWs.

Executive Summary

Key themes and messages

Introduction

The sharing of relevant and necessary information between mental health professionals and carers is identified as a vital component of supporting carers and for improving the recovery outcomes for service users. However, in spite of these apparent benefits, in practice information sharing between professionals, carers and service users can raise many problems. In this report the results of a national study addressing effective ways for professionals to involve carers in information sharing are presented.

Literature and policy review

The protection and use of information in mental health is deeply embedded in ethics and professional codes, policy and law, values and professional practice. While central Government policy has attempted to promote the role of carers in care planning, policy guidance on information sharing between professionals and carers has failed to address the practical application of patient confidentiality. Professional codes as they stand neither explore nor develop the moral ground that lies between a carer's need for information to enable them to care and the service user's need for privacy. Policy guidance is both inconsistent and scattered in a range of documentation. Professionals are uncertain about what they may share and carers are often unaware of their rights. Yet the need to balance rights with responsibilities deriving from advances in case law and the Human Rights Act 1998 is an imperative for constructing an ethical basis to enable professionals and carers to share appropriate information. Furthermore, evidence also suggests that carers need certain information to safeguard their own health and well-being, though this will often be general rather than person specific. Examples of advances in practice exist in the shape of international law, policy development and service innovations. The models identified as possible ways forward strongly suggest that the rules governing confidentiality at the sharp end of practice cannot be wholly prescriptive.

Methods

This study used multiple methods of data collection to identify examples of good information sharing drawing upon the experience and expert opinion of several stakeholder groups connected with old age and adult mental health services: service users; carers (including young carers); mental health professionals; and CSWs. The key components of the study were:

- policy and literature review
- national surveys to review information sharing practices with five different stakeholder groups: service users (n=168); young carers (n=29); adult carers (n=496); professionals (n=212); CSWs (n=93)
- 34 in-depth interviews with stakeholders to identify good practice experiences
- our group discussions with groups who had been reached less successfully through the survey
- two multi-disciplinary workshop events held to assess the impact of policies for carers on the ground.

Data synthesis relied on triangulation of results. Throughout the study an extensive network of stakeholder contacts, termed the ‘expert panel’ and ‘virtual network’, provided support and assistance. They commented upon survey questions and interview schedules and shaped the final report through an extensive consultation process. The whole project is grounded in the experiences of service users, carers, mental health professionals and CSWs.

Results

The policy search produced 91 relevant documents, 56 policies and 35 supporting documents. From the 56 policies only 11 documents (20%) contained a robust carer focus. Several policies provided conflicting statements on sharing information with carers, reflecting ambiguities of guidance from government. The documents that contained positive carer guidance revealed a number of good practice points. These suggest the importance of introducing a carer strategy to provide a framework for the development of carer services.

Collating information from across the study, the service user data suggests there are no single models that can be applied to information sharing in mental health; individual solutions that are acceptable to the relevant involved stakeholders in any individual case are required. Recommendations to drive the decision-making framework governing how to share information and how to support carers do emerge and these are listed below:

- Consent should be collected before information is shared with carers, including the use of advance agreements.
- Better communication is needed in mental health based upon openness, honesty and respect between all stakeholders.
- Carer involvement should not diminish service user wishes.
- Service users should be involved in decisions to invite carers to meetings.

Carers are each managing unique circumstances and thus their individual needs will vary widely. Professionals must be aware of the carer context (including possible abusive relationships between carer and service user) and make decisions regarding the sharing of information as appropriate to each individual contact. The main findings in relation to carers include:

- Carers do not have sufficient general or personal information to support the service user. Mental health services must provide carers with basic information on mental health problems and ways of coping as a carer.
- Carers do not have the skills to manage severe mental illness (SMI). A range of services including carer education programmes and peer support groups are required to support and effectively empower carers, supporting their own recovery journey.
- Carers are often not given opportunities to discuss information they have found with professionals and feel staff do not listen to carer concerns.
- Where professionals cannot share personal information with carers because service user consent has not been provided, a supportive explanation should be given to prevent confidentiality being perceived as a ‘block’ to professionals engaging with carers.
- A cultural shift within mental health is required, including a change in professionals’ attitudes towards working with families. Carers ask for respect of their expertise and knowledge from professionals.
- Hospital and the processes surrounding discharge from hospital are reported to be most troublesome to carers. Particular strategies are needed to support carers whose relatives/friends have an inpatient hospital admission.
- Carers often need to be pro-active to develop effective relationships with professionals and gain support for themselves and the service user.

A range of issues hinders information sharing from a professional perspective. At the heart of the professional role are principles of clinical, practical and professional judgement that rely heavily on information gathering, training and support, knowledge of both the service user and carer and the care context. The following recommendations emerge from the professional data set to guide good practice:

- Policies specifically outlining guidelines for working with carers should be provided locally.
- The mental health system should address practical constraints that restrict professional involvement with carers.
- There should be recognition of the carer role by professionals.
- Professionals need training in the application of confidentiality.
- Consent should be collected and reviewed routinely.
- When working with carers of people with dementia, professionals must consider the impact of information sharing on the carer and support them appropriately.
- Support delivered to carers should include carers' assessments and general information packs.
- Improvements in communication would be helpful between all stakeholder groups.
- A collaborative approach should be adopted which involves all relevant stakeholders.

Recommendations

In summary, the implementation of effective information sharing in mental health on a nationwide scale will require substantial commitment from all stakeholders across the mental health system in years to come to rectify the widespread current poor information sharing practices. In this research we have reported the many problems that carers, service users and professionals experience with regard to information sharing primarily based upon poor policy guidance, lack of knowledge and training, no routine collection of service user consent, and a lack of recognition of the role of carers in the mental health care 'team'.

In order to improve information sharing in mental health, changes are required as outlined in the suggested framework, encompassing: practical actions; structural changes; application of good practice principles; and decision-making based upon knowledge, good quality training/support and awareness of the context.

The Report

Section 1 Introduction

1.1 Contemporary developments

1.2 Carer context

1.3 Summary

Until recently I did not know there was support for carers

(Carer quotation from *Who Cares? The experiences of mental health carers accessing services and information* Rethink, 2003a)

The sharing of relevant and necessary information between mental health professionals and informal carers is crucial for the operation of 'safe, sound and supportive' modern mental health services (Department of Health, 1998a) and a vital component of supporting carers (Department of Health, 2002a): a willingness to do so is central to the relationship between both parties. Recovery outcomes for service users are also improved where carers are given information they need to care effectively and keep well themselves (Rethink 1999). (Note: The term service user is preferred throughout this report to describe a person who uses or has used psychiatric services. The term patient refers to a service user who is subject to compulsory powers of the Mental Health Act 1983 liable to be detained or hospitalised on an informal basis; the term is also used where it is referenced in Government policy.) However, in spite of these apparent benefits, in practice information sharing between professionals, carers and service users can raise many problems (Arksey *et al.,* 2002). A recent survey reported that carers feel mental health professionals use confidentiality as a 'block' to withhold information from them even when service users encouraged their relative/friend to be involved in their care (Rethink, 2003a). Barriers to communication can occur at the point of statutory assessment (Rapaport, 2001), and are known to contribute to the cultural insensitivity of services as a result of, among other things, a lack of interpreters (Hatfield *et al.*, 1996; National Institute for Mental Health in England, 2003). In a different context a review of the ethical dimensions of caring for people with dementia has also highlighted confidentiality as a key issue (Hughes *et al.*, 2002).

The Department of Health (1995), professional bodies (including the Royal College of Psychiatrists, Royal College of Nursing, British Psychological Society and the British Association of Social Workers) and voluntary sector agencies have issued guidance on the protection and sharing of information. Local mental health policies have also developed in collaboration with a wide range of allied services. The

Surrey-wide Operational Partnership in Mental Health (SWOP) is one example, producing confidentiality guidelines in 2001. However, in spite of the central importance of communication between professionals and carers, there has been no national research into the effectiveness of these policies in relation to the position of carers. Furthermore, the views of carers, service users and professionals on this crucial topic have not previously been sought in any nationwide project.

1.1 Contemporary developments

This study began in August 2003 and ended in June 2004. It occurred in the wake of data protection policies and a series of Government initiatives to support carers. These include the Carers Act 1995, the National Service Framework (NSF) for Mental Health (Department of Health, 1999a), the National Strategy for Carers (Department of Health 1999b), the Carers and Disabled Children’s Act 2000 and the Carers (Equal Opportunities) Bill 2004. See Appendix 2 for a summary of carer policy and legislation. During the period of the research the Royal College of Psychiatrists and the Princess Royal Trust for Carers combined to launch Partners in Care and compiled a series of checklists for carers, service users and professionals to stimulate communication (Partners in Care, 2004). Data protection and carer initiatives were influencing Trusts and professional bodies, several of which were updating their policies during the early stages of the research.

The wider political scene has influenced mental health legislation. The Human Rights Act 1998 requires British law to comply with the European Convention on Human Rights (Council of Europe, 1950). The act highlighted the case for reform of the Data Protection Act 1984 and the Mental Health Act 1983. The new Data Protection Act came into force in 1998 and new policy recommendations governing the flow of information between NHS and partner agencies were issued by the Caldicott Committee (Department of Health, 1997). Deliberations regarding a new Mental Health Act and mental capacity legislation were ongoing throughout the period of research. The cases of JT (JT v UK, 1997) and FC (FC v UK, 1999), which featured serious abuses by relatives and others closely involved, have major implications regarding the rights of psychiatric service users to choose their representatives and the role of the carer in mental health.

The rise of the public health agenda under World Health Organisation influence has provided the rationale for incorporating social and environmental services within health (Department of Health, 1999e), modernisation programmes (Department of Health 1997 and 1998a) and agency partnerships. Modernisation programmes have spurred evidence-based practice, outcome measures and professional regulation and governance (Department of Health, 1998b). The National Institute of Clinical Excellence (NICE) and the Social Care Institute of Excellence (SCIE) have been established to promote research and evidence-based practice to supplement clinical governance frameworks.

1.2 Carer context

The term carer was introduced in community care discussions in the 1970s but was not recognised in law until the NHS and Community Care Act 1990 (Twigg, 1994). Most carers are also relatives (Carers National Association, 1997), but friends and neighbours may also provide care. The 2001 population census in England records around 6.8 million carers of whom approximately 1.5 million are providing care for a relative or friend with mental illness or some form of dementia (Maher and Green, 2002). Community care statistics reveal that one-quarter of all adults assessed during 2001/02 by mental health services were identified as having an informal carer (Department of Health, 2002d). The carer role is a vital component of community care, though it is important to emphasise that the carer role is not always a component of the community care team. For many service users, family and friends do not take on a formal ‘carer’ role.

Yet in spite of their centrality in many service users’ lives, in community care and in the recent government carer initiatives, research suggests that carers still feel marginalised by services. Indeed, only a minority have received their carer entitlements (Rethink, 2003b). The position needs to be understood in its wider historical and political context.

The last 60 years have been characterised by a sea change in ideologies, policies and service configuration. The shift from asylum to community care has been the most dramatic change with major implications for families and carers. Families and carers were not consulted about the shift from hospital to community care (Ramon, 1985). There was also an implicit expectation that families would fill the vacuum of care (Jones, 2001). Families felt unsupported, particularly at times of crisis when they found that hospital admission was increasingly difficult to procure, and excluded from professional decision-making, although they were providing most of the care. The frustrations of families led to self-help initiatives (Iodice and Wodarski, 1987), including the founding of voluntary sector bodies such as the National Schizophrenia Fellowship in 1972.

Legislation and policy initiatives to support carers were instigated by the Governments’ concern about the sustainability of community care (Parker and Clarke, 2002), the wider disability movement and carer-lobbying power. However, the carer cause has been characterised by gains and losses. The principle loss relates to proposals to abolish the role of the ‘nearest relative’ under the Mental Health Act with powers to influence a close relative’s detention and be involved in decision-making. The replacement roles of ‘nominated person’ and ‘carer’ have rights (identified in 2.2.4 below) that. even combined, have less power than the nearest relative. Gains include rights to involvement in care planning, an assessment of their own needs and access to services (identified under 2.2.2 below). The development of education programmes for carers (for example the Carers' Education Support Programme [CESP] run by Rethink in collaboration with local services), and the introduction of CSWs has been popular among carers. Carers are represented on national, regional and local strategy groups such as the National Institute for Mental Health in England (NIMHE) and local mental health forums. Carer recognition, training and strategic involvement are important landmarks in carer history and complement many parallel developments to empower service users. These advances play a prominent role in facilitating channels of communication between professional and carer roles at strategic, service development and personal healthcare levels.

1.3 Summary

This study occurs at a timely juncture in the development of mental health policy, coinciding with several other initiatives addressing patient confidentiality and information sharing between relevant parties and agencies in mental health. The role of carers in mental health, and the responsibility of statutory services to respond to the needs of carers, is also attracting increased recognition at both national and local levels. One vital component of mental health care is access to information, particularly for service users and carers to support informed choice. Developing and embedding sustainable frameworks to promote the flow of appropriate and necessary information is a crucial dimension within modern mental health services.

Section 2 Policy and literature review

Much has been written about the need for carer involvement in care planning but very little on how to involve carers in practice. Current legislation provides carers with few specific rights. The protection and use of information in general and specifically in relation to carers is deeply embedded in ethics and professional codes, policy and law, values and professional practice. This section reviews ethics, professional codes, general legislation, carer legislation, carer guidance documents and good practice approaches.

2.1 Frameworks governing confidentiality and information sharing

2.1.1 Ethical issues

Non-malificence and Beneficence are important principles in medical bio-ethics (Beauchamp and Childress, 1994). Non-malificence requires that no harm be intentionally inflicted. Beneficence requires positive action to prevent harm and promote good. Harm prevention and the promotion of good or best interests in respect of patient care are traditionally core elements of ethical practice.

Health professionals believe in the right of an individual's privacy in relation to his or her psychiatric condition, and are trained in 'patient confidentiality' rather than information sharing (Leggatt, 2001). They are concerned to keep the trust of the patient (British Medical Association, 1999) and fear being sued (Montgomery, 1997; Leggatt, 2001), although litigation is rare (Department of Health, 2001). Yet rights to confidentiality are not absolute, may be breached in cases of societal and public interest (W v Edgell, 1990), and need to reflect social responsibilities (Etzoni, 1999). Backlar (2001) contends that although in Western societies confidentiality in healthcare is implied and broadly assumed, providers should be clear about what information can be divulged to families and under what circumstances the patient has privacy rights. Furlong and Leggatt (1996) suggest a conceptual framework is needed to balance the rights and interests of patients with the needs and responsibilities of carers. Confidentiality is seen as a particularly taxing ethical issue when the family's involvement appears justified but the service user is withholding consent (Szmukler and Bloch, 1997). (Note: throughout the report consent is taken to mean informed, written, voluntary, recent and competent. It may also be independently witnessed and is often viewed as a process rather than an event.)

Carers need some kinds of information to enable them to provide effective care (Fruin 1998; Dowling 1995; Foundation for People with Learning Disabilities, 2002), to access their entitlements to an assessment of their own needs, services and welfare rights and to make decisions about how they want to lead their lives. They also need to be listened to, not only to contribute to the professional assessment of the service user's care but also to elicit from professionals information pertinent to informal care. However, carers and relatives may also be reluctant to share information with professionals in certain situations. These include not only feelings of family loyalty but in addition, fears of hospital admission, indiscriminate sharing of their confidences especially with the person cared for and reprisals within close relationships (Rapaport, 2002). Carer reluctance to share information for whatever reason is likely to restrict meaningful dialogue between professionals and carers.

Mental health service users face particular restrictions on their private lives. The right to privacy is essential in the interests of maintaining self-respect and enabling human interaction without constant social breakdown (Nagel, 1998 cited in Backlar, 2001). 'Patient confidentiality' is an essential component of the therapeutic alliance between the service user and professional to engender service user trust and facilitate recovery (Backlar, 2001). 'Patient autonomy', the right of a competent person to make decisions about his or her own life, is becoming an increasingly important part of healthcare policy. Significantly, an adult patient's right to refuse medical interventions is well-recognised in common law (British Medical Association, 1995).

Patient privacy and autonomy are vital components of mental health recovery. However, privacy and autonomy principles are subject to restrictions because of:

- doubts about an individual's capacity to make rational judgements
- public and personal safety considerations
- the treatment criteria of the Mental Health Act 1983 (where a person is detained).

The carer's need for information to support the caring role further threatens service user autonomy and privacy. Firstly the service user may have no choice about the identity of the carer, or the right to refuse to have one. The position is further complicated by

- disaffected and abusive relationships (Mental Health Act Commission, 1991)

- connotations of overprotection associated with the term carer, that conflict with the ethos of independence fostered by community care (Twigg, 1994)
- potential vested interests exist in close relationships (Brazier, 1992).

Professionals have concerns about disadvantaging the service user by sharing their personal information with the carer.

2.1.2 Professional codes and integrated working

Beauchamp and Childress (1994) observe that professional organisations impose obligations to ensure the trustworthiness of their members. They argue that professional codes are helpful if these recognise the complexity of moral issues and focus on the rights of individuals for veracity, respect for autonomy and justice, rather than being confined to the obligations of professionals.

Traditionally, professional codes have been generated without scrutiny or acceptance by patients and the public (Beauchamp and Childress, 1994). Many are being revised with stakeholder assistance (namely service users, carers, mental health professionals and CSWs). As a result, professionals with entrenched attitudes are seen to be breaching the new guidance of their own professional bodies (Department of Health, 2001). Professionals now run the risk of carer litigation where harm to carer (Zinn, 2003) or depriving carers of information to enable them to exercise their role (S v City, 2002) can be shown as a result of failures to communicate appropriately. As examples of change, the British Medical Association (1999) and General Medical Council (2000) guidelines indicate that disclosure may be made to carers without the service user’s consent if it is clearly in the service user’s best interests and to enable carers to provide care. The code of ethics for social workers (British Association of Social Workers, 2002), while upholding ‘patient autonomy’, exhorts social workers to help individuals and their families to explore options for resolving or balancing conflicts of interest.

The introduction of community mental health teams comprising health and social services staff are relatively new. Professionals have been required to learn very quickly how to work together even though they have been subject to different professional codes. These codes have not always explored the moral ground in relation to the carer’s needs or the complexity of partnerships, and multi-agency objectives. An assessment of services involved in mental health, drug and alcohol and child care provision found many examples of poor inter-agency communication. This was in spite of guidance from the Royal College of Psychiatrists (2000) urging co-operation with local area child protection committees.

> *There is a fundamental disagreement about the nature of confidentiality and professional responsibility in this area. SSDs comment on their*

> *frustration at being unable to have a debate or enter into negotiation with medical colleagues about these matters. Consultant psychiatrists are reported as concerned that child protection investigation or assessment will jeopardise their patient's treatment and improvement or that it attacks the civil liberty of the patient. GPs are equally concerned about a possible breach of medical confidentiality and damage to the doctor/patient relationship, including litigation.*
>
> (Kearney *et al.*, 2000, p.20).

However, there is hope that over time teams will work better together, develop joint practices and trust (Rapaport, 1996). Progress will be further enhanced by the government's modernisation imperatives. Given the critical position of the carer and service user relationship, professional skill in managing the interface is of utmost importance. This stance is supported by Experts by Experience (EbE), a group of service users and carers who advise NIMHE on their concerns. An unpublished discussion paper (2003) noted:

> *... Handling tensions between users and carers should be regarded as a core skill for mental health professionals and included in all qualifying training programmes and continuing professional development.*

2.2 Legislation and policy

2.2.1 The general legislative background

Building Bridges (Department of Health, 1995) provided the basis for confidentiality and information sharing policy within the multi-agency setting:

> *To help staff to balance the sometimes conflicting demands of patient confidentiality and sharing information, health, social and other agencies (in particular the police probation services and voluntary agencies) should discuss their policies over disclosure of information and produce an agreed written policy. This policy should:*
>
> - *Reflect the common law of confidentiality and the Data Protection Act [...];*
> - *Identify clear mechanisms for disclosure; and*
> - *Be available to users and carers for inspection.*
>
> (paragraph 1.5.12)

The European Convention on Human Rights (now incorporated into UK domestic legislation by the Human Rights Act 1998) requires clarity regarding the rules governing the protection and sharing of information. The need to balance carefully the respect for privacy with an overriding imperative to share information under the broad agenda of public interest is highlighted under Article 8, the right to respect for private and family life. With relevance to the respective positions of both service users and carers this states:

> 1. *Everyone has the right to respect for his [her] private and family life, his [her] home and his [her] correspondence.*

> *2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health morals, or the protection of the rights and freedoms of others.*
>
> (Council of Europe, 1950)

Government policy supports openness in information sharing wherever possible. The Data Protection Act 1998 is the main statute governing the protection and use of personal information. *The Protection and Use of Patient Information* (Department of Health, 1996) and the Caldicott Committee report (Department of Health, 1997) provide the basic framework for confidentiality and information sharing. Revised guidance on the care programme approach (CPA) (Department of Health, 1999c) reinforces the importance of information sharing between the relevant agencies, including the criminal justice system, as part of effective care co-ordination and risk management. All official policy must now be compatible with the European Convention on Human Rights.

The Data Protection Act 1998 concerns the whole process of acquiring and keeping personal information on living individuals. It also provides individuals with rights of access to their records and a means of taking action to rectify factual errors. Eight Data Protection Principles require data to be:

1. fairly and lawfully processed (with regard to obtaining, recording, storing and disclosing data)
2. processed for express purposes
3. adequate, relevant and not excessive
4. accurate
5. not kept longer than necessary
6. processed in accordance with the data subject's rights
7. secure
8. not transferable to countries outside the European Economic Area without adequate protection.

The Caldicott report makes recommendations regarding information flow between NHS authorities and allied partners 'for purposes other than direct care, medical research or where there is a statutory requirement for information' (Department of Health, 1997: 1). The recommendations are underpinned by six general principles that overlap and complement the Data Protection principles. The six underpinning principles to guide information sharing are:

1. justify the purpose(s)
2. anonymise information where possible
3. minimise use of identifiable information
4. restrict access to those with a need to know

5. ensure staff are aware of their responsibilities
6. ensure legal compliance.

While the Data Protection Act 1998 and Caldicott recommendations tighten the rules regarding the protection of information, the Freedom of Information Act 2004 represents government policy urging organisations to be as open as possible with information. Furthermore, from April 2004 service users have rights to see letters written by their clinicians regarding their care (Department of Health, 2003a). While trials of copying letters to service users have been welcomed by service users and carers, and have had little impact on clinicians' workloads, the full implications of the initiative in mental health are as yet unknown.

2.2.2 Carer legislation and policy guidance

The NHS and Community Care Act 1990 laid the foundations for the CPA and the involvement of carers in care planning. The Patient's Charter (Department of Health, 1992) states: 'if you agree, you can expect your relatives and friends to be kept up to date with the progress of your treatment'. The Carers (Recognition and Services) Act 1995 introduced the carer's right to an assessment of his/her own needs. This was subsequently extended under Standard 6 of the NSF for Mental Health (Department of Health, 1999a) which states:

> *All individuals who provide regular and substantial care for a person on CPA should:*
>
> - *have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis*
> - *have their own written care plan which is given to them and implemented in discussion with them..*

The NSF also identified social services as the lead agency for carer services. The national strategy for carers (Department of Health, 1999b) for the first time introduced extra funding of £140 million to help local authorities to provide carer respite services. The Carers and Disabled Children's Act 2000 empowers local authorities to provide services to carers in their own right. These include short-term break voucher schemes and direct payments to carers. Local authorities can also charge carers for the services that they receive and although carers have the right to have their needs assessed, they are still not entitled to have their needs met. However, carers need general as well as personal information. They may also need confidential information about the person cared for if they are to be enabled to implement their rights, which is arguably a positive outcome of these new initiatives.

In addition a new Carers (Equal Opportunities) Bill focuses on carers' health, employment and life-long learning issues. The Bill places duties on local authority social services departments (SSDs) to:

- inform carers about their rights to an assessment

- develop information strategies to ensure that carers know about their rights
- promote the health and welfare of carers
- ensure other parts of the local authority works with social services to deliver information strategies to help carers.

Developing Services for Carers and Families of People with Mental Illness (Department of Health, 2002a) provides guidance for the implementation of Standard 6 of the NSF for Mental Health (Department of Health, 1999a). It states that services should be:

- positive and inclusive: carers should be involved in decision-making and recognised as partners and co-experts
- flexible and individualised, person centred and able to reflect the diversity of carers
- accessible and responsive, available at all times and able to offer a rapid response
- integrated and co-ordinated, carer services being embedded in mainstream services.

The document also emphasises the importance of engaging carers as soon as possible during or after the first episode of mental illness of the individual concerned. However, guidance from the government is also contradictory. Social services, the lead carer authority, are advised that '... informal carers may also need to be given some personal information about that person' (Department of Health, 2000: 6.16). The NHS code of practice on confidentiality (Department of Health, 2003b) is highly circumspect about carer involvement:

> *Carers often provide valuable healthcare and, subject to complying with the best practice outlined, every effort should be made to support and facilitate their work. Only information essential to a patient's care should be disclosed and patients should be made aware of this. However, the explicit consent of a competent patient is needed before disclosing information to a carer. The best interests of a patient who is not competent to consent may warrant disclosure.*

Although breaches in confidentiality are conceived if in the best interests of the service user who is considered to be incompetent, this facility rests on professional discretion that is inevitably value-based. Given current ambiguities, professionals may assume that it is safer not to share any information with the carer in the absence of service user consent.

2.2.3 Mental health legislation

The 'nearest relative' defined under Section 26 of the Mental Health Act 1983 is identified using a hierarchy based on British genealogical traditions underpinned by principles of 'kindred and affinity' (NKH, 1959). The Act gave priority to a relative identified in the hierarchy who cares for the patient with the effect that the nearest relative is in most cases also the patient's main carer. The role has discretionary powers to influence a close relative's hospital detention and in this regard, an 'encoded' right to be involved in decision-making (Twigg, 1994: 295). The nearest relative is officially regarded as a patient safeguard (Department of Health and Social Security, 1976 and 1981) and where the powers combine with carer entitlements, creates a type of champion carer. However the role has, until recent changes made by case law (R on the application of SSG v Liverpool County Council, the Secretary of State for Health and LS [interested Party], 2002) excluded same sex partners. SSDs are not required to publicise the role. Hospital authorities are only required by the Mental Health Act 1983 to provide information to the nearest relative if the patient agrees. Evidence suggests that carers and healthcare staff generally do not know about the nearest relative role (Hart 1998; Gregor, 1999) and that the powers are rarely implemented (Rapaport, 2002). Professionals have not promoted the 'encoded' right and the ethical and moral issues of sharing information within the bounds of the powers have not been shaped by professional practice.

2.2.4 Mental Health Act Reform

The government appointed an Expert Committee to advise on legislative reform (Department of Health, 1999c). While the reform has been delayed to allow for a further period of consultation it is anticipated that the nearest relative will not feature in a new Act. Under the current proposals (Department of Health, 2002b and 2002c) the nearest relative will be replaced by the roles of 'carer' and 'nominated person'. The latter will be appointed by the patient subject to the approval of the approved mental health professional who replaces the approved social worker (ASW). The carer and nominated person (who may be one and the same) will have rights that even when combined in no way equate with the nearest relative's powers. The new roles are distinguished in that the carer has the right to request an assessment of the patient whereas the nominated person can appeal to a new tribunal, convened within 28 days of a preliminary assessment, on the patient's behalf. Both roles have rights to be consulted about care plans and discharge, and staff will have duties to provide information about services and how these can be accessed. However, of great significance to carers, professional discretion to exclude the carer from consultations is also proposed especially where:

> *Consultation will be inappropriate or counterproductive, for example where there is conflict of interest between the patient and carer.*
>
> *(Department of Health, 2002c, clause 8).*

Clause 8 considerably reduces the new carer's position in comparison with the statutory authority of the nearest relative.

However, the patient's capacity to make an informed and rational decision allowing his or her carer to receive personal information is fundamental to information sharing between professionals and carers. Problems occur because of the fluctuating nature of mental health problems and the patient's hostile reaction to his or her carers arising from mental illness. The law is currently silent on this issue. Proposals issued by the Lord Chancellor's Department (1997) to clarify the carer's position in respect of people whose ability to make decisions is temporarily or permanently impaired were deferred. However, in this regard a Mental Capacity Bill was issued in June 2004 (followed by the Mental Capacity Act 2005). This gives carers who have been appointed as lasting power of attorney, powers to make decisions about the patient's finances and welfare. If enacted the patient would have the power to appoint his or her carer as attorney when he or she was well, thus in some measure addressing weaknesses in current carer and mental health law.

2.3 *International policy and law*

A survey by the European Family Network EUFAMI, involving Britain, Switzerland, Norway, Spain and Germany, found that most family members feel they are not respected or listened to (Brand, 2001). However, Norway together with the United Kingdom are identified as having new laws recommending families be accepted as partners in the care team.

New Zealand developed a strategy for carer involvement in mental health that was championed at ministerial level (Mental Health Commission, 1998). This succeeded a statement by the country's Privacy Commissioner regarding his frustration at 'the refusal of some hospitals to adopt sensible policies governing the release of information about mentally disordered patients to their care-givers' (Office of the Privacy Commissioner, 1998). The model of carer involvement at strategic and care planning levels was largely influenced by the strong family traditions of the Maori community. Subsequent guidance issued by the New Zealand Ministry of Health (Royal Australian and New Zealand College of Psychiatrists, 2000) supports close co-operation with families and 'sharing information, planning, decision-making, and providing support and education when necessary'. The guidance identifies the complex cultural, ethical, legal, financial, organisational and treatment issues which affect the involvement of families in 'patient care' and the potential for conflict over the rights and responsibilities of consumer privacy and family concerns. While patient consent is upheld, the document states that the country's Privacy Act 1993 and Health Information Privacy Code 1994 do not prevent most aspects of working with families.

German law appears to take a strongly prescriptive stance about confidentiality. Under Section 203 of the German criminal code which deals with confidentiality (*Die Schweigepflicht: Juristische Grundlagen*/Confidentiality: Legal Basics) professionals are forbidden from sharing information that they have discovered in the course of their work or that has been found out in any other way. However, echoing the British 'Spycatcher' judgement (Attorney General v Guardian Newspaper, 1990) only 'secrets' are protected by confidentiality, not well-known facts . Thus, in respect of families where service users refuse to consent to information being shared only passing on secrets is forbidden. Where the family is aware that the patient is in hospital professionals may:

- contact the relatives and discuss facts that are already known to the family
- ask the family for information without the consent of the service user.

The family can also ask for a conversation with the professional without the service user being present. The policy advises professionals, in conversing with families, to allow family members to talk to establish how much they know. For example, do they know the diagnosis? Passing on the diagnosis can be a secret under Section 203, especially if it is the first diagnosis. If the family knows the diagnosis this can be passed on and the doctor can provide general information about the illness. The family must also observe confidentiality in respect of information received and the doctor must not tell the service user what he has told the family.

Their differing legal frameworks complicate comparisons with Australia and the United States. Furlong and Legatt (1996) suggest that a close reading of the amendments to the Victoria Mental Health Act Section 120A(3) (Australia) allows for an interpretation of confidentiality to permit meaningful collaboration between clinicians and families, enabling the clinician to share information in general terms to the next of kin or close relative. In New Hampshire, USA the normal rule that protects the privacy of communication between the treatment providers and service user does not apply when disclosure of information is to a close family member or carer (Foster, 2001).

Models of surrogate decision-making that address the position of an adult deemed to lack capacity to make informed choices already exist elsewhere. In Scotland (The Adults with Incapacity (Scotland) Act, 2000), South Australia (the Guardianship and Administration Act, 1993) and Ontario (Consent to Treatment Act, 1992; Advocacy Act, 1992; Substitute Decision Act, 1992) legislation allows for the appointment of a surrogate decision-maker or close equivalent. Appointees whose interventions must be in the best interests of the service user have certain rights to be involved in decision-making about the service user's welfare and, apart from Scotland, also medical treatment. These initiatives can be used in both learning disability and mental health scenarios.

2.4 Good practice approaches: selected examples

Good practice is found within individual practice, service developments and policy guidance. A few such models are identified and described below, this is not an exhaustive selection and is provided to indicate a range of current activities for supporting carers.

2.4.1 Advance statements

Advance statements or directives are potentially a method of supporting values-based information sharing practices between professionals and carers. These enable people to state their wishes in relation to their treatment and care, in advance of mental health breakdown. They have been used successfully to help people to plan ahead and maintain a degree of autonomy and control during crisis (Diggins, 1993) with beneficial outcomes on rates of hospital admission (Sutherby *et al*., 1999). They also enable the service user to nominate people to have control over their affairs. This may enhance the carer's position in decision-making where he or she is nominated. The Manic Depression Fellowship's *pro forma* [n.d.] also indicates people who should not be identified. Advance statements are recommended by the Expert Committee (Department of Health, 1999d), and actively promoted as part of a reformed Mental Health Act by the 60 organisations of the Mental Health Alliance (2003). However, as yet advance statements are not recognised in mental health law. They may be overridden. Prudent professionals may of course choose to state why they have acted against an individual's wishes. Advance statements are recognised in case law and healthcare policy and usefully promote service user values and autonomy. They avoid the problem of paternalism associated with best interests.

2.4.2 Casework

Social work education and practice has long recognised the importance of the family. Hollis (1965) states:

> *Thus far we have been discussing treatment goals from a client-centred perspective. A further dimension must of necessity be added. It is the exception rather than the rule that the worker can be concerned with the welfare of only one person. The caseworker always has an overall responsibility to the people with whom the client is interacting … . The worker must take into consideration the effect on others in the family of changes sought in the individual who for the moment is the focus of attention. … it is his responsibility to bring into the treatment planning in both his own and the client's mind pertinent inter-relationships between the client and other members of the family. … neither worker nor client can move wisely without giving full consideration to the interactions among family members. Complementarity exists in family relationships. A change in one part of the equilibrium not only brings changes in other parts but also results in 'feedback', counteractions that in turn affect people with whom the change originated.* (p.213)

The importance of involving those closest to the individual who is the focus of concern is thus not only important in enabling families and others to provide care, but is also an important part of treatment. Psychoeducation programmes (see for example National Institute for Clinical Excellence 2003 guidelines on the treatment of schizophrenia) have sought to involve families using psychological interventions without reference to formal confidentiality policies. While mainstream healthcare services have traditionally focused on the service user, the current problems experienced by carers suggest that even ASWs, though directed 'to ensure the best possible service to mentally ill persons and their families ...' (Department of Health and Social Security, 1986: para 15), have in a significant number of cases neglected their duties towards families and carers. The quest for good models in information sharing thus in some measure involves resurrecting former principles.

2.4.3 Forensic mental health – risk assessment

Family members and those closest to the service user are the most likely victims of psychiatric homicide (Sheppard, 1996). From the standpoint of forensic mental health, Reith (1998) suggests that the key tasks for agencies are to engage relatives in the care plan, explain mental illness and involve them in the risk assessment within the frame of balancing the rights of the individual with responsibilities towards the family and wider community:

> *It may be simpler to argue ... that the service user's right to confidentiality means that seeking out the views and feelings of immediate family members can be side-stepped. It is important to re-evaluate the concept of confidentiality. Practitioners must ... recognise the responsibility that professionals must accept in this difficult culture of community care for the mentally disordered offender, balancing the right of the community to be safe while not riding roughshod over civil liberties.* (p.64).

Reith also advocates providing the service user with a thorough explanation of the reasons for sharing information with the family with reference to inquiry reports held in her office.

Family group conference project, North Essex Partnership Trust

Decisions about confidentiality are also to be found deeply embedded in initiatives that recognise the interconnectedness and interdependence of families and those for whom they provide care. From within community services the North Essex Partnership Trust (2002) has based its family group conference (FGC) project on the New Zealand strategy described above. The FGC aims to empower service users and recognises the family as a valuable source of knowledge and understanding to help the individual with mental health problems. The ethos supports the family's right to be involved in decision-making. Service users agree to sign family reports so that these can be shared with relevant family members and friends. Thus the model requires the service user's co-operation.

2.4.4 Carer training

The CESP is an example of carer training delivered by Rethink in collaboration with local mental health services. Rethink and the Sainsbury Centre for Mental Health developed the model (1999), which is conceptually based on well-researched psychoeducation programmes. CESPs inform carers about mental illness, psychosocial interventions and how to assert their rights (Shore and Holnshaw 1998). As such they give carers:

> *... basic skills to advocate for services for their relatives and themselves, acknowledging different perspectives on need.*
>
> (Rethink and Sainsbury Centre, 1999).

CESPs are important in information sharing in that they provide carers with a knowledge base about mental illness to enable them to understand and communicate with professionals. CESP courses have been implemented in many parts of the country, for example Essex, Birmingham, Guildford and Warwickshire, and they are popular among carers. Other models of carer training include the Family Education Training Programme (another Rethink programme), and the Meriden family support programme (see below).

The Meriden West Midlands Family Programme

This programme was set up in 1998 following a West Midlands regional request to develop evidence-based interventions in adult mental health. The primary aim was to develop family sensitive mental health services and practitioners skilled in evidence-based family work, where a service user lives with what might be described as severe and enduring mental ill health. This approach has a robust research base to it proving to reduce relapse rates for service users, reducing family care-giving stress and increasing effective communication and problem-solving within the family. Ongoing evaluation and feedback from families has been consistently good, helping families engage with professionals and feeling valued.

The concept of confidentiality is often a concern to clinicians training in this work and one effective way of raising the profile of the needs of carers has been to involve carers directly in the teaching and training process to ‘tell their story’ of their own experience. Carers are usually very willing to do this and clinicians repeatedly report this has major impact on how they go on to engage families following the training in family interventions. One main component of the model is information sharing between the service user and the family members. This often takes the form of the service user describing to the other family members their experience of being unwell. During this process, information about the service and the particular difficulty the user identifies is discussed. With this approach both the service user and the carer has control over what information is divulged. However, the evidence base for this work maintains that, by encouraging greater effective communication between people who significantly influence each other, outcomes for both parties are dramatic. Service satisfaction through a positive experience is well known to enhance future relationships between users, carers and clinicians. With more than 100 trainers and 1450 people trained in this intervention in the West Midlands, families are hopefully beginning to receive a service which is long overdue.

Marie Crofts, senior project worker, Meriden

2.4.5 Early intervention services

The government is introducing early intervention services (EIS) to pro-actively support young people managing mental health problems for the first time. The target was to introduce 50 EIS in England by December 2004. In a visit to the carers' support group attached to the Lambeth Early Onset Service (LEO) the research team heard how well-supported family members felt by LEO professionals. Below, the LEO team outline their specific approach to working with families.

Lambeth Early Onset Service (LEO)

The service is for younger people (16-35), particularly those in their first or second episode of psychotic experience. The ethos is to provide early intervention, individual help and treatment to reduce the duration of untreated psychosis and to inform, empower and involve the client and their family in all aspects of their care.

People access the service via the crisis assessment team, who refer either to the community team or the inpatient service.

LEO is staffed by a multidisciplinary team of psychiatrists, nurses, psychologists, social workers, and occupational therapists. Its approach to working with carers is:

- To engage with families as soon as possible after crisis.
- To provide written and verbal general information for the carer on the service, psychosis and their rights.
- To explain to the service user the importance of engaging their carers.
- To provide more specific client information where the service user gives consent.
- To review service user consent where this has been withheld.
- To obtain information from families about what has led to the crisis.
- To explain the role of the primary nurse in the context of 'patient care' and keeping the family up to date with weekly appointments.
- To work with carers and service users separately and together.
- To address carers' anxieties by finding ways of helping them.
- To facilitate carer/family access to an appointment with professionals including psychiatrists.
- To involve the carer where appropriate in giving medication before discharge.
- To provide information about carer groups.

2.4.6 Family therapy - psychoeducation programmes

Within the frame of family therapy Szmukler and Bloch (1997) acknowledge the potential ethical dilemma of observing patient confidentiality and involving the family in the service user's care. To avoid damaging 'patient' autonomy and the therapeutic relationship the authors suggest a set of guiding principles to structure information sharing practice. The approach involves a clear explanation at the outset about information sharing, and recognition that service user consent can be renegotiated as part of a dynamic process during the journey from breakdown to recovery. Where the service user refuses to give consent the professional should persevere in seeking the service user's agreement, clarify why the information is needed and seek to understand the reasons behind the refusal. If these approaches fail the professional can negotiate restricted conditions of disclosure. As a last resort, factors to be weighed in deciding to act against the service user's wishes are identified as follows:

- the nature and magnitude of the harm to be avoided
- the availability of alternative courses acceptable to the service user
- the service user's capacity to make choices based on his or her understanding of the proposed treatment
- an assessment of the quality of family relationships and the longer term concerns
- the feasibility of using less restrictive care alternatives where the family is involved
- a duty of care on the part of professionals to help families, given the huge impact mental health problems has on their lives.

In addition, considering nearest relatives who abuse, the authors acknowledge that professionals need to discriminate against families and carers who have an inappropriate relationship with the service user. This stepwise approach provides professionals with a set of principles to guide discernment and discretion in communicating with families and carers.

Surrey-wide Operational Partnership Group in Mental Health (SWOP)

In 2001 the group produced a multi-agency policy document with four main interactive parts covering:

- The partnership ethos and mechanisms for multi-agency working
- The key principles and procedures on confidentiality and information exchange
- The duties of healthcare staff and basic procedures
- Carers' issues and confidentiality.

The document was expressly written for staff and volunteers in statutory and voluntary organisations with mental healthcare responsibilities. The separate carers' section was designed in collaboration with a local carers' group. This section identifies the carer role, context of care and carers' rights under mental health and carer legislation. It links with the sections on principles and procedures and responsibilities of staff in a wide range of health and welfare areas such as security of records, welfare benefits and housing. The policy attempts to provide workers with general guidance regarding the circumstances in which information should be protected and shared and to clarify the steps that should be taken in the decision-making process. These include obtaining the service user's consent wherever possible, consulting colleagues and in extreme cases taking legal advice. The document attempts to address the factors professionals should consider when sharing information with carers and what carers might wish to consider when imparting information to professionals. The importance of recording the decision-making process so that actions can be justified if so required is also emphasised. The first edition of the policy (SWOP, 1999) was promoted in the government consultation document *Guidance on the Section 31 Partnership Arrangements* (Department of Health and Department of Environment, Transport and the Regions, 1999, p.30)

2.5 Summary

While central government policy has attempted to promote the role of carers in care planning to sustain community care, policy guidance on information sharing between professionals and carers has failed to address the problems that occur because of the fluctuating nature of mental illness and its effects on decision-making. Professional codes as they stand neither explore nor develop the moral ground that lies between carers' needs for information to enable them to care and the service user's need for privacy. Policy guidance is both inconsistent and scattered in a range of documentation. Professionals are uncertain about what they may share and carers are often unaware of their rights. Yet the need to balance rights with responsibilities deriving from advances in case law and the Human Rights Act 1998 is an imperative for constructing an ethical basis to enable professionals and carers to share appropriate information for the benefit of service users and patients. Furthermore, evidence also suggests that carers need certain information to safeguard their own health and well-being.

Examples of advances in practice exist in the shape of international law, policy development and service innovations. The models identified as possible ways forward strongly suggest that the rules governing confidentiality at the sharp end of practice cannot be wholly prescriptive. They must allow for professional assessment and discretion not only of the patient or service user's situation, but also the context of care, the carer's commitment and the overall objectives of providing or withholding information. Judgements are inevitably based on values and experiences. Professionals in their daily contact with service users and carers hold the key to balancing the perspectives of the different parties involved, including their employers and professional bodies. Carers who are committed to the welfare of the person cared for are potentially important agents of value-based practice. The fuzzy complex of community care institutions, of which families and carers form a major part, poses major challenges for ethical practice in information sharing between professionals and carers. It is this conundrum that this research sets out to explore and unravel.

Section 3 Method

This study used multiple methods of data collection to identify examples of good information sharing practices between mental health professionals and carers. This section outlines the specific aims of the study and describes the data collection and analysis process in a series of related stages.

3.1 Aims

The study had four main aims, all in relation to information sharing between mental health professionals and carers of people with mental health problems:

1. To identify examples of good practice for information sharing with carers.
2. To identify the contrasting perspectives of three stakeholder groups – carers, service users and professionals – on priorities in information sharing.
3. To identify differences between the views of carers of adults of working age and carers of older people with mental health problems.
4. To develop synthesised model(s) of good practice, which are widely applicable and appropriate for multi-disciplinary use.

In addition to these aims the study also considered the information sharing requirements for young carers, carers from black and minority ethnic (BME) communities and carers supporting a person with an eating disorder.

3.2 Study management

The study was co-ordinated by the Section of Social Work and Social Care, Health Services Research Department, Institute of Psychiatry (IOP), London. The research team was led by Dr Vanessa Pinfold and the study employed a part-time research worker (Dr Joan Rapaport) for 11 months, a full-time research assistant (Sophie Bellringer) for eight months and a bank research worker (Samantha Waitere).

The research team was supported by the principal investigator of the study (Professor Peter Huxley) and the project grant holders. The research team held regular project meetings and two members of this group also formed part of our expert panel. The grant holders have all commented on this final report.

The expert panel consisted of 19 members (see Appendix 1). Individuals were recruited because of their interest in mental health information sharing practices and to provide a balance of stakeholder presentation from the following groups: people who have used services, professionals (old age and adult consultant psychiatrists, psychiatric nursing, social work), CSWs (young people, adults), carers (supporting person with dementia and adults of working age) and academics. The expert panel met on three occasions with the following brief:

- Session one: define key parameters for the study and develop survey questionnaires.
- Session two: discuss findings to date and design interview question schedules.
- Session three: develop model(s) of good practice – key principles underpinning information sharing between mental health professionals and carers.

The expert panel members all had the opportunity to comment on the final draft of the report.

In addition to the expert panel we planned to recruit and work with a virtual network (n=60), to correspond through e-mail communication. In practice we recruited a large network of people interested in the study – 250 individuals on the project database plus connections through e-mail lists. This network received a project newsletter regularly by e-mail and 14 people were officially recruited to the virtual panel. Our contacts helped in the promotion of the survey (see Section 3.3.2) and the 14 virtual panel members assisted with specific tasks and also commented on the final report.

3.3 Data collection and analysis

The study was arranged in a number of stages:

- policy and literature review
- national survey of current good practice
- in-depth interviews with key stakeholders
- group discussions with key stakeholders
- two multi-disciplinary workshops.

These stages are outlined in more detail in this section, alongside considerations for research ethics and the mechanisms used for study management. A flow chart describing the research process is provided in Figure 1.

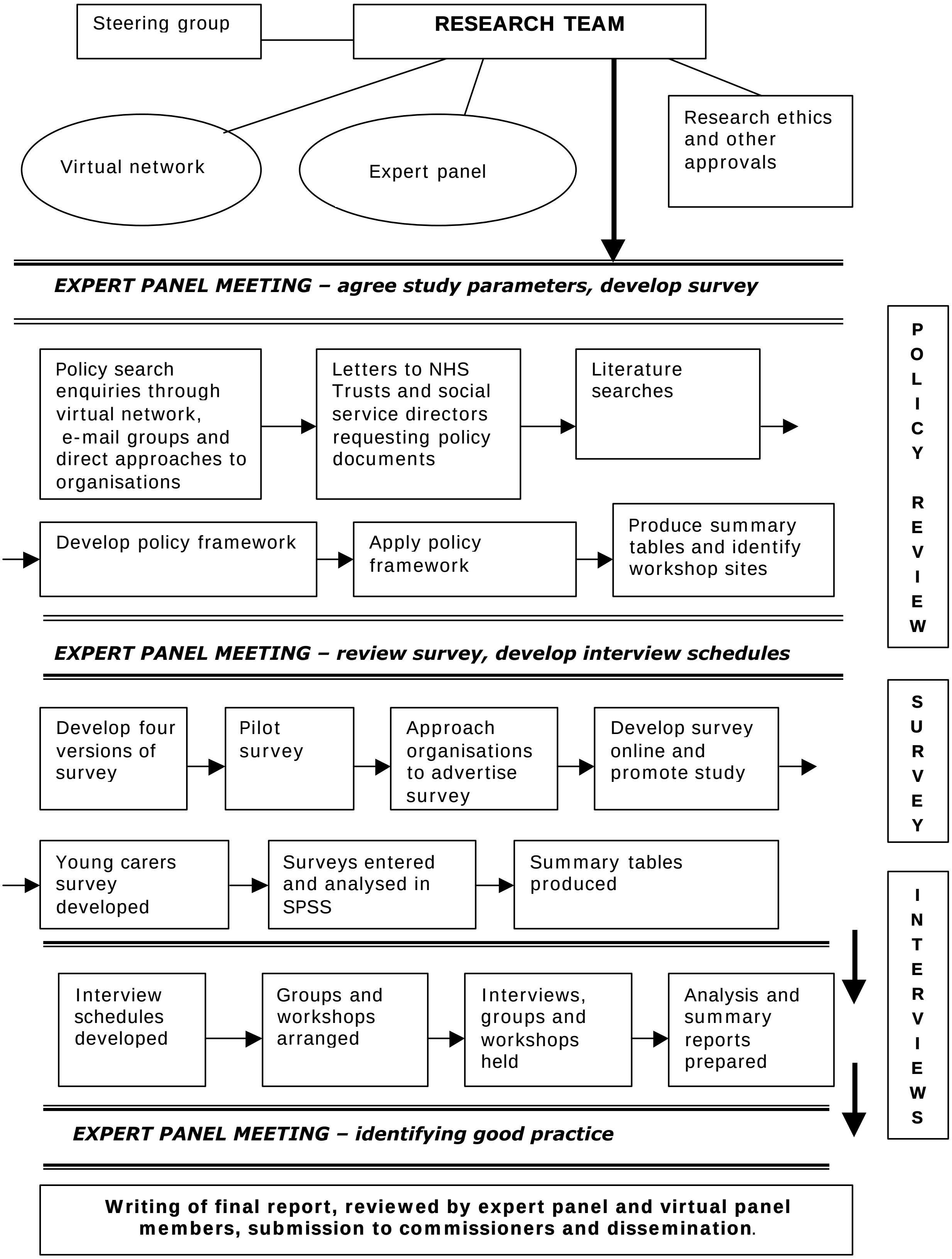
The rationale for carrying out a multi-method grounded study, where each stage in the research process built upon the preceding research activity, was based upon the complex nature of the research subject, with limited previous research in this area, necessitating data collection to be derived from a range of different stakeholders in an exploratory manner. The study operated in a pragmatic framework, balancing time pressures with research rigour. A multi-method approach enabled the research team to draw upon information resources shown by policy and research literature in this field of expertise to be relevant.

3.3.1 Research ethics

The research governance framework at the IOP requires all studies to be approved by the IOP research ethics committee. Where researchers are recruiting participants from South London and Maudsley NHS Trust, R&D committee approval and honorary NHS research contracts with the Trust are obtained.

In this study we sought research ethics approval from the local research ethics committee (LREC) at the IOP. Through the Central Office for Research Ethics Committees (COREC) we applied for Multi-Centre Research Ethics Committee (MREC) approval. MREC approval is required when studies are multi-site. In our case the national survey would include participants from across England. The study was granted MREC approval from the Metropolitan Multi-Centre Research Ethics Committee in August 2003.

Figure 1: Research process



The study was constrained by requirements for research ethics approval at a local level. Although we had obtained MREC approval, to promote the survey within NHS Trusts in England we needed individual LREC and R&D approval. This would have meant obtaining approval in all mental health provider Trusts in England, an impossible task in the timescale of this project. Instead of promoting the survey through NHS Trusts and social service departments the study team relied on networks of contacts though professional and voluntary organisations. This will have introduced bias into the samples as all those participating in the research had to be well-networked to find out about the research.

In the final part of the study we worked in two sites where good practice carer policies were identified through stage one of the data collection process. In these sites we attempted to run multi-disciplinary workshops involving carers, service users and professionals. The carers and service users were recruited locally through user and carer forums and voluntary sector agencies, for example Mind, Rethink and the Mental After Care Association. The professionals were recruited through NHS Trusts. The requirement for LREC and R&D consent, and the process of obtaining honorary contracts with police checks, delayed us in one site. We had to remove the Trust staff part of the sample from one workshop group. Where research data were collected through in-depth interviews or workshop settings, written consent was obtained.

The study team recognise the importance of research governance frameworks. In retrospect they would have designed the study differently to take account of the short timescale of the project and the increasingly involved nature of local health and social care research governance processes.

3.3.2 Policy and literature review

The first stage of data collection was concerned with identifying and reviewing the policy context for supporting carers, and in particular for promoting best practice information sharing principles in mental health. This included obtaining and reviewing a range of materials including legislation such as the Data Protection Act, health and social service policy documents and guidance notes, and good practice documents produced by voluntary sector organisations.

Policy searches

Policy information was obtained from two policy searches. The first search occurred during August and September 2003 and was conducted largely by email. Mental health professional, carer and service user organisations including the Mental Health Alliance and the Care Programme Association were approached and asked to identify and send examples of confidentiality policies that incorporated information sharing between professionals and carers, and other documents related to supporting mental health carers. They were also asked to send the information to any other organisations and individuals who might know of or be able to locate examples of documents that addressed the carer perspective.

The second search targeted the Directors of 171 Trusts and Social Services Departments (SSDs) in England. These authorities were asked to pass on the request to the appropriate stakeholders and to include general policies on the protection and use of personal information in addition to those incorporating carer issues. (Note: This list could have contained a few duplications where recent mergers or structural changes to status as a provider of mental health services had occurred.)

This policy trawl extended from November 2003 to the end of February 2004 to maximise the potential of the search. The websites of professional and voluntary organisations were also searched for information and these contacts were also followed-up by telephone. In addition, we searched for international examples through our network of contacts, particularly in Europe, Australia and New Zealand and North America.

Literature review

The research team also undertook a review of literature through data base searches (PsyInfo, Medline, Assia) and manual follow-up of extended reference lists. The search terms used by the team included: carers, relatives and families, confidentiality, patient confidentiality, ethics, information sharing, and carer involvement. The team used Rethink and IOP research sources and a professional search organisation specialising in health and social care issues.

Framework for policy analysis

The framework to inform the analysis of the policies was devised by core members of the research team and a senior researcher at the IOP. The document was largely informed by the Surrey-wide Operational Partnership Group policy (1999) and the principles suggested by Szmukler and Bloch (1997) to guide professionals when sharing personal information with carers. The expert panel agreed the framework as an appropriate analytic tool at the second expert panel meeting held in January 2004. The framework incorporates the following main items:

- structure and document description
- content: guiding principles
- content: legislation and national policy
- content: staff duties
- content: application of principles in practice
- content: carer perspective.

One member of the research team applied the framework to the collected documentation, and a small sample of the documents were also analysed by a second researcher to address inter-rater reliability. Data entered into the framework were subsequently transferred to tables summarising the information.

As well as reviewing the policies as specific documents, the study also investigated the impact of having established carer policies on information practices in two study sites: West Sussex and Derbyshire (see Section 3.3.4).

Criteria for identifying good practice policy documentation

The study identified two sites to work in to assess the impact of information sharing policies on the ground. These sites were selected on the basis of the policies they submitted to the research project. The first process was to identify policies (see ‘Policy searches’ page 37) and secondly to review the policies using a standard framework (see ‘Framework for policy analysis’ page 38) and assess good practice credentials. In order to identify good practice models for use in the research, the study team developed the following criteria:

- policy should have a specific focus on carers
- policy should be a partnership document involving an NHS Trust and social services
- policy should be written with and for carers in a language that is accessible to all relevant stakeholders
- policy should acknowledge the care context and the balancing of carer and service user needs.

The two sites selected in the study had developed information sharing policies with carers, and these were being implemented on the ground. They also covered two different areas of England and were selected to provide an insight into the relationships between policy development and actions in practice on the ground.

3.3.3 Survey of current good practice

To identify examples of good practice from the field, a brief survey was developed for national use. The goal was to capture the perspectives of various stakeholder groups so four versions were created for: service users, carers, mental health professionals and CSWs. Some respondents would have multiple roles and so people were asked to choose one version to complete. Each questionnaire asked respondents about their different roles as service user, professional, CSW and carers. In addition to the four core surveys an additional version was created for young carers.

Survey development

The four versions of the main questionnaire were developed by the research team in consultation with the expert panel and contacts within the study support network. The versions were also piloted with stakeholders from each group and amendments made. This was carried out through face-to-face interviews as well as mailing the questionnaire to stakeholder groups and collecting written and verbal feedback. Two CSWs (one for young carers and the other for adult carers), two professionals (one psychiatrist and one ASW) and ten service users were involved in the survey pilot.

Each of the surveys had a set of core questions that were included in each version and additional questions as appropriate for a particular stakeholder group (see Appendix 3 for one example). The service user version has been criticised for being over-complicated and difficult to complete. This must be taken into account when considering findings from the study alongside other recruitment issues associated with a convenience, purposive and snowballing sampling technique.

The four main versions of the survey were developed as self-completion questionnaires. In order to increase access to the survey, they were made available online through the IOP/Rethink website for carers (www.mentalhealthcare.org) and as paper copies. The research team provided telephone support where needed and a researcher visited one Mind user group to complete questionnaires face-to-face with a small group of service users. Copies of the questionnaires can be obtained from the research team.

The young carer questionnaire was developed with two CSWs. The survey was designed specifically to be completed with the assistance of a CSW.

Survey content

The main questionnaires were designed in sections addressing:

- demographic and background characteristics of the sample
- information sharing experiences including main barriers to information sharing
- resolution suggestions and examples of good information sharing practices.

The service user questionnaire paid particular attention to when, if at all, personal information should be shared with carers, what information should be shared and how it should be shared. The questionnaire was designed for people with experience of carers being involved in their care though a small number (n=32) identified they had no carer.

The professional questionnaire – designed for a range of mental health professionals - asked in addition about information sharing practices as applied to different mental health problems (SMI, dementia, eating disorders and learning difficulties/mental health problems).

The CSW survey was produced because these workers (in relatively new roles) provide advocacy, respite and other support services for carers to address the needs of the carer that arise as a consequence of supporting a person with mental health problems. This survey asked about the CSW role, working as a bridge between professionals and carers.

The carer version asked respondents to describe their caring context in some detail, for example ‘Do you live with the service user?’; ‘How long have you been the main carer?’; ‘Do you provide support to more than one person?’ It also addressed how included and involved carers felt in the care of the person supported.

Survey promotion and sampling

The four main questionnaires were extensively promoted through professional and voluntary sector networks. We relied on an extensive network of contacts to advertise the national study and encourage people to go online or fill out a paper copy of the questionnaires. To preserve the anonymity of our research contacts we have not provided a detailed list of the groups that were involved, however a summary of the types of dissemination routes adopted is provided in Table 1 and Appendix 4 lists all the organisations that supported the project.

Table 1 Promotion routes for national survey on information sharing practices in mental health

Type of promotion	Number
Website adverts on organisation sites	13 website links to online survey
E-mails sent to staff or groups within an organisation	7 group lists sent advert promoting survey
Promotion at conferences	5 conferences attended to promote survey
Promotion to groups	53 groups received copies of surveys
Magazine adverts	3 adverts placed
Specific promotion with BME groups	5 projects/networks contacted
Specific promotion to young carers	66 projects contacted
Individual contacts	290 people/organisations on database
	85 telephone contacts requesting survey

The survey responses do not provide a representative sample of service users, professionals, carers and CSWs’ views because we relied on convenience, purposive and snowball sampling techniques. The purposive sample were recruited via direct approaches to services in Rethink working with carers from BME communities, and visits to Mind and Rethink services to fill in surveys with service users. The snowballing technique was used through Rethink and partner networks sending an advert e-mail to key individuals who send out to contacts on appropriate e-mail lists as well as promoting the survey through Rethink care group co-ordinators. The responses were mostly achieved through direct approaches to individual stakeholders and groups (convenience sampling) via Rethink and partner networks.

Survey data synthesis

The surveys were filled in both online and in hard copy. The data sets were cleaned to remove duplicate entries and cases containing no data where forms were submitted online. The data were analysed using SPSS (version 12.0) for each of the individual surveys separately, and one merged data file for questions that were repeated across user, professional, carer and CSW versions. To produce descriptive statistics one member of the research team carried out quantitative data analysis of the survey using SPSS; missing data was not adjusted for in analyses but is reported in all data tables. The survey versions also contained a number of qualitative responses to open-ended questions and these were explored using content analysis. Members of the research team coded these data independently. A rater to ensure the coding frames were being applied consistently checked a sample of responses from each question. The whole research team and a senior qualitative researcher who was also a study grant holder generated the coding frames for the qualitative survey data. This process involved: reading through responses (hard copy print outs), creating thematic coding trees, applying coding frame to a sample of responses, revising coding frame where necessary, applying final coding frame to complete data set on paper and transposing these responses into SPSS data sets to generate strength of theme data.

In the report, the data are presented as a series of summary tables and selected quotations are used to highlight key themes from the qualitative data sets.

3.3.4 Qualitative interviews and groups

In-depth interviews with stakeholders

In the study, each stage built upon the preceding data collection process. In-depth qualitative interviews were planned with stakeholders to discuss experiences of good practice. At this qualitative interviewing stage, the research team were less concerned with the problems and barriers surrounding the sharing of general, personal and sensitive information. Emphasis was on learning how individuals were managing information sharing in practice, including resolutions that were acceptable to service users, carers and professionals.

The research team recruited individuals using a quota sampling procedure. It was important to interview stakeholders from different groups (service user, professional, CSW, carer) but also be mindful of the different contexts that people worked or lived in relating to geographical location, ethnic background, gender, age, length of experience in role and mental health specialism. Table 2 describes the characteristics of the 34 interviewed.

Table 2 Summary characteristics of stakeholder interviews

Stakeholder group	Number of interviews	Diversity characteristics
Mental health service users	5	3 female, 2 male 2 South East, 2 London, 1 South West All white ethnic backgrounds
Professionals working in mental health and ageing	5	3 female, 2 males 3 London, 2 South East All white ethnic backgrounds 2 social workers, 2 psychiatrists, 1 hospital day unit manager
Professionals working in adult mental health services	9	5 female, 4 male 2 North, 3 Midlands, 2 London, 1 South West, 1 South East 1 BME group, 8 white 1 GP, 2 psychiatrists, 5 social workers, 1 nurse
Carers for people with severe mental illness	7	7 female 2 London, 1 South West, 2, Midlands, 2 North 1 BME group, 8 white
Carers supporting people with dementia	5	3 female, 2 male 4 South East, 1 London All white ethnic backgrounds
Carer support workers	3	3 female 1 Eastern, 1 London, 1 South East 1 BME group, 2 white

Note: The above figures relate to the recruited role of each participant. Several participants had dual experiences e.g. a GP who was also a carer, a CSW who was a trained community psychiatric nurse (CPN).

The in-depth interviews were conducted as telephone interviews and lasted between 25 and 90 minutes, except for five interviews that were carried out face-to-face at the request of the individual participant. The interviews were carried out by two of the study researchers using a brief interview schedule (see Appendix 5). Detailed notes were taken during the interviews which were written up immediately afterwards.

Stakeholder groups

While recruiting for qualitative interviews and analysing the survey responses the research team became aware of some gaps in our data set. The survey was less successful at reaching carers of people with dementia, carers from BME communities and service users. To supplement the survey and in-depth interviews, the project team ran group discussions to identify points of good practice. These homogeneous groups were held with:

- carers attending a mosque in Southern England, in a building situated on the campus of the mosque (n=12)
- service users attending a day centre service in Southern England run by a voluntary sector organisation on behalf of the local Trust (n=20 though by end of session n=6)
- carers of people with dementia attending a support group in Eastern region (n=23)
- carers of people with dementia attending a support group in a London borough (n=23)

The groups each had two facilitators, one person leading the discussion and a note taker who made detailed notes from the discussion and recorded summary good practice points on a main flip chart. The groups were informal discussions, not focus groups, but they each followed a consistent structure:

- introduce the research topic and researchers
- short presentation highlighting key points relevant to the topic
- facilitated open discussion
    - what hinders information sharing between professionals and carers?
    - what helps information sharing practices between professional and carers?
    - recommendations for improving the information sharing process.

Each group lasted between 1.5 and 2 hours. The groups were written up using a simple grid and they were analysed alongside other qualitative data from the study. The material from the groups was summarised in a table and these were sent to lead participants for verification.

Data synthesis qualitative data

The interviews were analysed manually. The applied analysis procedure was systematic and rigorous, following well defined principles of qualitative analysis (Silverman, 2001). Two members of the research team led the process under supervision from a third member of the team. The actual steps used in the coding of the interviews are outlined below:

1. Complete set of transcripts distributed to four members of the research team. Individual team members read transcripts in preparation for group discussion of key themes.
2. Day long coding meeting where four researchers went systematically through a sample of interviews generating a preliminary coding framework to apply across:
   i) interviews relating to people working in services for older adults and carers of older people with mental health problems
   ii) interviews relating to those associated with adult mental health services (service users, professionals, carers).
3. The preliminary coding structure was applied to full data set and amendments to framework were made by the researchers.
4. Full coding framework generated and applied to all interview notes (n=34).
   i) Coding sheets used to record transcript numbers where coded themes are identified to provide content analysis grid for:
      - carers of older adults
      - professionals working with older adults
      - carers of people with mental health problems who are adults of working age
      - professionals working in adult mental health services
      - mental health service users
      - CSWs in adult mental health services
   ii) Interview notes coded, with individual codes being applied to blocks of text and key statements highlighted to provide selected quotations for use in the report.

3.3.4 Workshops to investigate policy implementation

The research team wanted to examine the impact of ‘good practice’ policies on the ground, to assess key influential factors for their successful implementation. This part of the study was an extension of the original research protocol, and it was included in the study design after meeting with NCCSDO (the funder) in November 2003.

A half-day workshop on information sharing between carers and professionals involving carers, service users and professionals was held to investigate the link between policy documentation and clinical practice for information sharing between professionals and carers. Two Trust policies – Derbyshire and West Sussex – were selected as demonstrating commitment to carers’ needs for appropriate personal healthcare information about the people for whom they were providing care (see ‘Criteria for identifying good practice policy documentation’, page 39).

The research team negotiated with the ethics committees and research governance bodies in both of the selected Trusts to hold a workshop in each area. The process of obtaining consent from research governance and two ethics committees in each area was complicated by the different requirements of each organisation, service reconfiguration and the implementation of new rules governing the approval processes. These factors caused delays in both organising and promoting the events. Table 3 describes participant details for those attending the two events.

Table 3 Workshop participants

	West Sussex	Derbyshire
Carer	4	11
Service user	2	1
Nurses	1	-
Social worker/assistant social worker	1	-
Manager (patient advice and liaison service)	1	-
Manager (community mental health team, day centre, NHS)	2	1
Community support officer	2	3
Carer development officer	1	-
Rethink staff member	-	3
User advocate	-	2
Solicitor	-	1
Total number of attendees	**14**	**22**

The main objective of the workshop programme were to address the following areas:

- difficulties in information sharing between professionals and carers
- conflict resolution
- stakeholder views on the content of the local policy and its implementation
- the principles underpinning good practice
- recommendations for practice.

Two researchers facilitated the workshops. They generated data using pair exercises, mixed stakeholder groups using case vignettes and focused discussion to generate data. Case vignettes (see Appendix 6) based on an amalgam of real-life scenarios encompassing mental health situations involving carers in supporting adults of working age and older people and young people with eating disorders. One case encompassed the minority ethnic perspective. Participants were asked to identify the different needs and perspectives of each of the stakeholders, potential conflict areas and how conflicts in information sharing might be resolved.

The workshops used flip charts to record key discussion points and detailed written notes were taken. The results from the workshops are described in Section 8, which includes information supplied in a feedback *pro forma*. At the beginning of the workshop each participant was asked to fill out a feedback *pro forma* providing their views on how local carer information policies were impacting on current practice. All the participants in West Sussex completed a *pro forma* as did 16 out of 22 participants in Derbyshire.

3. 4 Summary

The aim of this study was to identify examples of effective ways for mental health professionals to involve carers in information sharing. This study used multiple methods of data collection to identify examples of good information sharing practices drawing upon the experience and expert opinion of several stakeholder groups connected with old age and adult mental health services: service users; carers (including young carers); mental health professionals; CSWs. The key components of the study were:

- widespread consultation with stakeholders via expert panel and virtual network of key contacts
- policy and literature review
- national survey to review information sharing practices in mental health
- interviews with stakeholders to identify good practice experiences
- four group discussions and two workshop events.

Section 4 Policy analysis

The search for policy and guidance documentation followed several routes of inquiry (see Section 2). The first direct approaches produced eight responses and documentation including four from statutory bodies although two of these were in early draft format. With regard to the second trawl, 40 NHS Trusts and eight SSDs (out of 171) responded with policy documentation. Several social services respondents sent Trust policies, which in two cases had already been received. Two Trusts and one SSD advised that they had no confidentiality policy. Another Trust stated that they used the Data Protection Act. Three SSDs suggested an approach to their respective local Trusts and most (apart from six) of the Trust policies reflected social services input. Three Trust policies were described as still being in draft format. Most policies had been produced since 2000, although four were respectively dated 1989, 1995, 1996 and 1999 and two were undated. The continuing reconfiguration of Trust boundaries was evident in that five Trusts advised that they did not provide or were no longer providing mental health services.

The relatively low Trust and SSD response may be due to several reasons such as:

- the request did not reach the right person
- the organisation was reluctant to share their policy because it did not reflect carer issues
- policy is reflected in a wide range of documents rather than one succinct document – there may therefore have been a degree of uncertainty about what to send
- trusts and SSDs have only recently merged – many organisations may therefore be in the process of re-aligning their policies
- SSDs have traditionally used procedure manuals - confidentiality is deeply embedded in a range of procedures rather than discreet policies.

The probability that the research did not identify all potentially relevant policy documentation was confirmed after a workshop in West Sussex was undertaken (see Section 2). The event subsequently revealed a carer's strategy document, action plan, information booklet and young carers' action plan and in addition, a video *Do you care?* The latter was modelled on a video produced by another local authority in partnership with carers (whose information was also not received). The research team is thus aware that despite considerable efforts to obtain policy documentation from across England, the analysis does not provide a complete national policy review on information sharing in mental health.

Policy guidance, guidelines, protocols and interagency agreements on information sharing were all defined as policies. A very wide range of policy documents was received, and confidentiality and information sharing approaches were varied. The variable nature of the documentation made categorising data and making comparisons complicated.

4.1 Policies received

We received policies directly from 34 NHS Trusts and five SSDs. Some organisations submitted a range of documentation and more than one policy. The reference to policies therefore exceeds the number of respondents. Table four summarises the types of documents submitted and the lead agency. The majority of Trust policies refer to data protection (n=12), followed by policies written for mainstream purposes (n=7) for example to cover general inpatient services. Apart from one organisation (the Royal College of Psychiatrists), the majority of professional bodies were non-specialist and sent mainstream documents. Carer organisations submitted carer and general mental health guidelines and in three cases young carer documents. The data protection-focused guidance that also included a short piece on the carer position under recent case law was submitted by a general mental health organisation (MIND). Overall, 56 relevant documents were submitted to the study but of these only 11 (20%) contained a robust carer focus. Five carer focus policies were from Trusts, five from carer bodies and one was from the national body NIMHE that submitted a unique document designed in partnership with a carer organisation.

4.2 Supplemental information

Organisations also submitted a wide range of documentation either instead of, or in addition to their policies. Table 5 reveals the high number of CPA policies (11) that were received from Trusts and SSD partnerships (see column 1). Also submitted were carer strategy documents (n=4), strategies to support service user and carer involvement in services (n=3) and individual examples of carer assessment, policy and information (in written and video formats). Policies on clinical standards and safe haven procedures were also received. One SSD submitted a full carers' strategy (column 2*)* and stated that a confidentiality policy would be based on the strategy. Two statutory and carer partnerships (column 3*)* and three carer organisations (column 5*)* produced information booklets for carers, and guidance for professionals when helping carers. One voluntary organisation provided information relating to an actual project and a residential service *(*column 6*)* submitted a framework of open-ended questions designed by a psychologist to facilitate professional communication with the carers of the hostel residents.

Table 4 Types of policy and issuing body

	1	**2**	**3**	**4**	**5**	**6**
Policy focus	**Trust or Trust/SSD partnership***	**SSD**	**Statutory/ carer partnership**	**Professional body**	**Carer body/ other NGO**	**Other**
General policy (all services)	7	1		3		
Data protection/ access to records	12	1		1	1	
General and mental health	2					
Mental health general document	5			1	2	
Mental Health plus separate carer section	2					
Dedicated carer policy (adult)	2		1		2	
Dedicated young carer document	1				3	
Housing and social care focus	1					
Inter-agency risk management	1					
Child protection, mental health, substance misuse	1					
Interagency agreement	6					
Total	**40**	**2**	**1**	**5**	**8**	**0**

*Note: Some organisations sent more than one 'policy'); *In most cases also incorporates SSDs.*

Table 5 Range of supporting documents submitted to study

	1	2	3	4	5	6
Documents	**Trust or Trust / SSD partnership***	**SSD**	**Statutory / carer partnership**	**Professional body**	**Carer body / other NGO**	**Other**
CPA	11					
Carer's assessment	1					
Carer strategy	4	1	1			
Policy guidance on carer issues	1					
Leaflet/booklet for carers on information	1		2		3	
Complaints procedures	1					
Service user and carer involvement	3					
Clinical standards	1					
Safe haven procedures	1					
Project information					1	
Information packs						
Guidance for professionals on carers					2	
Framework for professional/carer interaction						1
Video on carer issues	1					
Total	**24**	**1**	**3**	**0**	**6**	**1**

4.3 Meeting carer needs: policy statements

The policies submitted to the study (as listed in Tables 4 and 5) have been analysed for content for supporting carers, and a summary is provided in Table 6. Twelve out of the 40 Trusts who responded have policies to address carer needs, and 12 policies suggest a conceptual framework to facilitate information sharing between carers and professionals. Notably, in eight cases, carers' rights to have their own confidences respected are also recognised. Three policies address carer access to services and three expand on welfare and social care issues. While in most cases policies identify the principles of confidentiality, only seven policies had related those principles to the caring situation. NHS Trusts and SSDs focus heavily on the Data Protection Act and Caldicott principles. The CPA, reference to the Mental Health Act 1983 and to a lesser extent the carer's assessment, are also strongly represented.

By way of contrast, the statutory and carer partnerships and carer organisations (columns 3 and 5*)* made only cursory, if any, reference to the Data Protection Act. This small group of respondents focused heavily on carer issues, and wider social and welfare issues. Only one professional document related to families and carers, issued by the Royal College of Psychiatrists, took account of social and welfare issues. A subjective observation is that whereas the majority of Trust information was written in official language, the policies designed for carers, in most cases in collaboration with carers, were much easier to read.

Common features of the conceptual frameworks promoting carer and family involvement included:

- an explanation to the service user about the limits of confidentiality
- an explanation of why carers need information
- recognition of the carer role
- the importance of obtaining and reviewing the service user's stance regarding consent to disclosure of information.

There were signs that carer needs for information were being taken on board. However, not infrequent positive statements about carer involvement were weakened by more cautious approaches made later in the same document or accompanying guidance. Where this occurred professionals were presented with a confused picture on which to base decisions about sharing information with carers. Risk of danger was typically cited as being the sole criterion on which to legitimise disclosure of information to the carer where the service user withheld consent (see Table 7 below). The ambiguities found in Trust documentation reflect the conflicts in national policy identified in Section 2. These statements refer to boundaries around the sharing of confidentiality information and do not take on a more inclusive strategy of 'supporting carers' through information sharing. Where service users refuse consent to share information with carers there are a range of other strategies open to professionals (as will be identified in later sections of the report). These other strategies do not entail breaching of confidentiality, and could helpfully be addressed by the identified policy statements.

Table 6 Assessment of submitted policies – content and carer focus

	1	**2**	**3**	**4**	**5**	**6**
Content and focus	**Trust or Trust/SSD partnership ***	**SSD**	**Statutory/ carer partnership**	**Professional body**	**Carer body/ other NGO**	**Residential**
Principles into practice – carer issues*	7		1	1	3	
Core policy - DPA/Caldicott/HR	30	2		3	3	
MHA	13		2	2	2	
CPA	17		3		3	
Carer assessment	10	1	3		4	1
Carer recognition, perspectives and needs	12	1	3		4	
Conceptual framework to promote carer involvement in patient care	12				4	
Information about how to access mental health services	3		1		3	
Welfare and social care issues	3		2	1	3	
Carer confidentiality	8		1		4	
Accessible and easily understood by carers and professionals	2		3		3	
Young carers	1		1			
Number of items submitted	**64**	**3**	**4**	**5**	**14**	**1**

*Notes: *Only the policies that addressed the need to explain confidentiality and the processes surrounding non-consent and disclosure in relation to carers were counted; DPA: Data Protection Act; MHA: Mental Health Act; HR: Human resources.*

Table 7 Examples of ambiguous statements in individual sets of Trust guidance

Supporting carer involvement	**Grounds for carer involvement**
Trust A Where consistent with the service user's wishes, effort should always be made to seek the involvement of carers, relatives, friends, advocates	Trust A Disclosure outside the team should only occur with the expressed consent of the service user or where disclosure can be justified as being in the public interest.
Trust B Good practice means that staff explicitly seek the service user's consent to information to be shared … where a user lacks capacity sharing information may be necessary.	Trust B In the case of 'need to know' the scenario given is 'high level of prevention of serious harm'.

4.4 Good policy models

Good policy models, as defined using criteria outlined on page 39, were produced by statutory or professional bodies in partnership or association with carer organisations. Good policy models were reflected in a range of approaches: policy documents, information booklets, questions to help carers prepare for meetings with professionals and website information. In most cases carers had been involved in the development of these models either as consultants or as partners with statutory/professional organisations. Typically the importance of the CPA, carers' rights under the Carers Act 1995 and the Standard 6 of the NSF for Mental Health featured as important components. Many of the documents also included general information about services and treatment and the contact details of useful organisations. The carer partnership strategy model (ID 6) identified in Table 8 uniquely provides strategic guidance for carer service development.

Table 8 Overview of good policy examples

ID	Organisation and brief description of documents	Some key features
1	NHS Trust and partners *Confidentiality policy*	Accessible; concise **confidentiality policy**; expands on areas where information may need to be shared without consent (see Box 1); written for all stakeholders.
2	NHS Trust and partners *Carer and confidentiality leaflet, CPA and access to medical records policy*	Carer strategy. Comprehensive information. Accessible information – **leaflet on carer rights & information sharing** (see Box 2); video
3	Carers' advisory group *Mental health charter*	Comprehensive **general information** and guidance for carers; explains professional position on confidentiality & importance of service user consent; highlights the importance of carers being given sufficient information to provide care; identifies useful contacts.
4	Voluntary sector *Carer website, carers' leaflets, information for carers*	**Principles:** persevere with explaining confidentiality to the patient; review consent; assessment of service user's capacity. Listening to and involving carers; young carers; carers' rights; helpful questions for carers to consider before meeting professionals
5	Voluntary sector *Information pack for carers*	Comprehensive **general information** for carers – similar to ID 3) above but does not include professional position on confidentiality.
6	Carer partnership strategy *Communications between informal carers and mental health workers and supporting documents*	**Strategic guidance for services**; communication strategy; early involvement of carers; carer needs; importance of general information; professional honesty; importance of accuracy of information, assessment of service user capacity; explanation of agency protocol; advance statement by service user regarding who should be contacted.
7	Professional body and voluntary sector partnership *Checklists for carers, service users and psychiatrists*	**Promotes dialogue**. Developed during the period of research. Provides questions carers and service users can ask psychiatrists and care team about mental illness, treatment and care. Provides prompts for psychiatrists to consider when meeting carers and service users.

The Derbyshire policy *Confidentiality and Carers: Guidance on the disclosure of information in mental health services – keeping carers appropriately informed* (see Box 1) was identified as an exceptionally clear and concise policy. While expressly not a reference document it focuses on the rights and responsibilities of carers, services users, professionals and voluntary agencies and clarifies that the process of weighing up what should and should not be shared needs to be related to the practicalities of each particular caring context. The document identifies that there are limits to what the service user may withhold from carers and also limits as to what carers may expect to be told. It also highlights the importance of the law and therapeutic relationship in the weighing up process and identifies the access point for complaints in the event of carers or services users feeling aggrieved about information sharing practice.

Box 1 Derbyshire

Confidentiality and Carers: Guidance on the disclosure of information in mental health services. keeping carers appropriately informed **(2001)**

Produced by North Derbyshire Confederation of Adult Mental Health Services; Derbyshire Social Services; Community Health Care Services; North Derbyshire NHS Trust; Derbyshire Carers.

This guidance is focused on the carer perspective. It addresses the needs of young carers and provides helpful contacts. It refers to the CPA and carers' rights.

Explains and considers:

- what information is confidential and why
- how confidentiality affects the involvement of carers in planning support
- the situations and instances when confidential information can or must be shared.

Examples of carer 'need to know':

- information about the service user's admission to and discharge from hospital
- risk of dangerous behaviour
- information to meet a specific responsibility – for example management of the service user's financial affairs
- disclosures under the law or where a person has clearly lost capacity.

Additional guidance: steps professionals should take when weighing up difficult decisions; what carers and service users should do if they think information has been dealt with inappropriately.

Easy to read for carers, service users and professionals (though not a reference document, it refers to Data Protection Act for further information). Provides glossary of terms. The document is currently being reviewed.

The West Sussex Health and Social Care Partnership was identified as having an informative and accessible leaflet. This was produced in collaboration with the local carers' network as part of the strategy underpinning Standard 6 of the NSF for Mental Health. Although the leaflet is briefer than the Derbyshire example, it explains the essential factors that need to be considered in the context of professionals sharing information with carers and hones in on the identity of the carer, duties regarding the protection and disclosure of information, and carer rights and entitlements (see Box 2).

The West Sussex leaflet suggests that a procedure will be followed in obtaining, recording and reviewing service user consent. Carers' views and wishes will be listened to. Even where the person cared for withholds consent to disclosure carers should be given sufficient information to enable them to provide care effectively. The leaflet states that listening to carers and providing general information does not entail breaching confidentiality. It further pledges support to carers where the consent of the person cared for has been withheld.

Box 2 West Sussex

Confidentiality for Carers **(2003)**

Produced by West Sussex Health and Social Care NHS trust in consultation with the Carers Network West Sussex and the Mental Health Carers' Group

Focused on patient consent; carers' rights and entitlements; young carers. It provides helpful contacts.

Explains and considers:

- who is a carer
- meaning of informed consent, duty of confidentiality and non-consent
- where information may be shared without patient consent, e.g. court requirements; risk
- professional discretion to provide information to enable the carer to care effectively
- young carers' needs
- the legal rights of the nearest relative under the Mental Health Act 1983.

Easy to read, well presented, succinct information leaflet written for carer usage. Provides contact point for complaints. The document was issued in November 2003.

Both documents provide carers with a framework through which to understand the meaning of confidentiality and professional duties in this regard. They also suggest that where the service user withholds consent consideration will be given to appropriate information sharing taking into account the care context. It is the recognition not only of the carer's position, but also the importance of professional discretion influenced by a set of guiding principles in deciding the appropriateness of information sharing that sets these documents apart.

4.5 Summary

A wide range of documentation was submitted in response to the policy search. The carer perspective was only robustly represented in a small proportion of policies issued by Trusts and professional bodies. Several policies provided conflicting guidance on information sharing with carers, and reflected the ambiguities of government guidance.

The documents that contained positive carer guidance revealed a number of good practice points. These suggest the importance of introducing a carer strategy to provide a framework for the development of carer services. Factors to include in developing good practice information sharing policies for carers include:

- policies designed to support the carer role written in collaboration with carers
- documents that are jargon-free and easily located
- documents that identify and explain the rights and responsibilities of users and carers
- documents that outline various professional roles and responsibilities with regard to patient confidentiality and the central role of consent
- helpful contact points
- reference to the unique needs of young carers
- a conceptual framework to support appropriate information sharing between professionals and carers
- summaries of the law and government policy on carer issues
- examples of situations where information may be shared without the service user’s consent, for example by order of a court or in cases of risk.

A range of good practice measures to support appropriate information sharing between professionals and carers were assembled from the analysis of carer-orientated policies. These identified the following professional responsibilities:

- To provide an explanation of confidentiality and the agency protocol to all parties.
- To seek service user consent to disclosure of personal information to support carer ‘need to know’.
- To review consent at regular intervals.
- In the event of the service user withholding consent, persevere with seeking consent, where appropriate, working with service user to help them understand why their carer may ‘need to know’ specific personal information regarding their care and treatment.
- To assess the capacity of the service user to give consent.
- To ensure information is accurately recorded.

- To assess the nature of the care context and relationships.

The advance statement registering the preferred contact and helpful questions written for psychiatrists, service users and carers to promote meaningful dialogue were also identified by carer organisations as good practice points. The carer-orientated documents promoted positive and inclusive approaches in respect of carers. The underpinning principle was the balance of ensuring carers had sufficient information to enable them to provide care and attain their entitlements, while simultaneously upholding the service user's autonomy and privacy and the therapeutic relationship.

Section 5 National survey

5.1 Introduction

The surveys were distributed using mainly convenience and snowballing sampling, directing respondents both to an online website version and paper hard copies. It is therefore impossible to provide an accurate response rate for the study but we estimate that this would be extremely low. The final survey samples across the five groups are:

- mental health service users (n=168)
- professionals (n=212)
- carers (n=496)
- CSWs (n=93)
- young carers (n=29).

A more detailed description of the sample is provided below. This section of the report considers the survey findings from key stakeholder perspectives individually, before moving on to analyse the contrasting perspectives of the different stakeholder groups. Throughout the survey we have been focusing on examples of good practice, but in order to understand the information sharing context that people work and live within it is also important to explore views on both carer involvement and information exchanges in mental health more broadly. Thus, in each section, we describe key findings from the individual data sets that contribute to models of good information sharing practice in mental health. These findings are drawn upon in Sections 9 and 10 which present recommendations for good practice.

5.2 Good practice views from service users

5.2.1 Service user sample

Service user views on information sharing between professionals and carers are highly individualised. Views are often dependent on a number of key factors describing the caring context including the quality of the user-carer relationship, type of relationship (for example mother/son, husband/wife), length of relationship, living arrangements, degree of disability/stage of illness and service users' preparedness to consent to having a 'carer' involved. The background characteristics of the service users (n=168) are described in Table 9. The sample are mainly people who live with psychosis, have been a service user for more than six years and have not been sectioned in hospital in the last three, are from white ethnic backgrounds (only 4% of the sample live in BME communities), live in the same house as their carer, and are fairly or very comfortable with their carer being involved in their care. This is not a representative sample of service users, and the results should be read with this as a consideration.

Table 9 Background characteristics of service user sample (n=168)

Characteristic	**Sample**	
Gender	Female: 98 (58%)	Male: 70 (42%)
Age	18-30: 40 (25%) 31-45: 61 (38%)	46-60: 52 (32%) 61+: 8 (5%)
Ethnicity	White: 158 (96%) Mixed: 1 (0.5%) Chinese: 1 (0.5 5)	Black/Black British: 1 (0.5%) Asian/Asian British: 1 (0.5%) Other ethnic groups: 3 (2%)
Region	Eastern: 12 (8%) South East: 46 (30%) Greater London: 22 (14%)	South West: 23 (15%) Midlands: 25 (16%) North: 27 (17%)
Contact with mental health system	First saw psychiatrist about mental health problems: <12 months: 26 (16%) 1 – 5 years 43 (26%) 6- 10 years 27 (16%) 10+ years ago 66 (40%) Been 'sectioned' in last 3 years? 30 (18%)	
Supported by	My mother 55 (33%) My father 28 (17%) My husband 23 (14%) My wife 12 (7%)	My partner 21 (13%) Other family member 16 (10%) My friend 23 (14%) No carer identified 31 (19%)
Your diagnosis	Psychosis - 91 (57%) Clinical depression – 59 (37%) Anxiety related disorders – 28 (18%)	Dual diagnosis – 3 (2%) Personality disorder – 29 (18%) Eating disorder – 5 (3%) Don't know/none given - 8 (5%)
Carer lives with you?	73 (57%) service users live in same house as their carer	
Caring at a distance?	Only 6 service users (5%) live 1.5 hours from carer	
Comfortable with carer involvement?	58 (37%) very comfortable 49 (31%) fairly comfortable	27 (17%) slightly uncomfortable 12 (8%) uncomfortable
Other roles for service user	Also a carer? 39 (27%) Also a CSW? 20 (15%) Also a mental health professional? 22 (16%)	

5.2.2 Service user views on information sharing

In addition to background characteristics relating to demographics and the caring context, the surveys asked service users to rate their views on information sharing for carers, reflecting their thoughts on good practice.

Service users were asked if they were aware and whether they agreed with current government policy regarding carers. The statement included in the survey read:

> *The government is committed to supporting carers. They say carers should expect that mental health staff will encourage service users to allow their carers to be involved and consulted unless they have clearly stated an objection.*

In the sample, 78 users (48%) were aware of the government commitment to carers, and on reading the statement 81% reported they were in agreement with the policy. Service users were also asked whether carers needed personal information (in other words information shared in confidence and would be seen as ‘confidential’) about them in order to provide adequate support. In response, 110 service users (69%) agreed that their carers should access personal information, 32 (20%) disagreed and (18) 11% said they did not know.

Most of the sample were broadly supportive of carer empowerment, of carers being involved in their care and for personal information to be shared as long as service user consent was given. However, one in three service users in the sample were not comfortable with information being shared without their consent or for carers to have separate time with professionals (see Table 10).

Service users were asked whether professionals, as part of routine clinical practice, collect consent to share information. For those service users with a named carer, 12% were always asked, 25% sometimes asked, 24% rarely asked and 18% never asked (n=128). A total of 72% of service users with carers reported never having signed a disclosure to consent form, and only 55% reported never having their confidences broken by mental health professionals. Fifty-five service users with carers (45%) reported having confidences they have shared with professionals being discussed with their carers, most commonly by a psychiatrist (40% of cases), followed by psychiatric nurses (7%).

Table 10 Considerations regarding carer access to information

Item	n	Service user response
Should carers be offered separate time with professionals to discuss their concerns regarding your mental health, treatment and care?	158	No = 50 (32%) Yes = 88 (56%) Don't know= 20 (13%)
Are there any occasions when information should be shared **without** your consent?	157	48 (31%) feel there are **no** situations where info should be shared without consent
For service users who agree to information being shared WITHOUT their consent:	**109**	
Sharing without consent when I am very unwell		Agree = 63 (58%)
Sharing without consent when I have agreed in advance		Agree =70 (64%)
Sharing without consent if people are worried about my safety		Agree = 67 (62%)
Sharing without consent if there are concerns about my harming other people		Agree = 54 (49%)
Sharing without consent if my carer lives with me		Agree = 27 (25%)

5.2.3 Main information sharing problems identified by service users

The survey asked 'What do you think are the main problems with information sharing?' in relation both to general and personal information types. A total of 112 service users (65%) provided a response, though 11 of these were not directly relevant to the question, leaving 101 responses for coding. The main problems encountered with regard to information sharing between professionals and carers were wide ranging, generating 41 separate codes. These codes were grouped under the following headings:

- General issues
  - for example invasion of privacy (4), definition of carer uncertain (3).
- Problems relating to professional role
  - for example assumptions made about best interests (4), confidentiality used instead of honesty with user or carer (3).
- Problems relating to the carer role
  - for example carers are not experts like professionals, so do not need same information (4), carers may be worried, made unwell by information received (4).
- Problems for service user

- for example damage relationship between user and carer (4), can increase feeling of paranoia, lack of control in situation (3).

The most common themes to emerge are listed in Table 11. A selection of quotations is also provided to illustrate the key barriers identified by the service user sample. The background and study ID number of each person quoted is included alongside each quote.

Table 11 Service user views of the main professional-carer information sharing problems

Theme	Responses (n=101)
General issues: information sharing practice problems	45 (45%)
- invasion of privacy	4
- definition of carer uncertain	3
- information should not be shared without service user consent	11
- misinterpretation of information among professionals and carers.	7
Problems relating to professional role	46 (46%)
- assumptions made about best interests	4
- confidentiality used instead of honesty with user or carer	3
- incorrect information shared, professional opinion may change	9
- lack of understanding limits confidentiality, confidences broken	8
- damaging relationship between professional and user	5
- professionals do not attempt to engage with carers, thus don't share info.	4
Problems relating to the carer role	15 (15%)
- carers are not experts like professionals so do not need same info	4
- carers may be worried/made unwell by information received	4
Another example is that carers feel unable to ask for information.	
Problems for service user	22 (22%)
- damage relationship between user and carer	4
– increase feeling of paranoia, lack of control in situation	3
- service user disempowered: user voice silenced, ignored, undermining independence.	10

> *Service user's voice may be silenced by professionals and carers believing that they always know best. (That is why tripartite meetings are best). Also, depends on the quality of the professional and carer - very difficult to generalise.* (Service user 30)

> *It can become like a game of Chinese Whispers. I object to information sharing without my being told what information is being shared so that I can correct errors. I think that it can also cause rifts in families.* (Service user 67)

> *Professionals do not always listen to carer's concerns when the patient is becoming unwell. The service user should either consent or be made aware. Professionals don't share information enough or regularly. They should be sensitive to carers' feelings about the information.* (Service user 97)

5.2.4 Positive practice examples from a service user perspective

In another qualitative section of the questionnaire (using open-ended questions) service users were asked to provide examples of solutions, positive experiences and recommendations. These answers have been coded and are summarised below. Unsurprisingly solutions to problems are unique to each context and person; recommendations are also diverse and cover a large number of often contradictory pathways. It is also important to note that for some service users solutions are not needed to information sharing 'problems' between professionals and carers, because they do not want information to be shared with carers and thus the solution is preserving patient confidentiality at all times.

Sixty-two service users (37%) provided solutions to information sharing problems between professionals and carers, generating 21 codes. These are all listed in Table 12 to illustrate the range of strategies needed to address criticisms of poor practice within this small sample.

> *Doctor and patient situation private - unless the service user wants to discuss - always involve the S.U first - sit down with service user first then carer. The carer shouldn't be able to sit alone with professionals - results in lack of trust between service user and professionals.*
> (Service user 167)

> *More care and consideration by the key worker and more time allowed by the CMHT (community mental health team) per client to enable joint and individual appointments.* (Service user 43)

The survey also asked: 'Please tell us about any positive experiences where problems over information sharing have been resolved.' These responses were coded to provide examples of good practice and secondly recommendations for good practice. From the service user sample, only 28 (17%) provided descriptions of positive experiences and recommendations. For this small number, the principles governing good information practices were reported as:

- establishing and maintaining dialogue (i.e. better communication)
- collecting consent
- pro-activity (of both user and carer)
- attitudes of professionals (openness, honesty, caring, respectful, non-patronising)
- flexible and creative approaches to information sharing
- recognition of carer rights and 'need to know'
- recognition of service user rights to privacy and user lead on sharing of personal information
- effective professional and carer training programmes.

Table 12 Suggested solutions to overcome barriers to information sharing in mental health - service user perspectives

Service user solutions:	**Service users (n=62)**
Better communication, openness and honesty between professionals, carers and service users	25
Written agreement outlining what can (and cannot) be shared with carers e.g. advance statement	18
Respecting other people's perspectives, addressing these differences in building relationships	4
Providing copies of written reports and letter to service users, and to carers when consent is given	4
Meetings: user always present when information is shared	4
Meetings: meeting held individually (with carer or service user) and jointly (three-way)	1
Meetings: acknowledge that carers work, can't always attend meetings – need alternative ways to share information (flexibility)	1
Education: provide more resources for carers (leaflets, training courses)	2
Education: provide better training for professionals on working with carers	2
Create time to share information	2
Listen carefully to service users so that inaccurate information is not shared	2
Use the NHS complaints procedure to address problems	2
Use e-mail to speed up transfer of information	1
Use jargon free language when information sharing with carers and service users	1
Support service user to understand issues around consent	1
Build better therapeutic relationships – basis for trust to aid sharing of information	1
Proactive service users challenging (encouraging) professionals to involve the carer	1
Use of advocates instead of carers	1
Avoid using mental health services	1
Reciprocal rights respected – user can expect to know as much about carer as carer knows about user	1
Incorporate information sharing within CPA process more effectively	1
Psychiatrists sharing decision making (and their power) with care team, users and carers	1

A selection of service users' recommendations is provided below, with contradictory approaches offered.

> *This questionnaire has an unreasonable bias in favour of information sharing. Patient confidentiality in relation to users of mental health services should be respected in exactly the same way as it would be for users of any other health services.* (Service user 22)
>
> *Good communications between people can lead to better care. A lot depends on the attitudes of the people involved.* (Service user 136)
>
> *People with mental illness need to take responsibility for safeguarding their own health. Allowing other people to interfere in their care will only lead to a culture of dependency and a downward spiral in their levels of occupational and social function.* (Service user 99)
>
> *The carer should ALWAYS be involved in care and decision-making processes and should always be kept informed.* (Service user 98)

5.2.5 Summary of good practice principles from the user perspective

The service user data suggests there is no single model that can be applied to information sharing in mental health. Individual solutions that are acceptable to all stakeholders are required. Recommendations to drive the decision-making framework governing how to share information and how to support carers do emerge through the service user data, and these are listed below:

- Consent should be collected before information is shared with carers, including the use of advance agreements;
- Consent should be regularly reviewed.
- Service user reservations of carers receiving information about their care and treatment should be taken into account when decisions are made by professionals.
- Respect for other people's perspectives is paramount in building effective relationships (particularly trust) in mental health.
- Better communication is necessary in mental health, between all stakeholders.
- Values of openness, honesty and respect between stakeholders should be prioritised in mental health.
- Carer involvement should not diminish service user wishes.

Other key considerations:

- Strong service user view that information should not be shared without consent in any circumstances.
- A third of service users did not want carers to be given separate time with professionals to discuss their concerns, reporting that the service user should always be present if they are being discussed by professionals and carers.

- In certain circumstances the definition of 'carer' is unclear requiring clarification through policy guidance or the law.
- Information sharing problems relating to the professional role (see Table 11) require both system level changes and professional training.
- Advance statements were proposed as a suggested solution.

5.3 Good practice views from adult carers

The largest response to the surveys came from carers (n=495), a reflection of the importance of information sharing for this group. In a recent survey by Rethink, 37% of carers (approximately 1 in 3 from a survey of 1400) reported that in their view professionals used confidentiality as a 'block' to sharing information with carers, despite service users' willingness for them to be involved in their care (Pinfold and Corry, 2003). In this section we explore the views of carers and the sub-groups where appropriate – namely carers of people with dementia and carers of people with SMI (or psychosis).

5.3.1 Carer characteristics

The carers in the sample (see Table 13) were recruited through membership networks and thus reflect characteristics of these networks. These carers are primarily white (96%), female (78%), aged 46 or over (84%), providing support to their children (62%) particularly sons (44%), support a person with psychosis (67%) and they live with the person supported (54%). Three out of five carers (60%) in this sample were aware of the government commitment to 'supporting carers' reflecting the continuing low status and unrecognised roles that many carers occupy. The low response from carers living within BME communities and those supporting people with dementia was identified as a limitation in this component that was addressed in the qualitative interviews (see Section 6). In considering the information needs of carers, the caring context is of particular importance.

Table 13 Background characteristics of carers (n=495)

Characteristic	Sample	
Gender	Female: 376 (78%)	Male: 109 (22%)
Age	18-30: 10 (2%) 31-45: 67 (14%)	46-60: 240 (50%) 61+: 161 (34%)
Ethnicity	White: 463 (96%) Asian/Asian British: 2 (0.5%) Other ethnicity: 5 (1%)	Black/Black British: 11 (2%) Mixed: 2 (0.5%)
Region	Eastern: 66 (15%) South East: 107 (24%) Greater London: 63 (14%)	South West: 67 (14%) Midlands: 48 (11%) North: 101 (22%)
Length of time as a carer	Average 11 years, range 1 to 43 years	
Relationship to person supported	My son 214 (44%) My daughter 86 (18%) Other relationships 77 (15%) 121 (25%) of carers provide support to more than on person	My husband 68 (14%) My wife 43 (9%)
Diagnosis of person supported	Psychosis - 330 (67%) Clinical depression - 65 (13%) Anxiety related disorders - 65 (13%) Dual diagnosis – 40 (8%) Personality disorder – 40 (8%) Eating disorder – 30 (6%) Dementia - 31 (6%)	
Person supported lives with carer?	269 (54%) carers live in same house as person supported	
Caring at a distance?	31 (14%) live at least 1.5 hours travel time from service user (distance carers)	
Amount of contact	Face to face: 24 hours, 7 days 185 (40%) Daily 129 (28%) Weekly 119 (26%) Telephone support: Daily phone contact 128 (26%) Weekly phone contact 82 (17%)	At least once a month 25 (5%) Less often 10 (2%)
Information requirements:	162 (35%) have insufficient information to support them in their caring role	
Sharing information with professionals:	177 (37%) carers are at times reluctant to share information with professionals for fear their confidences could be broken, carer-service user relationship damaged, professionals do not listen.	
Awareness of government carer commitment	287 (60%) aware of government commitment to carers 192 (40%) unaware of government carer policy position	
Other roles for carer	Also a service user? 70 (14%)	

	Also a carer support worker? 87 (18%)
	Also a mental health professional? 37 (8%)

5.3.2 Carers' views of information sharing practices

Carers were surveyed to establish both their information requirements and how these needs were being met both by mental health professionals and other networks. One in three carers (see Table 13) report they do not have sufficient information to support them and only 56% of carers report having the opportunity to discuss information they have come across with mental health professionals. It is recognised that access to information is only one part of the support process, and that carers need support to make most use of available information sources. These sources are numerous, and most carers are not receiving information direct from mental health professionals. Carers with information in the sample (n=474) gain their general information from carer support groups (46%), voluntary sector agencies (44%), other carers (34%), websites (31%) and CSWs (27%). When information is gathered from professionals this is most likely to be from a psychiatric nurse (26%) or psychiatrist (20%). However, 44% reported not having access to professionals to discuss information.

The difference between *general* information and *personal* information is critical in the study. Carers were asked if they needed access to personal information about the service user. In the sample, 379 carers (79%) do feel they need access to certain personal information in order to continue effectively (and safely) in their carer role. When assessing 'who' requires personal information, these are significantly more likely to be parents as compared to partners (83% compared to 66%; p=0.001). Partners may already be party to much personal information because of their particular relationship and living situations. Carers who *do not* live in the same home as the service user are more likely to want personal information (86% compared to 73%; p=0.003).

Understanding the reasons why groups feel information is not shared will help identify potential solutions. In Section 5.5.3 we report professional views on why they do not share information with carers. The responses from carers to the same questions are provided in Table 14. These responses are from the 214 carers who report that they need personal information, but within the past 12 months they have not been provided with any personal information about the condition, treatment or care of the person they support.

For carers, one in four do not ask professionals for any personal information although 79% say they feel they need personal information to help them in the carer role (see Table 14). For 44% of carers, confidentiality is the reason they feel information is not being shared but in only one in four of these cases are carers being given supportive explanations.

Table 14 Why professionals do not share information: carer perspective

Information not shared with carers because:	Carers (n=214)	%
I have not asked for any	56	26%
Service user did not provide consent	45	21%
Service user unable to give consent	12	6%
Service user not asked to provide consent	41	19%
Reason provided 'confidentiality' but *without* supportive explanation	68	32%
Reason provided 'confidentiality' but *with* supportive explanation	26	12%
Don't know	28	13%
Other comments:	26	12%
Service user provides consent and then changes mind, out of respect for service user would like to know but respect their wishes so don't persist, carer is not next of kin, language barriers		

Carers are involved with professionals in a variety of settings. The research team asked carers to report how they accessed information across different settings. Table 15 describes the settings most used by carers in the sample and their information accessibility rating.

Table 15 Carer access to personal information by setting

Information obtained from:	Not relevant	Always difficult*	Sometimes difficult*	Never difficult*
GP surgery (n=427) / (n=328)*	23%	121 (37%)	89 (27%)	118 (36%)
Hospital (n=455) / (n=338)*	26%	118 (35%)	163 (48%)	57 (17%)
On discharge from hospital (n=442) / (n=317)*	28%	117 (37%)	145 (46%)	55 (17%)
CMHTs (n=431) / (n=360)*	71%	89 (25%)	156 (43%)	115 (32%)
CPA reviews (n=386) / (n=268)*	24%	82 (31%)	87 (34%)	99 (35%)
Social services (n=386) / (n=226)*	41%	83 (37%)	84 (37%)	59 (26%)
Voluntary sector services (n=360) / (n=144)*	60%	9 (6%)	33 (23%)	102 (71%)

*Note: * denotes number of respondents where the question was relevant*

Taking into account that, for a proportion of carers, each setting will not be relevant to their caring context, the settings fare evenly across carer ratings except for voluntary sector services. In this case 71% of carers report no difficulty gaining access to personal (confidential) information, suggesting services in these settings adopt a different approach – though this is not necessarily a positive observation. The most difficult setting for accessing information was reported as hospital; both during inpatient stays and on discharge with 83% of carers noting access was always or sometimes difficult here. For GPs, CMHTs and social services variable experiences were described with equal proportions of carers finding it *always* difficult to access information and *never* having any difficulties.

5.3.3 The experiences of young carers

The carers of people with mental health problems include young people, who provide support to their parents. The needs of young carers for support, information and services are increasingly being recognised and in some areas of the country there are specialist young CSWs to facilitate support networks and to provide help including information. The research team created specific surveys for young carers (aged 12 and over) which were filled in with a CSW, and the results from these surveys are provided in this section.

We had 29 responses from carers aged 12 to 22. The mean age of young carers was 15.41 (median 15). This small sample provided care to a mother (12 young carers – 41%), a father (eight young carers – 28%), a sister (6 young carers – 21%) and a brother (seven young carers – 245). Twenty-six of the young people live with the family member they support, one girl’s mother had died and two carers had left home. In the sample, 23 had been given an explanation for their relatives’ ‘mental health problems’, but only 12 described this condition using terms such as ‘depression’ or ‘mental disability’. Most of the young carers (23) reported having enough general information to support them in their role, obtained mostly from: Family and friends (19); CSW (10); the relative with mental health problems (9); websites (9); carer support group (8); helplines (7); and social workers (5).

The young carers were asked to set out the main problems they experienced with information sharing between professionals (for example doctors) and young carers; 23 people provided a response. The most common problems, reported by ten young people, described poor communication and associated difficulties. One 18-year-old young woman supporting her sister wrote: ‘They don’t communicate well with each other.’ A 14-year-old boy supporting his father explained: ‘No freedom of information so having to repeat myself with different groups.’ Other issues raised by young people were:

- not knowing who to ask for information (3)
- feeling as though the young carer is excluded by professionals (2), for example a 16-year-old woman supporting her mother and father said: ‘Professionals do not believe that the young carers need to

know (only the people who are being cared for need to know supposedly!).'

- the way information sharing can lead to confusion as professional opinions differ or only partial information is shared (2).

Nineteen young people provided solutions. The most frequent suggestion was for the service user to sign a form detailing what information should be shared with the young carer (5). The need for young carers to be formally recognised was also raised (3), for example a 20-year-old woman supporting her mother with depression said: 'I am not sure about this. I think as long as you are treated with respect and talked to in a way that you clearly understand that would help. Good communication and recognition of young carers is needed.' Young carers also recognised their own role in promoting more effective communication, by being proactive and seeking out more information (2). Related to this last point a general plea was made for more information about the illness to be readily accessible (2). Other suggestions included:

> *Not sure really I just think everyone needs to know the facts of whatever they need to talk to everyone about. If they all get told the same information it may work.* (Young carer 9027)

> *By involving all the family.* (Young carer 9026)

> *Education of teachers of how to cope in situations and that caring for someone does not mean that the carer will not achieve anything in life – because we can!* (Young carer 9028)

5.3.4 Problems and resolutions for carers (SMI)

In this section we consider the views of carers supporting a service user with SMI. In order to capture the problems associated with information sharing, carers were asked to detail the consequences of poor information sharing. Carers responded by addressing consequences for both themselves and the person supported. The most frequently cited themes are listed in Table 16. A high level concern from SMI carers related to a lack of basic information being provided, leaving many carers feeling unsupported and vulnerable. These information gaps related in particular to information about medication and the content of CPA care plans. One carer stated:

> *On my son's discharge from hospital after an episode of acute psychosis we had no information about his condition, how he would behave, how we should react to him. We had no experience in dealing with him when unwell. We were expected to just cope – a complete nightmare!* (Carer 337)

Carers were also concerned that their lack of direct involvement in certain decisions, particularly through exclusions from meetings (for example CPAs, ward rounds), had a detrimental affect on a service user's recovery journey. Several carers reported that they were not being listened to particularly regarding side effects of medication:

> *We feel that if information had been provided our son's care would have been better and recovery quicker. In CPA reviews we have not been involved in the discussion, just told the outcome.* (Carer 32)

> *Concerns I had were treated as irrelevant and never followed-up. Medical team felt patient was fine and taking medication. Months later, he relapsed and they discovered he'd stopped his medication. So much distress could have been avoided.* (Carer 140)

Carer education programmes are an important resource for supporting carers without compromising service user autonomy. In the sample 14% of carers noted they lacked sufficient skills to effectively support the service user and cope with their caring role.

Table 16 Consequences of poor information sharing with carers

SMI carer response:	**Respondents (n=252)**	**%**
Carers lack of knowledge and information to support them in their caring role	78	31%
Carers not being involved and listened to in areas where their involvement could make a difference in terms of outcomes for the service user	40	16%
Mental health of service user affected through delayed access to help or loss of social support e.g. accommodation	36	14%
Carer lacks skills to effectively support service user	35	14%
Service user is discharged from hospital without carer knowledge and support	30	12%
Health of carer affected – through worry, anxiety	18	7%
Opportunities for professionals to learn important information about service user and context of illness lost – carers a rich source of information	17	7%

In responding to these identified problems, carers were asked how information sharing problems in mental health could be avoided in the future. From the SMI group 254 carers responded and the main themes generated by these are provided in Table 17. In particular, SMI carers felt that the culture of mental health services had to change to improve communication across the whole system and recognise the value and importance of the carer role.

> *By a generally more open attitude to the involvement of carers in the care scene, if not the care team! Carers do not want to know a person's secrets but do need to know openly about such things as nature of illness, prognosis, medication, relapse, side effects of medication and coping strategies with voices and delusional thinking.* (Carer 92)

Carers also noted that their support can lead to cost savings for the NHS and encouraged better training to support staff who feel uncertain about the application of capacity assessments and confidentiality in practice. One carer noted:

> *I think there should be more legal rights for carers accompanied by some serious compulsory training of all mental health professionals and GPs, which illustrated the benefits to everyone involved for service users, carers, professionals and Trusts etc. Better support means less admissions, better recovery. In my own experience it is partly the good relationships between myself and the care team that has resulted in my husband being stable for so long, using very little resources, which with a poor relationship, could be the opposite.* (Carer 117)

Table 17 Carer views on how poor information sharing practices can be avoided

SMI carer response:	**Respondents (n=254)**	**%**
Improve communication within the mental health system between all parties – professionals, service users and carers	49	19%
Professionals must recognise the expertise and experience of carers. By changing attitudes towards carers, problems can be overcome	48	19%
Change professional culture to embrace partnership working with carers. A cultural shift is required to involve SMI carers in mental health care	41	16%
By providing carers with specific supports and services including carers' assessments, respite, support workers, support groups, information resource packs, carer education programmes	41	16%
Improve the quality of mental health services delivered to support service users living with SMI	38	15%
Involve carers in meetings, discussions, written correspondence	32	13%
Listen effectively to carers' concerns, take on board and respect their comments and feedback	31	12%

In addressing problems and resolutions, carers were also asked to provide examples of 'any positive experiences where problems over information sharing had been resolved'. A total of 152 carers responded (31%) though 23 (15%) reported that they had no positive experiences to draw upon, leaving 129 statements for coding. These statements were coded for content and good practice principles. The main good practice principles identified (coded as one principle per carer) were:

- proactive carer, 24% (31)
- recognition of carer needs and rights, 22% (29)
- establishing and maintaining dialogue (better communication), 25 (19%)
- attitudes of professionals (openness, honesty, caring, respectful, non-patronising), 12 (9%)

- collecting consent, 9 (7%).

Eighty five carers described clear strategies, and these statements were analysed using a maximum of four 'content codes' per statement. These are summarised below with the numbers in brackets indicating strength of theme:

1 Strategies that involve professionals supporting carers (121):
    - support provided by psychiatrist (25)
    - professionals provide general information and explanation to carers (14)
    - professionals sign post to carer support groups (12)
    - support provided by CPN (9)
    - support provided by social worker (9).
2. Carer actions (38):
    - persistence (14)
    - complain (8)
    - act as advocate for service user (8).
3. Strategies based on collaborative approach (24):
    - carer involvement in decisions (medication, treatment plans) (14)
    - use of carer as information resource (5).
4. Service user action e.g. providing consent, leading process of involving carer (9).

5.3.5 Problems and resolutions for carers of people with dementia

The survey data set for carers with dementia is small (n=31) and only 14 carers in this group provided descriptions of both the problems they face as a result of poor information sharing practices and suggested resolutions. Thus a detailed analysis was not attempted and summary descriptions are provided instead. The key problem for all 14 carers was poor communication. This can lead to worry and anxiety for family members, for example when they do not understand the diagnosis or are unaware that a person is being discharged from hospital. Lack of involvement in treatment decisions was another area causing carers concern, particularly as it compounded lack of access to information (general and personal) because carers are unaware of medication plans or opportunities to attend new services such as memory clinics. The solutions to these difficulties that carers could impact upon were:

- attend a good carers' group (e.g. Alzheimer's Society)
- persist with professionals to establish good relationships.

Other solutions involve improvements in professional practice, grounded in training from induction programmes to continued staff development. As with other carers, those supporting people with dementia feel professional attitudes need to change to include the carer as a core part of the CMHT based upon effective communication strategies, as illustrated by the selected quotations below:

> *Felt very alone, unsupported and helpless at the beginning of the diagnosis. Mental health professionals need to explain to care staff the problems relatives experience as they take things out on you as you're their support network.* (Carer 26)

> *When no one keeps in touch it causes me a lot of worry and makes my health conditions worse – I find I have to visit my doctor with the problems this causes. If people who have information regarding the patient's condition - the doctors, nurses and CPN - let the carer know it would greatly help.* (Carer 36)

> *My father-in-law has Alzheimer's. Unknown to us he went to the GP with a urinary infection and was prescribed antibiotics. Since he couldn't take any of his pills reliably, and usually had them all in a pill-organiser (done for him) these antibiotics were 'no use'. Doctors need to appreciate that where someone's logic/judgement/memory is impaired (which it clearly is if a diagnosis of Alzheimer's has been made by a specialist) it is imperative that carers are kept informed of any medical problems/appointments/tests etc.* (Carer 10)

> *Lack of information on prognosis. Lack of information regarding admission procedures. Never saw care plan. Only know what medication she was on because we asked a care home assistant. Solutions –(a) Staff to have more time/less form filling, (b) Staff to trust carers more, (c) Staff to cease to huddle in the office. turning their backs, physically and metaphorically on carers and relatives, (d) More attention to detail of interactions.* (Carer 50)

> *I am left totally outside the system. The most useful leaflet I found by accident was a leaflet on Alzheimer's care – no-one in the NHS has talked to me of psychosis, seizures, altered behaviour, altered conscious, non-epileptic attacks, post traumatic stress. Access to professionals who could impart or explain, for example, non-epileptic attacks, post traumatic stress disorder, liver disease, stomach ulcers, heart condition etcetera, etcetera. All things I have to take into account on a daily basis. I do not see that this breaks any confidentiality. I had to write a letter for my husband to sign for our GP to even speak to me, despite my husband saying it was OK.* (Carer 15)

5.3.6 Problems and resolutions for carers supporting a person with an eating disorder

Among carers supporting a person with an eating disorder, a small number in our sample (n=30) again described difficulties with confidentiality where an adult service user does not want the parents involved, but the parents are desperately concerned for their well-being, particularly in regard to suicide attempts (5). The problems facing this group mirror areas identified in the main carer sample (Table 15 and 16), namely: lack of communication; poor engagement with anxious family members, lack of access to information and support. The resolutions equally reflect themes emerging from the main carer data set: listen to carers; respect carers' expertise and their knowledge of the service user; provide updated general information; provide carers with education in skills to support their relative with an eating disorder.

> *Manipulative problems, the patient will tell you how she wants to be rather than what has been discussed and agreed with her doctors. By changing the rules on confidentiality and getting professionals to understand that this is a team effort and without a calm approach the sufferer will/may not recover fully.* (Carer 49)

> *If your child is classed as an adult your hands are tied. I feel that when a person is so unwell then the family (parents) should be told whatever treatment is available and be part of decision making.* (Carer 53)

> *Problems: inappropriate level of services; lack of understanding; no risk relapse plan; no care plan shared; poor transition from inpatient to local CMHT. Possible solutions: smooth transition; risk relapse plan; continuity of levels of care; immediate outpatient support.* (Carer 48)

> *My daughter was taking Seroxat aged 15. She missed dosages and became suicidal in thought and behaviour. She took three overdoses. No member of CAMHS (child and adolescent mental health service) discussed this with us and used 'confidentiality' as an excuse. Listen to carers with an open mind and acknowledge the fact that they have known this person a long time..* (Carer 23)

> *My daughter refused treatment, I came very close to complete collapse as I had no information/help/support and had no idea what to do. This could have led to tragedy and/or death or chronic illness for my daughter. It took me two years to find EDA (the Eating Disorders Association) and information.* (Carer 50)

> *Don't know how to help our daughter. If we had info regarding how her illness was affecting her and why we maybe could help her more. We need a proper structure set up and a dedicated unit for eating disorders. More education for doctors who are first port of call and more education in school to aid prevention and knowledge, 99% of all help is voluntary.* (Carer 87)

5.3.7 Summary of good practice principles from the carer perspective

The carer data set has provided wide-ranging views on both the problems of poor information sharing and how 'good practice' can be achieved. A summary of the main issues raised is outlined below.

Good practice recommendations across all carer groups:

- Carers do not have sufficient information to support them – both general and personal information. Mental health services must provide carers with basic information on mental health problems and ways of coping as a carer.
- Carers do not have the skills to manage SMI. A range of services including carer education programmes and peer support groups are required to support and effectively empower carers, supporting their own recovery journey.
- Professionals need to provide carers with opportunities to discuss information they have found from a variety of sources and to listen to carer concerns.

- Where professionals cannot share personal information with carers because service user consent has not been provided, a supportive explanation should be provided to prevent confidentiality being perceived as a 'block' to professionals engaging with carers.
- The difference between general and personal/sensitive information should be clearly understood by carers in the context of their support role and the views and wishes of the service user.
- Improvements in communication between all stakeholders in mental health and allied services is required to improve the quality of services provided.
- A cultural shift within mental health is required, including the changing of professionals' attitudes toward working with families. Carers ask for respect of their expertise and knowledge from professionals, and to be listened to.
- Develop collaborative working culture in mental health to support the empowerment of carers.

Good practice specific to carers of people with dementia:

- Carers supporting people with dementia require the same respect and support as other carers, regardless of their age, acknowledging their experience and expertise and their role as a member of the care team for the service user.
- The quality of services for people with dementia should be improved.
- Listen to carers, respect their views and expertise viewing them as part of the care team (where appropriate).
- Address poor communication in dementia services particularly in hospital services. Carers want access to information about diagnosis and treatment as well as personal information (where appropriate).

Good practice specific to young carers:

- Young carers need to be proactive in seeking information and involvement.
- Professionals should not exclude young carers from discussions and better communication should be promoted.

Other key considerations:

- Carers are each managing unique circumstances and thus their individual needs will vary widely. Professionals must be aware of the carer context (including possible abusive relationships between carer and service user) and make decisions regarding the sharing of information as appropriate to each individual contact. The study found that carers who did not live with the service user, and carers who were not partners (but were parents) reported being in most 'need' of personal information. This reflects their own carer circumstances, in that there is less ordinary sharing of information between the carer and the service within their everyday relationship.

- Hospital stays and the processes surrounding discharge from hospital are reported to be most troublesome to carers. Particular strategies are needed to support carers who are relatives/friends of those who have been admitted to an in-patient hospital. However, another relevant issue at this point in the care pathway (often at the beginning) is the level of uncertainty for professionals, carers and service users. Poor information sharing practice relates both to a lack of information and support being provided, and to the sharing of inaccurate, insensitive or inappropriate information. A key theme across the data sets was values (openness, honesty and respect for other viewpoints), which includes acknowledging for example why a diagnosis is not provided or treatment options not decided.
- Carers often need to be proactive to develop effective relationships with professionals and gain support for themselves and the service user.

5.4 Good practice views from professionals

5.4.1 Professional sample

Professionals' views on information sharing may well depend on their professional background, length of experience working in mental health and experiences in other related roles, for example 27% of the professional sample are also carers and 14% describe themselves as mental health service users. In Table 18 we outline the characteristics of the professional sample (n=212), and these characteristics will be used in this and subsequent sections to explore variations in opinions between key professional groups: social work; psychiatry; psychology; and psychiatric nursing. The sample is small compared to the number of practising mental health professionals but the distribution is a reasonable reflection of the proportions of professional groups in the workforce except for those in the 'other' category, for example GPs and managers. It is also important to note that people working with adults of working age dominate the professional sample.

Table 18 Background characteristics of professional sample

Characteristic	Sample	
Gender	Female: 124 (59%)	Male: 85 (41%)
Ethnicity	White: 185 (89%) Mixed: 6 (3%) Other ethnic groups: 6 (3%)	Black/Black British : 8 (4%) Asian/Asian British: 2 (1%)
Workplace region	Eastern: 55 (28%) South East: 24 (13%) Greater London: 34 (18%)	South West: 29 (15%) Midlands: 10 (5%) North/North West: 41 (21%)
Profession	CPN - 74 (35%) Social work - 35 (17%) Psychiatrist – 34 (16%) Other – 31 (15%) [inc. GP, CMHT managers]	Psychologist – 24 (11%) Occupational therapy – 7 (3%) Therapist – 7 (3%)
Work place setting	Community teams - 124 (59%) Inpatients – 59 (28%) Day centres – 28 (13%) Other settings – 35 (16%) [inc. rehab, management, education]	Primary care – 12 (6%) Supported housing – 11 (5%) Outpatients – 7 (4%)
Employer	181 (85%) employed by statutory sector	
Client group	Working age adults - 161 (76%) Older adults - 36 (17%) Mentally disordered offenders - 19 (9%) Substance misuse services - 16 (8%) Children and adolescents - 12 (6%) Liaison psychiatry - 9 (4%) Eating disorders - 9 (4%) Other - 15 (7%) [inc. carers]	
Years working in mental health	Median 11 years Range 1 - 40 years	
Other roles for professional:	Also a carer? 54 (27%) Also a carer support worker? 27 (14%) Also a service user? 27 (14%)	

5.4.2 Professionals' views of information sharing practices

The respondents were asked to indicate why professionals do not share information with carers (see Table 19). The research team provided respondents with six options plus the 'other' category.

Table 19 Reasons why professionals do not share information with carers

Information not shared with carers because:	Professionals (n=207)	% of professionals	% of carers* (n=214)
Service user withholds consent	167	81%	21%
Carers not immediately accessible	118	57%	-
Staff have insufficient time	105	51%	-
Service user not asked to provide consent	91	44%	19%
Service user unable to give consent	59	29%	6%
Other reasons	36	17%	

*Note: *See Table 14*

Thirty-six respondents provided other reasons reflecting the involved and complex nature of decisions regarding the sharing of information with carers. From these open responses 21 themes emerged, in line with those reported by carers in Table 14, plus additional codes relating to professional views on how to share information appropriately. The most commonly reported open-coded themes were:

- professional uncertainty surrounding patient confidentiality and what can be shared (14)
- professional reluctance to work with carers (10)
- professionals avoiding the issue of information sharing with carers as it is not seen as a priority issue (8)
- problems over the definition of a carer (6).

Considerable difference in opinion is reported between professionals and carers mostly probably reflecting personal experience, which for a carer relates to individual family members and peers, but for professionals is drawing on relationships from large client caseloads over several years. For example, carers do not view service users withholding consent as a key issue (21%) compared to 81% of professionals.

When a comparison between staff groups is made, the most common reason provided by psychiatrists related to time constraints (68%) compared to 41% of psychiatric nurses who gave insufficient time as a barrier to information sharing with carers ($p=0.047$). Obtaining consent as a barrier was reported by 74% of psychologists compared to 28% of psychiatric nurses and 38% of psychiatrists ($p<0.0001$).

The study explored the link between policy and practice, and professionals were asked about the policies in place in their workplaces. For those professionals working in the statutory sector (n=171), only 48% were aware of a policy on sharing confidential information with carers, 11% were clear no policy existed to their knowledge, while 41% did not know. However, where known policies were reported respondents viewed these as helpful, with 20% rating their available policy as ‘very helpful’ and 62% reporting it as ‘quite helpful’. Psychiatrists were more likely to report access to specific policy documents compared to social workers (61% *versus* 31%, p=0.024).

In contrast with the service user sample where one in three stated there were no circumstances where information should not be shared without consent, in the professional sample 97% identified circumstances where ‘patient confidentiality’ could be broken. Assessments relating to risk were most commonly cited, for example concerns over patient safety (75%) and safety of others (87%). Sixty-five per cent of professionals would share information with carers where this had been agreed in advance, a similar proportion to service user responses (see Table 10). Professionals less frequently cited a service user lacking capacity, and being ‘unwell’ (43% compared to 58% of service users). Professionals also listed other circumstances including child protection issues, where the service user is a minor and during assessments under the Mental Health Act 1983.

5.4.3 Main barriers to information sharing when working with people with dementia

The research team were interested in the specific information sharing barriers related to specific mental health disorders. This section addresses professional views of barriers to information sharing with carers supporting people with dementia. This primarily concerns working with older adults, though it does not preclude working with younger adults who have early onset dementia. From the 212 respondents, 75 (35%) described barriers to information sharing relating to dementia. Of these 19 people worked with older adults. Across the responses it was stated that information sharing with carers of those with dementia occurs more frequently, though this does not remove professional responsibility to adhere to codes of practice regarding patient confidentiality and take into account the needs of the carer and their caring context.

> *I think it is generally more accepted that carers of people with dementia are included in their care. However, some carers do not want to be confronted with the diagnosis or the prognosis and therefore professionals can be reluctant to discuss such matters.*
> (Professional 99, psychologist)

Thirty-one emergent codes were identified from the qualitative data set on dementia. The key themes are listed in Table 20 and a selection of illustrative quotations are also listed. The most frequently cited problems were: difficulties obtaining consent from service users with dementia (27); professionals’ understanding and application of patient confidentiality (13); concerns over impact of information sharing on well-being of carer (7); and balancing user empowerment with carer involvement (6).

Table 20 Barriers to information sharing between professionals and carers of people with dementia

Theme	Responses (n=75)
Dementia specific issues: Denial of diagnosis by family and service user; lack of diagnosis; early on-set dementia and sharing info with carers; service user lacks capacity and difficulties obtaining consent/formally testing capacity, availability of good materials explaining dementia.	34 (45%)
General issues: Relating to professionals understanding confidentiality, involvement of advocates; definition of carer; use of professional judgement; quality of relationships (service user, carer, professional); service user's unwillingness to share personal information with carers; and carers having different role to professionals requiring access to less technical information sources.	31 (42%)
Disempowerment: concerns that carer involvement will undermine service user; professional reluctant to recognise carer rights or engage with carers.	14 (19%)
Fears (carer, professional and service user): professional lack skills confidence to share information with relatives of person with dementia; concerns over impact of information on carers (worry, distress, anxiety); carers fear their reactions to information will impact on service user; professional fears for conflict of interest and impact on user/carer relationship.	12 (16%)
Practical barriers: Difficulties having open discussion in front of service user; difficulty finding space for sharing of confidential information; time/workload pressures; carer not available.	8 (11%)
Carer context: age of carer; health of carer; knowledge of carer-user relationship.	6 (8%)
Carer frustration with services: Quality of services; attitude of staff to service user; difficulty accessing hospital beds.	2 (3%)

Note: More than one code could apply to each response, thus the percentages add up to over 100%

> *I think sometimes staff are worried about saying the wrong thing i.e. don't know what language to use, are frightened of upsetting the carer, and aren't sure what they can and cannot share.*
> (Professional 174, CPN)
>
> *Having this diagnosis is frightening for a carer. Information, education should be over a time, and in the carer's time, as too much information can be overwhelming.* (Professional 242, social worker)
>
> *Begs the question of capacity. Does this person have the ability to give consent or withdraw permission to share information with carers.*
> (Professional 80, family therapist)

When developing good practice models for information sharing in mental health, these will draw upon recommendations emerging from the current barriers being cited by professionals. For example, stakeholder 'fears' whether they belong to service users, carers or professionals will have to be tackled (through training in particular) if best practice information sharing strategies are to become part of routine clinical practice.

5.4.4 Main barriers to professionals sharing information with carers of people with eating disorders

The research team considered the area of 'eating disorders' as a specific case within the adults of working age group. Professionals were asked to describe specific barriers to information sharing with carers supporting people with eating disorders. Only the responses that describe specific eating-disorder-related issues are described, provided by 52 professionals out of the data set of 212 responses (25%). From the sample 58% of both the psychiatrist and social worker groups provided a response, along with 45% of psychiatrist nurses and 35% of psychologists.

Seventeen codes emerged from the 52 responses. Nine of these codes were single responses from one professional relating to a specific aspect of working with eating disorder carers. These included: culture of protecting the service user from the family; involving the family placing too much pressure on the service user; and the stigma of the disorder. The most frequently cited issue from 30 professionals (58%) described how service users with eating disorders did not want to disclose personal information to their carers or did not want them involved. In addition family dynamics (6), ignorance of professionals to eating disorders (3), families being unaware of the problems (3), and manipulative behaviour by service user (3) were described as illustrated by the selected quotations below:

> *Service users with an eating disorder have often denied any problems. They have often hidden the fact that they have a problem. In my experience such service users have often been students living away from home and have not wanted their families to be contacted*
> (Professional 227, social worker)

> *The key issue is addressing any family dynamics that may have had an impact on the onset of the eating disorder.* (Professional 111, CPN)

> *Professionals can tend to infantilise the service user and marginalise the carers.* (Professional 195, social worker)

5.4.5 Main barriers to information sharing for carers of people with severe mental illness

Service users living with SMI are described as those people with psychosis, schizophrenia, manic depression and chronic depression. A total of 173 professionals (82%) described barriers to information sharing with this group (31% described one barrier, 30% two barriers, 16% three barriers and 5% more than three barriers). This response provides an indication of the relevance of this question to the sample and the scale of the 'problems' that are currently experienced. The data describing barriers to information sharing with SMI groups were coded using 54 themes. These themes are described below in five categories in Table 21. The largest group of codes are described under the theme ‘practical issues affecting professionals in relation to information sharing with carers, including responses relating to difficulties collecting consent (46) and confidentiality itself – understanding, fears of breaching (32). Professionals noted:

> *Patient alienated from carer following section/delusional system. Written consent from the patient is useless as they change their mind when ill - at exactly the time the carer wants to know what is going on.*
> (Professional 21, psychiatrist)

> *Confidentiality makes it almost impossible for a clear open dialogue to be established. This is a detriment to all involved in the process and it hinders everything!* (Professional 62, psychiatrist)

> *Consent is a major barrier also instinct in relation to the service users mental state.* (Professional 170, CPN)

Key issues related to the service user were also noted, most crucially where service users do not want to share information with their carers (37). Professionals have to balance a carer’s ‘need to know’ with principles of patient confidentiality relying on their professional judgement and duty of care to the ‘patient’. Associated with service users’ unwillingness to involve carers was the issue of ‘patient capacity’ as a barrier to information sharing (18), including acknowledgement that paranoid feelings directed towards family members during periods of acute illness can prevent professional sharing information that would at other times be shared with service user consent. There was also recognition among professionals that the carer role is not sufficiently embedded within the workings of community mental health care, thus hindering information sharing because of poor professional cultural awareness of the carer (32). The lack of carer recognition also led to poor awareness of the impact of sharing information on carers (13) where information should be sensitively shared to avoid undue distress to carers, for example one professional listed the barriers as:

> *Identifying what is confidential; ensuring you have consent; avoiding causing distress to carers.* (Professional 163, CPN)

> *Uncertainty about the nature or cause(s) of the mental health problem (e.g. illicit drug use); uncertainty about the carer’s own mental health; uncertainty about the nature and stability of the carer’s relationship with the patient.* (Professional 24, psychiatrist)

This emphasised the role of professional judgement in all information sharing activities.

Practical issues also act as barriers to effective information sharing and professionals did emphasise that time and workload pressures were factors hindering work with carers (28). When solutions are sought to the current difficulties of professionals sharing information with carers, practical issues including time constraints, difficulties accessing and identifying carers, the stigma of mental illness and unclear service protocols will all need attention.

> *The main barriers are: patient consent; service protocols; communication method, e.g. telephone; determining level of carer; differentiating between direct carer and involved family; patient illness and behaviour, staff time.*
> (Professional 232, social worker)

Table 21 Barriers to information sharing with carers of people with SMI

Theme category	Professionals (n=173)
Practical issues affecting professionals in relation to information sharing with carers (18 codes; range 1to 46 cases)	122 (71%)
For example: consent, confidentiality rules, carer definition, uncertainty of diagnosis or prognosis – not knowing what 'facts' to share, impact on service user-professional relationship, balancing confidentiality *versus* carer need to know, risk assessments.	
Key issues relating to service users (6 codes; range 1 to 37 cases)	63 (36%)
For example: service user not wanting to share information (involve) carers, service user capacity, service user lack of awareness of benefits of sharing information with carers.	
Professional recognition of carer role (7 codes; range 1 to 32 cases)	58 (34%)
For example: lack of confidence (skills/training) for working with carers, resistance to working with carers, lack of awareness of impact of information sharing on carer.	
Issues relating to carer (relative or friend) and wider family (14 codes; 1 to 13 cases)	52 (30%)
For example: relationship conflicts between carer and service user, understanding family dynamics, potential carer abuse, over involvement of carers, carers unwilling to be involved.	
Practical barriers (9 codes; range 1 to 28 cases)	50 (29%)
For example: lack of staff time to work with carers, difficulties arranging mutually convenient time for working between carer and professional, difficulties accessing the carer, lack of space on wards for private time with carers.	

5.4.6 Resolutions

The professionals responded to a series of open-ended questions to provide an indication of their experiences of solutions, good practice examples and recommendations for addressing information sharing problems in mental health. One hundred and sixty professionals (74%) provided suggestions on the strategies needed to improve information sharing practices with carers. Their responses generated 51 codes and these have been themed under three main headings. For the professional-led actions and system-led changes, several sub-themes were also identified (Table 22):

- carer-led actions (9)
- professional-led actions (137)
- system changes (151).

Table 22 Professional views on changes required to improve information sharing experiences for carers

Solutions to improve working with carers	**Responses (n=297)**
Carer-led actions	**9 (3%)**
Professional-led actions:	**137 (46%)**
• related to changes in approach to working with carers, e.g.	73
- change attitudes to carers, involve carers (with consent), build open and honest relationships	
• related to application of policies in routine clinical practice, e.g.	24
- regular reviews of consent, risk assessments, explain need for carer involvement to service user, awareness of carers to boundaries of confidentiality	
• related to practical suggestions, e.g.	40
- carer 'surgeries' staffed by professionals, three-way meetings, better communication, collecting consent routinely.	
System changes:	**151 (51%)**
• provide training	51
• improve policy guidance notes	46
• provide services for carers	21
• improve educational resources available for carers	16
• address structural barriers e.g., workload pressures	12
• other e.g. management changes and health promotion emphasis	5

The main sub-themes for professional actions concern their approach to working with carers (73). Professionals should seek to involve carers from the start of their relationships with the service user, where appropriate. For this to occur it was recognised that attitudes would need to change with responsibility falling to all mental health disciplines. Professionals also recognised numerous problems with the 'system' supporting their working practices. The area of work highlighted by most professionals related to training – particularly providing professionals with training on working with carers, involving carers (51) and also to improved policy guidance (46) as the quotations below illustrate:

> *Firstly, carers need to be given the same respect for their confidentiality as is given to the patient and this urgently needs to be enshrined in law and guidance from the Department of Health.*
>
> (Professional 168, care centre manager)

> *Training for professionals around issues of confidentiality. Professionals to listen to the experiences of carers either through training opportunities or carers' assessments.*
> (Professional 58, social worker)

> *Clear protocols. More general information available to carers (e.g. written material about psychosis). Parent support groups. Establish information sharing agreement at start of treatment with all parties involved.*(Professional 45, CPN)

In addition to providing solutions for supporting carers through information sharing, 102 (48%) professionals also shared with the research team their positive experiences. These experiences were coded for content and underlying principles. The main underlying principles emerging from professional responses were:

- dialogue/communication (36)
- consent (22)
- recognising carer rights and 'need to know' (12)
- recognising carer role (4).

Sixty-one professionals described clear strategies that were coded for 'content'. These are summarised below:

- Strategies that involve professionals supporting carers (39)
  - carer assessments (3)
  - communication with carer (12)
  - general information provided to carer (7)
  - encourage service user and carer relationships to promote information sharing without involving professionals (5).
- Strategies based upon a collaborative approach (24)
  - carer involvement in decision-making, for example CPA reviews (12)
  - stakeholders work together to develop solutions (5).
- Strategies that rest on collection of consent (14);
  - professionals explain importance/benefits of sharing info with carer to service users (11)

  Professionals explain importance of consent to carer (3).
- Strategies that reply on delivery of effective services (11);
  - access to CPA (4)
  - access to advocacy services (4).
- Carer actions – persistence (2).

Professional strategies are based on professional-led actions. Only two professionals noted resolutions involving carers being more active, persistent and proactive and placed responsibilities on themselves and their colleagues to resolve information sharing difficulties. The quotes below illustrate some of the successful strategies adopted by individual professionals:

> *Communicate as much as possible in terms of what is going on. Sharing the care and burden. Education in letting go and prevention of over-involvement, being too protective not allowing the person who is ill to be as independent as they can within the limitations of our job role.*
> (Professional 34, CPN)

> *If you have received information from each side it is usually possible to raise relevant questions in a diplomatic way, at a joint meeting, to get issues out on the table in a positive fashion.*
> (Professional 41, psychiatrist)

> *I have found joint policies between agencies very useful. Once explained, most carers appreciate that we have to work within in a remit of respecting our client's right to confidentiality.*
> (Professional 46, CPN)

> *I have found some carers respond well to time spent talking through the service options before they need to make a decision with or for a user, as it is often the first opportunity they have had time to consider rather than just 'do'. (Professional 87, social worker)*

> *I have been training staff in family intervention for five years and seen a noticeable shift in attitude among those trained.*
> (Professional 157, CPN)

> *Drip drip approach - keep reinforcing possibilities and benefits; keep door open when initial reaction unfavourable - applies to colleagues as well as families. (Professional 162, occupational therapist)*

> *Often carers have not fully understood what has been said in ward reviews. Therefore it is helpful for ward staff to spend time with them afterwards and reiterate what decisions have been made and why.*
> (Professional 173, CPN)

5.4.7 Summary of good practice principles –from a professional perspective

A range of issues hinders information sharing in mental health from a professional perspective. These include practical constraints (for example staff not having the time to share information with carers); poor communication across the mental health service; fears on the part of service users, professionals and carers; and inadequate training and support for all stakeholder groups. A number of recommendations were made and good practice principles highlighted. At the core of the professional role are principles of clinical practice that rely heavily on professional judgement, which in itself requires effective information gathering and knowledge of both an individual and the context in which they live their lives.

Good practice principles:

- Accessible and useful policies or guidance on confidentiality are widely available to professionals (as well as to service users and carers). Where policies exist they are rated as useful by practitioners. –

- Service users do not want information shared without their consent but professionals recognise there are appropriate circumstances where patient confidentiality should be broken. When confidences are broken the reasons for this decision are shared with the service user at a timely and appropriate meeting.
- Consent is collected and routinely reviewed. Advance agreements are used to establish what information can be shared with a carer. Professionals may have to spend time explaining to service users why carers 'need to know' details about their care and treatment.
- When working with people with dementia, professionals consider the impact of information sharing on the carer and support them to 'hear information'.
- Professionals are be trained in the application of patient confidentiality to address lack of staff skills and confidence in working with carers and sharing information effectively.
- All professionals recognise the carer role, with active consideration of the involvement of carers being made 'from day one' though actual involvement will be undertaken in consultation with service user
- Carer's 'need to know' is balanced with service user's 'right to privacy'. Decisions are communicated honestly and openly.
- Support services are made available for carers, including carer assessments and general information packs.
- A collaborative approach is adopted in mental health involving all relevant stakeholders (members of mental health profession, family, advocates, service user, support staff).

Other considerations:

- Professional reluctance to work with carers who have traditionally been the responsibility of social services must be addressed if carers are to be effectively supported through appropriate sharing of information.
- In order for professionals to effectively support and involve carers they need sufficient capacity, and recognition of this resource commitment, within their role to enable them to work better with carers.

5.5 Good practice views from carer support workers

5.5.1 Carer support worker sample

CSWs' views on information sharing practices may bridge the gap between professional and carer opinions, as their role links carers and mental health services. Table 23 outlines the background characteristics of the CSWs who participated in this survey.

Participants are predominately female, and are largely employed by the voluntary sector. Respondents have typically worked as a CSW for less than four years, which reflects the recent introduction of this specific role.

Table 23 Background characteristics of CSW sample (n=93)

Characteristic	Sample	
Gender	Female: 76 (82%)	Male: 17 (18%)
Ethnicity	White: 89 (90%) Mixed: 3 (3%) Other Ethnic group: 1 (1%)	Black/Black British: 3 (3%) Asian/Asian British: 3 (3%)
Region	Eastern: 8% South East: 24% Greater London: 15%	South West: 11% Midlands: 17% North: 25%
Work status	Full-time: 53 (55%)	Part-time: 41 (42%)
How long working as a CSW	Mean: 3.8 years Maximum: 15 years Minimum: under 1 year	
Employed by	Statutory sector: 14 (15%) Voluntary sector: 66 (71%)	Private sector: 5 (5%) Other: 4 (4%)
Other roles	Also a service user: 14 (15%) Also a professional: 33 (36%) Also a carer: 43 (46%)	

5.5.2 Carer support worker views on information sharing practice in mental health

CSWs were asked whether mental health professionals regularly consult service users to gain their consent to share information with the carer. Only 12% of this sample stated that professionals always seek consent as part of clinical practice, 39% stated sometimes, and 27% stated that professionals rarely sought consent. At the same time, 3% suggested that professionals never asked for consent and 19% did not know. This sample of CSWs therefore suggests that obtaining consent is not an integral part of routine clinical practice.

CSWs in this sample were asked about carers' access to confidential information across a range of different settings. Their responses were similar to those of carers (see Table 20). CSWs suggest that carers always have difficulty obtaining information when the service user is in hospital (34%) and when the service user is being discharges from hospital (30%).

Participants were asked under what, if any, circumstances professionals should share information with carers without the service user's consent. In total 99% of CSWs stated that 'patient confidentiality' could be broken on certain occasions. The most commonly cited circumstances were: if there are concerns that the service user might harm other people (87%); if people are worried about the service user's safety (86%); and when the service user has agreed in advance (82%). A service user being unwell (69%) and the carer and service user living together (52%) were cited less.

5.5.3 Carer support workers' views on their role in sharing information

The research team were keen to observe the role of the CSW in assisting and bridging the gap between carers and professionals in confidentiality issues. Among CSWs, 21% suggested that it was not difficult to bridge the gap between professionals and carers, however, interestingly this is a similar percentage to those CSWs who suggested it was very difficult to bridge the gap (24%). The majority (55%) stated that they found it quite difficult to act as a bridge between the carer and professional in negotiating confidential issues.

CSWs were also asked which professions they most frequently negotiated confidentiality issues with, on behalf of the carer they support. Social workers (85%), nurses (47%) and psychiatrists (40%) were cited as the most likely professions in which they were involved in negotiating confidentiality issues.

5.5.4 Barriers in sharing information

Participants were presented with seven possible options as to why professionals do not share information with carers. Respondents were asked to indicate which they agreed with (see Table 24), the category of 'other' was also provided. Thirty-five respondents provided 'other' explanations as to why information is not readily shared, which suggests reasons for not sharing information are indeed multifaceted. From these open-coded responses 13 common themes emerged. The most commonly reported open-coded themes were: lack of recognition/consideration of the caring role (7), staff unaware of the boundaries as to what information can and cannot be disclosed (7) and patient confidentiality/data protection (5).

Table 24 Reasons why professionals do not share information with carers

Information not shared with carers because:	Carer support workers (n= 88)	%
Service user withholds consent	57	64%
Carers not immediately accessible	29	33%
Staff have insufficient time	50	56%
Service user not asked to provide consent	54	60%
Service user unable to give consent	33	37%
Service user lacks capacity	30	34%
Other reasons	34	39%

5.5.5 Information sharing problems for carer support workers

Participants were also asked to suggest any problems that can arise from poor information sharing practices. A total of 83 respondents completed this part of the survey. Responses predominately focused on the problems and struggles experienced by the carer. Thus, there was a definite carer focus when addressing the problems that arise from poor information sharing. Twenty-one emergent codes were identified from this qualitative data set. The key themes are listed in Table 25 and a selection of illustrative quotes are also provided.

> *Carer totally unprepared for the impact of caring, leading to crisis breakdown of caring situation (know of two who left the user and one who committed suicide): user not benefiting to getting maximum benefit medication or other intervention, due to reduced understanding by carer (exacerbation of condition, readmission to hospital, suicide of user).*
> [CSW 25]

> *The main problem is that it limits the carer's ability to care effectively. It causes problems in crisis situations in which the carer is involved. Its adds to carer stress. It denies the team caring for the service user information which the carer has, since if the team do not share with carer there is usually not an opportunity for the carer to share effectively with the team.* [CSW 30]

> *Extremely poor relationships between carer and staff and resentments on both sides largely due to poor communication and carers often feeling frustrated and ultimately communicating this. Poor trust of healthcare professionals due to poor communication and carers not feeling valued in their role and the support/care they provide.*
> [CSW 34]

Table 25 Problems arising from information sharing as identified by CSW

Theme	Responses (n=83)
Excluding carers: resulting in feelings of isolation, being undervalued, stress, anxiety, fear and frustration. Detrimental to carer's physical and mental health as well as general well being.	42 (51%)
Lack of carer knowledge: resulting in poor care provision and lack of understanding of mental health issues and services available, e.g. medication blunders.	31 (37%)
Well-being of service user: resulting in relapses, poor physical and mental health.	16 (19%)
Risk/harm concerns: to the carer, service user and general public.	14 (17%)
Communication/relationship breakdown: between carer and professional.	10 (8%)
Hospital discharge problems: resulting in carer being unaware of procedures and outcomes.	10 (8%)
Access to key information: e.g. carer is unable to provide key information to professionals to aid diagnosis, treatment and	10

recovery.	(8%)

5.5.6 Carer support worker positive experiences

The research team was mainly concerned with addressing good practice procedures acquired from the CSWs' experiences and opinions. Eighty-three respondents provided recommendations on the strategies needed for improving information sharing practices between professionals and carers. Their responses generated 21 codes and these have been themed under four main headings.

- information sharing procedures (66)
- carer consideration (63)
- service user consideration (13)
- professional approach (11).

These main headings and codes are presented in Table 25 and a sample of illustrative quotes is also provided.

Table 26 CSW solutions for improving information sharing

Theme category:	**CSW responses (n=151)**
Information sharing procedures	**66 (44%)**
• provide training for professionals	20
• improve communication between all parties	9
• consistent and implemented confidentiality guidelines	6
• provide 'general' information where possible	6
• acknowledge context of care	5
• advance directives	5
Carer consideration	**63 (41%)**
• inform and involve carer	20
• carer recognition	19
• carer regarded as part of the team	13
• provide support for carer	9
Service user consideration	**13 (9%)**
• request service user consent	7
• inform and involve service user in information sharing	6
Professional approach	**11 (7%)**
• professionals to listen	5
• professionals to be open and honest	2
• professionals to explain why decisions have been made	2
• professionals to have an accurate knowledge of mental health services	2

> *Include carers in medical discussion. Provide accessible, understandable information. Signpost carers to relevant self-help group if appropriate. Ensure relevant training/staff in place for voluntary sector. Provide specific support/advocate for carer.*
>
> [CSW 33]

> *Service users being asked routinely for their permission to share information – including explaining why this is important and recording their consent, visibly in service users records/files.*
>
> [CSW 80]

> *Education for carers about confidentiality issues. Education for professionals about listening to carers and in skills in providing general information about the illness and how the carers can support.*
>
> [CSW 94]

For the majority of CSWs, informing, involving and including the carer was identified as a key strategy to improve information sharing procedures (20). Engagement with the carer during the service user diagnosis, treatment, recovery and progression through mental health services was of great importance to CSWs. In addition, CSWs identified training (20) for all stakeholders as a fundamental strategy to enhance information sharing. They suggested training on carer issues, information sharing/confidentiality issues and mental health services/support as key topics to be considered. CSWs also suggested carer recognition (19) as a key strategy to improve information sharing practices. Recognition of the carer position, responsibilities, duties, and role knowledge base was important to the CSW sample.

As with the other stakeholder groups, CSWs (60% of them) also provided us with recommendations for good practice. The key principles identified were:

- dialogue and communication (14)
- recognition of carers' rights (14)
- consent (9).

CSWs named 33 separate strategies for addressing the problems associated with information sharing in mental health. These have been themed and provide the following approaches:

- professional actions (40)
- collaborative approach (13)
- consent (9)
- independent advocacy (3).

5.5.7 Summary of good practice principles –from the CSW perspective

The CSW sample data provides supporting information reinforcing the views expressed by other stakeholder groups. For example service users highlighted that consent is not routinely collected and this is also the view of CSWs. Carers highlighted that when service users are in hospital or being discharged , they find it particularly difficult to get supportive information. This observation was also made by CSWs. Professionals have acknowledged they lack expertise in applying confidentiality and in terms of barriers to information sharing the CSW group identified professionals' lack of awareness of boundaries for disclosure of information a severe limiting factor. Their recommendations for addressing these problems are summarised below:

- Provide training for professionals on how to work with carers, and the boundaries of information sharing practice.
- Improve communication between all parties.
- Increase recognition for role of carer, leading to increased carer involvement.
- Provide staff with more time to work with carers.
- Collect consent as part of routine clinical practice.
- Reverse the problems of carer exclusion by involving carers in mental health care and supporting them effectively.
- Provide carers with education and skills to support them in the carer role.

5.6 Contrasting stakeholder perspectives

The resolutions in Table 27 were options provided to all four stakeholder groups and respondents were asked to identify which solutions they felt were most appropriate to improve information sharing with carers. There were a number of individuals who ticked all the available suggestions: 16 CSWs (18%); 40 carers (8%); 36 professionals (17%) and 6 service users (4%). Overall, service users identified with the fewest number of resolutions with the 'median average' service user indicating seven out of 16 solutions as preferable. This compares to ten out of 17 for carers, 13 out of 17 for professionals and 14 out of 17 for CSWs.

Comparing preferences for each of the resolutions there were significant differences of opinion within each item when comparing the proportion of respondents agreeing with each item across the four stakeholder groups (see Table 27). However when the solutions are ranked and the top four solutions are compared, variation in opinion lessens (see Table 28). Ranking the solutions removes variability in response rates between stakeholder groups for each item. For example the bottom-ranking solutions for all groups included sharing information on a hypothetical basis. This was not well-received compared to the solution that involves professionals discussing issues of confidentiality with the service user and the carer together, which was rated in the top four across all four stakeholder groups. CSWs rated their role as advocates and the attendance of carers at care planning meetings more highly than the other groups.

Considering the responses in Table 28 in some detail shows some interesting contrasts in opinion. Some of these are listed below:

- Service users, carers and CSWs rank in their top three the solution 'explain to service user about their carer's need to know'. This was not as popular an option for professionals.
- Service users and professionals both favour 'help service user identify some aspects of their information that they feel comfortable sharing'. However this is not as highly rated by carers or CSWs who may be concerned that the information they 'need to know' is that which the service user is less willing to disclose.
- Carers and CSWs are not keen on professionals exploring alternative ways of sharing information, which ranks in their bottom two solutions. This solution appeals more to professionals and service users.
- Overall, service users rate professional actions as the most important solution.
- Overall, carers rate their own actions as the most important solution.
- Overall, professionals rate their own actions as the most important solution.
- Overall, CSWs rate professional support for service user and carer as the most important solutions.

Table 27 Overcoming information sharing problems in mental health

Resolutions	Service user (n=154)	Carer (n=475)	Professional (n=212)	CSW (n=93)
Professional actions				
Explain to service user about their carer's 'need to know'	60%	77%	73%	89%
Discuss issue of confidentiality with service user and carer together	71%	74%	82%	88%
Share information with carer on a general (hypothetical) basis	32%	49%	44%	48%
Help service user identify some aspects of their information they feel comfortable sharing	66%	56%	82%	80%
Consider long term relationship between service user and carer before deciding whether to share info	54%	66%	58%	63%
Explore alternative ways of sharing info that are acceptable to service user (e.g. sharing with other closely involved person)	53%	45%	71%	55%
Consent to disclose document of service user wishes	50%	52%	80%	74%
Make clear to carers the rules of the professional codes they are bound by	-	50%	77%	66%
In cases of serious disagreement carers, service users and professionals should be able to consult an officially-recognised, independent group	44%	65%	63%	80%
Support for carer/service user				
Service user supported by advocate	47%	54%	77%	79%
Carer supported by CSW or advocate	36%	66%	73%	91%
Carer supported through carer's assessment	36%	59%	79%	80%
Carer in carer support network	37%	64%	79%	84%
Carer undergoes carer training	30%	52%	63%	75%
Carer actions				
Carer seeks information/support from another mental health professional	42%	57%	62%	64%
Carer perseveres in their contact with professionals (assertive carers)	42%	73%	66%	73%

Carer attends care planning meetings	43%	70%	80%	94%
Average number of resolutions provided – median (mean)	**7 (7.49)**	**10 (10.3)**	**13 (12.55)**	**14 (12.83)**

Table 28 Service user, carer, professional and CSW rankings of suggestions for overcoming information sharing barriers in mental health

Resolutions	Service user	Carer	Professional	CSW
Professional actions	**Rank**	**Rank**	**Rank**	**Rank**
Explain to service user about their carer's 'need to know'	3	1	9	3
Discuss issue of confidentiality with service user and carer together	1	2	1	4
Share information with carer on a general (hypothetical) basis	15	16	17	17
Help service user identify some aspects of their information they feel comfortable sharing	2	11	1	6
Consider long-term relationship between service user and carer before deciding whether to share info	4	5	16	15
Explore alternative ways of sharing info that are acceptable to service user (e.g. sharing with other closely involved person)	5	17	11	16
Consent to disclose document of service user's wishes	6	13	3	11
Make clear to carers the rules of the professional codes they are bound by	-	15	7	13
In cases of serious disagreement carers, service user and professionals should be able to consult an officially-recognised, independent group	8	7	13	6
Support for carer/service user				
Service user supported by advocate	7	12	7	9
Carer supported by CSW or advocate	13	5	9	2
Carer supported through carer's assessment	13	9	5	6
Carer in carer support network	12	8	5	5
Carer undergoes carer training	16	13	13	10
Carer actions				
Carer seeks information/support from another mental health professional	10	10	15	14
Carer perseveres in their contact with professionals (assertive carers)	10	3	12	12
Carer attends care planning meetings	9	4	3	1

A comparison of the types of personal information that service users and carers feel should be shared also varies (see Table 29). This has implications for improving the relationship between service users and carers with regard to information sharing as priorities differ and each group may need support to understand the other group's needs/wishes. The top priority among carers for personal information related to future possible treatment options, yet service users ranked this 11th.

Table 29 Comparison of service user and carer responses over what personal information is required to support carers in the carer role

Personal information needed by carer to support role	**User view (n=112)***	**User rank**	**Carer view (n=379)****	**Carer rank**
Type of mental health problem (e.g. diagnosis)	86%	2nd	59%	6th
Likely progress of mental health problem	76%	7th	80%	2nd
How user's problems may affect carer	79%	3rd	54%	11th
Current medication – type, dose	77%	5th	57%	8th
Current treatments	69%	8th	55%	10th
Possible future treatment options	57%	11th	82%	1st
Access to medical notes	31%	14th	31%	15th
Content of care plan	60%	10th	70%	3rd
Who to contact in crisis	87%	1st	67%	4th
Who to contact for help and support	77%	5th	60%	5th
Early warning signs of possible relapse	79%	3rd	59%	6th
Risks associated with user's mental health problems	63%	9th	57%	8th
Content of risk assessments	34%	13th	48%	13th
Information for benefit claims	48%	12th	51%	12th
How to help attend to user's personal affairs (e.g. finances)	31%	14th	37%	14th

*Note: *49 service users (31%) do not feel that carers need access to personal information to support them in their caring role – the responses from users in this Table are from those that feel carers do need some personal information; **121 carers (21%) do not feel they need personal information to support them – the responses in the Table are from those that feel they do need access to personal information*

The data set also enabled a comparison of views on the principles of information sharing without service user consent (see Table 30). Service users differ to professionals and CSWs in their view on the sharing of information if there are concerns over risk to others. Only 43% of professionals felt a service user 'being unwell' was grounds to break patient confidentiality compared to 69% of CSWs and 58% of service users. A carer living with a service user was not sufficient grounds to break confidences according to service users and professionals (25%) while CSWs felt that living arrangements did provide grounds for information sharing without consent to take place.

Table 30 Stakeholders' views of appropriate and relevant boundaries surrounding the sharing of information in mental health

	Service users	**Professionals**	**CSWs**
Are there any occasions when information should be shared **without** service user consent?	**Yes** – 109 (69%) **No** - 48 (31%)	**Yes** – 200 (97%) **No**– 7 (3%)	**Yes** –87 (99%) **No**– 1 (1%)
Breaking confidentiality:	(n=109)	(n=207)	(n=88)
Sharing without consent when service user is very unwell	63 (58%)	89 (43%)	61 (69%)
Sharing without consent when service user has agreed in advance	70 (64%)	138 (67%)	72 (82%)
Sharing without consent if people are worried about service user's safety	67 (62%)	158 (73%)	75 (86%)
Sharing without consent if there are concerns about service user harming other people	54 (49%)	184 (89%)	76 (87%)
Sharing without consent if my carer lives with me (n=110)	27 (25%)	50 (24%)	46 (52%)

The final stakeholder comparisons involve the various resolutions provided and rated (See Tables 31 and 32). When solutions are addressed less variation is found. Service users, professionals and CSWs rated communication and dialogue as the most important principle whereas carers felt being proactive was crucial. When the strategies are compared (see Table 32), service users place emphasis on their actions, followed by those of professionals. The other three groups prioritised professional actions firstly. Collaborative actions also featured highly across the four groups.

Table 31 Good practice principles: comparison of rankings

Principles of good practice	Service user ranking (n=16)	Carer ranking (n=129)	Professional ranking (n=102)	CSW ranking (n=56)
Proactive carers	2	1	-	
Recognition of carer needs and rights	-	2	3	2
Establishing dialogue and better communication	1	3	1	1
Professional attitudes (open, honest, caring, non-patronising)	-	4	-	4
Consent	2	-	2	3
Recognition of carer role	-	-	4	
Proactive service users	2	-	-	

Table 32 Good practice strategies: comparison of rankings

Good practice strategies	Service user ranking (n=15)	Carer ranking (n=85)	Professional ranking (n=61)	CSW ranking (n=43)
Professional actions - supporting carers	2	1	1	1
Carer actions – persistence	4	2	5	5
Collaborative approach – stakeholders working together	2	3	2	2
Collecting consent	-	4	3	3
Service user action – proactive steps to include carer	1	5	-	
Deliver effective services		-	4	
Address carer/service user interaction	4	-	-	
Independent advocacy				4

5.7 Summary

In this section, a large amount of data has been presented considering the perspectives of the four stakeholder groups and in particular the application of good practice when working with carers of people with dementia and SMI. Each of these groups identified a number of problems with information sharing, including the adverse effects it can have on both the service user's recovery and the health of the carer, highlighting that work to improve practice is needed urgently.

A common theme across the stakeholder groups was the importance of effective communication and the basis for information sharing being open, honest and respecting relationships. For carers and CSWs the culture shift required in mental health, to place carer issues further up the priority list not only in principle but in practice, underpinned all solutions. The role of carers needs to be recognised by all practitioners, but currently professionals admit there is reluctance among some staff to work with carers. This reluctance has its roots in structural problems: lack of professional training (and hence confidence) to work with carers; insufficient capacity (acknowledged as lack of time) to work effectively with carers as well as service users on their caseloads; and the environment (most notably on wards) not being conducive to sharing information with carers. However it also stems from stereotypes of carers and family members as over-involved, difficult and better avoided.

Service users, who in this sample were comfortable with their carer being involved, were keen to have the principle of consent underpinning the sharing of all information with carers. Service users also had mixed views on the practice of carers having separate time discussing them with a professional. They also provided a large number of recommendations reflecting the individualised nature of 'solutions to information sharing difficulties in mental health'.

Differences in opinion were evident but there was symmetry in stakeholder solutions in relation to the central recommendations of:

- better communication
- discussing issues together with all parties
- openness and honesty
- balancing carer's 'need to know' with service user's right to privacy
- consent
- professionals to support carers more effectively.

Section 10 has a more detailed summary of this data. It collates and presents good practice recommendations from each component of the research study to provide an approach to addressing effective ways for professionals to involve carers in information sharing.

Section 6 Interviews

In-depth interviews with 34 stakeholders were carried out to specifically address areas of good practice. In this section the analysis of the interviews is presented thematically for stakeholders working with mental illness among adults of working age and older adults with dementia. The focus of the analysis has centred on two areas of the interview transcripts:

- good practice *principles* for information sharing in mental health
- good practice *strategies* to achieve effective information sharing in mental health.

In this section the interviews with CSWs (n=3) are presented alongside the professionals because the CSW sub-group was too small to consider as a separate grouping.

6.1 Interviews with stakeholders working with mental illness among adults of working age

The interviews with those affected by mental illness among adults of working age were recruited across three stakeholder groups (see Table 2). These were:

- mental health service users (5)
- carers supporting adults with psychosis (6), and a carer supporting an adult with an eating disorder (1)
- professionals working in adult mental health services: GP (1); psychiatrist (2); ASW (4); CSW (2).

The data from the interviews are reported for stakeholder groups separately: service user, carer, and professionals. For each group, two key themes are explored: principles of good practice and strategies.

6.1.1 Good practice principles

Principles: service users

The service user group focused on patient confidentiality as the key principle to be considered in professionals sharing information with carers, followed by the context in which care is provided. They were less concerned with developing a culture of openness that promotes information sharing and did not address the need to create recognisable services and professional roles.

The primary concern of the service user group was patient confidentiality. All interviewees stressed the need to obtain service user consent before professionals share information with carers: 'basic principle is service user consent' (service user 4). Most explored capacity and how this may impact the service user's ability to provide consent, but still respondents felt consent should be sought. Some interviewees were aware that withholding consent might have a detrimental impact on the standard of care they received yet they still felt professionals should obtain consent.

> *It's only some parts of the mind that are affected when the service user is ill. Professionals should not just disregard the service user and what they want. It is like the psychotic patient who can still drive their car: professionals need to consult the service user even if they are completely out of it.* (Service user 5)

Service users suggested written or verbal consent ensured their privacy and protected of private information. Consent therefore appears crucial to maintain the service user's self-esteem and public image as well as their basic right to privacy. Moreover, most of the group suggested that consent provides the user with an element of 'choice' (service user 4). Service users suggested personal choice promotes their autonomy, independence and general well-being as well as empowerment. 'Service user empowerment' (service user 1) was important to this group and could be achieved by professionals and carers acknowledging the service user's wishes. This appears crucial for service users as elements of a person's mental health such as paranoia or delusions may affect the level of information they want professionals to share. Service users felt these factors should be recognised by both the carer and professionals:

> *If a service user thinks the carer is the devil, even if this is false, it is clear it will distress the service user to inform the carer. The approach here is to wait until the paranoia has passed. My view here is to follow the service user wishes even if the service user is irrational.*
> (Service user 4)

> *When the patient is ill, it is often the carers who are part of the delusions and it is real for the service user at the time and therefore information should not always be shared with the carer.*
> (Service user 5)

The principles of sensitively recognising, respecting and understanding the service user's wishes of information restriction should be key within the information sharing process. However, in practice service users noted that some professionals actually fail to value the service user's wishes and thus behave unsuitably. All service users noted occasions when professionals breached confidentiality or used it as an excuse not to share information with carers.

> *There have been times when psychiatrists have bullied me into having my husband at meetings when really I don't want him there.*
>
> (Service user 1)

Consistent with the survey data, developing a culture of information sharing was not fully endorsed by the service user group. Interviewees felt that such a culture actually removes the 'service user's autonomy and basic right to independence and privacy.

Most service users identified the context in which care is provided as a key principle to be considered in information sharing. The majority of the service users showed an appreciation of the different types of caring relationships, the quality of these relationships, the family dynamics and the way in which information sharing might vary as a consequence of these. In particular, the difference between the parent/child relationship and the partner relationship was noted and its impact on the amount and type of information sharing highlighted.

> *I am very aware of the different types of caring relationships. It's different for me as my husband is my carer but parent dynamics, the parent/child relationship, offer a different caring situation where in some cases the child is still treated as the child whereas my husband and I have equal status.* (Service user 1)

Principles: carers

Carers supporting adults of working age were primarily focused on professional recognition of the caring role, mutual recognition between stakeholders, patient confidentiality and context of care as key principles in information sharing practices. They were least concerned with best interest and avoidance of harm.

Carers were foremost concerned with professional recognition of their caring role and noted how their specialist knowledge of the service user should be recognised by professionals:

> *Carers have got a role to play – we know a service user best of all.*
>
> (Carer 13)

Carers noted that professionals should acknowledge and recognise the tasks they have to complete such as overseeing medication and assistance in recovery. Carers felt that some professionals actually lacked insight and understanding of the caring role as well as empathy towards the carer's situation and needs. Recognition of the caring role was of great importance to this group.

> *It shows a complete lack of understanding around carers and the story they have to tell.* (Carer 9)

One interviewee addressed the need for professionals to recognise the difference in BME caring roles with professionals acknowledging the diversity within the BME caring community.

Each carer addressed the importance of mutual recognition and respect between all stakeholders especially between the carer and professional as a key principle for information sharing practices.

> *It's not that professionals need to agree with what I say or that I need to agree with what they say but it is important that carers and professionals know that both have experiences which are very important. We need mutual respect for our roles.* (Carer 12)

Carers suggest that mutual recognition and respect is vital for effective information sharing. It must involve trust, honesty and openness, particularly between carers and professionals. Carers noted how some professionals were disrespectful towards them and how this hindered information sharing. Several carers reported how professionals consider them as a nuisance and would fail to involve the carer in information sharing processes: 'You felt like you were the dirt under their shoe' (carer 1).

In addition, carers also explored the concept of confidentiality. The majority of carers accepted the service user's right to withhold consent, and felt that service users should be given such a choice. Like the service users they did note that this could impact the standard of care provided.

> *Unless the patient specifically states that they don't want the carer involved then confidentiality shouldn't exist. But by the same token the patient can't expect the carer to care if they use this confidentiality term.*
> (Carer 14)

Carers also noted that they did not need to know all information relating to the service user but only that information which was necessary and relevant and which would aid their care. Carers therefore showed an awareness of the different types of information that could be shared.

In practice, service users withholding consent was not a perceived issue for this carer group. Rather, the actual services and attitudes of staff towards confidentiality were the reasons given for professionals not effectively sharing information with carers.

> *The professionals see all things as confidential so I always gain consent – even when information is not confidential it is the professionals who are deciding what information is shared not the service user. Lots of service users are encouraged not to share information with anyone.*
> (Carer 12)

Like the service user sample, several interviewees touched on the notion of capacity and how this may impact on the service user's ability to provide consent. In general it was felt that if an individual is incapacitated consent should not be used as a barrier to exclude carers.

> *How can the sufferer withhold consent when he/she can't think properly and get their thoughts straight in their head.* (Carer 11)

Each carer addressed the importance of the context in which care is provided as a key principle to be considered in information sharing practices. In particular, this group was mainly concerned with professional recognition of carer's needs, especially the need for information. In addition, they noted the potential harm of not knowing information for both the service user and carer. They believed professionals should take this into account when sharing information with carers.

> *This care takes over our life so we need to be given enough information to best support the sufferer.* (Carer 11)

> *If carers don't have full knowledge this is very dangerous – you cannot care fully unless you have full knowledge – mistakes will be made and this could be harmful.* (Carer 13)

Interviewees also noted the type of relationship between the service user and carer and how this impacts on the amount and nature of information provided to the carer. In particular, interviewees addressed the difference between carers who live with the service user and those who do not. In general it was suggested that if a carer lives with the service user then they usually require more information on issues such as diagnosis, medication and discharge.

> *Because of the nature of this illness many sufferers will live at home with their parents – we need to know exactly when our daughter is coming home – not two hours before when my husband is supposed to be at a conference and I am elsewhere………. if the carer is a carer and the sufferer is coming back to live with the carer then there is a need for basic information.* (Carer 11)

Carers also noted that the quality of each caring relationship should be considered when professionals are sharing information with carers.

> *The hurdle of conflict of interests between the patient and carer.*
> (Carer 17)

Finally, the majority of carers explored the nature of mental health illness and how professionals should understand the specific features of each service users' condition. Characteristics and traits of certain diagnoses such as paranoia, delusions and distortions of truth should be acknowledged when sharing information with carers. This is because these characteristics have the potential to impact the amount of relevant information the service user provides, therefore additional information is required from the carer. Also, the level of care needed may vary as a consequence of these mental health characteristics.

> *Eating disorder sufferers have a tendency to lie and distort the truth regarding food, it's just the illness. If we had a diet plan we can see what she needs to eat and not necessary what she wants to eat.*
> (Carer 11)

> *He doesn't tell the truth. His memory is so bad. People don't grasp that he really can't tell them the answers to what they need to know. He will tell them anything to get them off his back and he is very plausible. Its only because we have written letters that they have taken notice.*
> (Carer 16)

Principles: professionals working with adults of working age

Professionals prioritised the principles of professional discernment, risk avoidance and confidentiality closely followed by understanding the context of care. They were least focused on the principles of carer involvement and developing a culture of information sharing. Disclosure of information to carers and others was variously influenced by:

- levels of risk
- objectives of information sharing
- advice of agency and professional codes
- professional values
- service user privacy, autonomy and consent
- legal and policy responsibilities
- the competence of the recipient of information
- the context of care.

Professionals commented on the need to be sensitive and ‘think out of the box’ to reach solutions; professional discretion; and reference to medical and nursing codes. Sensitivity and care were needed to manage situations where the carer mistakenly thought they had rights to receive information, or where information might be inadvertently divulged to the carer as a result of appeals against detention, court hearings or public protection meetings and correspondence sent to service user’s about their treatment. Sensitivity was also required in the event of the wrong person being identified as the nearest relative or carer. The reciprocal nature of information exchange to inform risk assessment while not divulging inappropriate service user information, required professional circumspection:

> *Over the contentious issue we have to be very cautious. Where the patient is challenging detention, the MHRT or the managers, if they want the carer there, that’s possible. It can be a forum where information can be inadvertently shared where the patient doesn’t want it. They want the family there but they don’t realise what might be discussed.*
> (Forensic psychiatrist)

> *There’s always the two-way side of things. If it’s obtaining information I would test the water with regard to risk. I would hold back and find out whether they already know a bit of information. They may know information that helps to put the picture together. ... I would have to ascertain what was hearsay.* (ASW/CPA manager)

The palliative care manager observed that in mental health, risk drives information sharing whereas in palliative care the focus is on informing those close to the service user about what is happening to enable them to say goodbye. The objective of information sharing under these circumstances was to avoid the risk of a highly complicated bereavement. Indeed the weighty responsibility of risk, intrinsically unpredictable, driving disclosures that inevitably eroded ‘patient privacy’ was at the forefront of most professionals’ minds. Professionals tended to focus on public safety rather than specific aspects such as service user or carer interests. While they were significantly guided by presumptions of service user capacity, service user consent could be dispensed with if there was clear evidence of risk. A nurse commented that if there was clear evidence of risk the professional duty to disclose information was also very clear. However, less straightforward situations involved disclosure of, for example, drug taking to carer partners where the service user was withholding consent. Here the risks were not always clear. Disclosure under such circumstances would break the service user's trust and could lead to the person rejecting services.

Professionals were conscious of the erosion of privacy that service users were enduring as a result of the public protection ethos and upheld the principle of service user consent wherever possible. Exceptions included not only public safety but also the legal obligations of ASWs to inform or consult nearest relatives (usually the service user's main carer) where an assessment under the Mental Health Act 1983 for compulsory admission was invoked. Even so, information under these circumstances was restricted to the purpose of determining the need or otherwise of the service user's detention in hospital, and one ASW mentioned that her team was trying to develop good practice on this contentious area. In the case of adolescents professionals also need to be wary:

> *If someone is under 18 you're dealing with a parent as a carer with more rights to information than normal because they're in a substitute decision-making role. This does govern relationships slightly differently.*
> (ASW/CPA manager)

The importance of explaining clearly to the service user how the information might be used to obtain consent and ensuring that he or she understood the reasons and options were also important professional considerations. One psychiatrist commented that it was often easier to involve the carers once the service user (in this case adolescents) had learnt to trust her. The social workers and the drug and alcohol services nurse were also conscious of the importance of identifying the carer's ability to comprehend information.

> *I think there are times when you really want to tell relatives about the patient's behaviour. Sometimes you have to say 'I can't let you go home unless I tell them this.* (Psychiatrist)

While the CSWs were unanimous about the importance of information sharing to support the carer and explanations about the need for communication to both the carer and service user in the early stages, only two thirds of the other professionals highlighted this point. Longer-term knowledge of the family circumstances was an important factor in influencing professional and carer trust to share information. Opportunities to share information directly related to the care context, though carer legislation could also help carers to obtain information.

> *Ask right at the beginning. If the professional spends a bit of time with carers to explain CPA, confidentiality and all of that without the patient being there. To explain to the user and patient about consent forms. Very few users and carers know about consent forms.* (CSW)

From the community perspective, the GP, social workers and CSWs focused significantly on the care context, understanding the different issues regarding different relationships such as parent child, partnerships and young carers. Here the importance of providing information to ensure the carer was enabled to provide care and prevent the carer from breaking down were important issues. Balancing the rights and needs of both parties was crucial. While the professional might sometimes feel constrained from taking action, understanding the care context was key. Helping the carer to face the losses resulting from mental illness and empathising with the carer were also important considerations. The ASW from a minority ethnic background commented that cultural issues should also be taken into account. She cautioned these might clash with the values of the professional.

> *Supporting the carer is paramount. The carer is going to provide far more care than us in a lifetime.* (Senior ASW and carer)

> *Her life hinges on Mum. Mum doesn't want change. Periodically Mum will come in, have a chat. She under-reports. I have a chat about what the boundaries are.* (GP)

6.1.2 Good practice strategies

Strategies: service users

The service user group was primarily focused on involving and informing the service user in information sharing, communication between all parties and professionals assessing the appropriate levels of information to be shared as the key strategies in information sharing. They were least focused on promoting continuity of care, supervision for professionals and recognition of diversity

Service users were foremost concerned with both professionals and carers informing and involving the service user at every level of information sharing as they noted that once information is shared there 'is no going back' (service user 1). Service users therefore wanted to be consulted when professionals share information with carers. They felt they should be informed of all information that is shared between professionals and carers, even if consent has not been obtained.

> *Possibly the most important thing about sharing is once you have you can't change things, you only get once chance, so it has to be right.* (Service user 1)

Service users also addressed communication as a strategy in information sharing. Most highlighted the benefits of all stakeholders coming and working together, with the service user's welfare at the heart of such meetings:

> *I used to work as a scientist in the lab for some time and I had to work with dangerous chemicals. I therefore had an arrangement in which my boss could go to my social worker if he suspected I was ill. I agreed to this, as I didn't want to endanger anyone. It worked really well as he would contact the social worker if he was concerned. It was arranged like a gentleman's agreement and it came about after my social worker came to my place of work and we all discussed it.* (Service user 1)

Although service users acknowledged the emotional and practical needs of the carer, in general they did not feel carers should be offered individual time with the professional. Individual time should only be given if consent was obtained or the service user trusted the professionals. Some interviewees felt separate time between the carer and professional actually disempowered the service user and exacerbated their paranoia.

> *Ideally service user consent should be obtained if carers want to meet alone with professionals. Ideally the service user would be present unless they are happy for it to go ahead without them.* (Service user 4)

The benefit of separate time between the service user and professional was recognised. Service users acknowledged that this time could help strengthen the therapeutic relationship, encourage independence and could be an opportunity to discuss anxieties that may even be caused by the carer.

Most service users addressed the need for professionals to consider the individual circumstance of each service user and assess accordingly which information is suitable to share. 'There is definitely an issue of appropriateness' (service user 4). Interviewees stated that the amount and type of information to be shared was often dependent on a host of factors such as the service user perspective, their consent, the context of care, harm avoidance and the quality of the caring relationship.

> *It should definitely be case by case. How much carers are informed should be different depending on the circumstance.* (Service user 4)

> *I suppose if you are living with someone then you have certain rights and perhaps need to know some information but I think it is very much an individual thing.* (Service user 1)

Interviewees felt that professionals should use their professional discernment, 'judgement and common sense' (service user 4) and thus be flexible in their approach when sharing information.

> *Judgement is important in all of this as demonstrated through my first cases in which the first instance I didn't benefit from (professionals allowing) the visitor but in the second instance I would have (but professionals stopped this.'* (Service user 4)

The interviewees were acutely aware of the 'different types of information' (service user 1) that could be shared with carers. However, there was little agreement about what 'type' of information should actually be shared with carers. Again this appeared to be highly individual and dependent on the context of care.

Several interviewees welcomed the idea of advanced agreements:

> *I'm very fond of advance directives, they are very good everyone. I would have one. Advance statements would clear a lot of this up.*
> (Service user 5)

Strategies: carers

For carers, carer engagement and communication were the most important strategies to be considered for professionals sharing information with carers. This group of carers was particularly concerned with professionals fully engaging with carers as a fundamental strategy for information sharing practices. As part of this engagement strategy all interviewees felt that carers should be respected, appreciated and listened to.

Carers suggested that they have a detailed knowledge of the service user, which could assist professionals in diagnosis, treatment and recovery. Carers felt that professionals should recognise and listen to this information.

> *They need to let you in – the carers actually know the relative – while the psychiatrist like this one sees them for half an hour a month.*
> (Carer 13)

> Carer 11: *The family is an integral part of the sufferer's life – they are a useful tool of information. By cutting out the family and not listening to their information, the professionals are missing out on 50% of the sufferer's life.'* (Carer 13)

All interviewees noted the importance of carer engagement. Carers felt they should be informed of and involved in the service user's progression through services to enable them to avoid unnecessary anxieties and concerns, to act as an advocate for the service user and to acquire an appreciation of the service user perspective. In particular, all interviewees noted the importance of knowing general information such as medication, prognosis, and future treatments. They felt such information was necessary to enable them to provide adequate care for the service user. In practice, however, carers were not provided with general information. The serious consequences of a lack of information were explored:

> *Carers are actually the ones dealing with the person – they need to know what medication, side effects of this medication, how to deal with treatment and what the future holds. If you are the carer you need to know all of these key things - if you don't you could do more harm then good.* (Carer 14)

> *Well on one occasion my daughter managed to leave the ward without a diet plan. We went to the supermarket to buy lunch and my daughter insisted that we bought low calorie bread. I didn't have the diet plan so wasn't sure – within ten minutes we were screaming at each other.'*
> (Carer 11)

Finally, carers explored the idea of working in partnership with staff and essentially being treated as part of the professional team. These carers wanted to be accepted as part of the expert team. Significantly, a few interviewees noted that they should work as part of the professional team but with different responsibilities.

> *Their attitude (professionals) is that they have got to help the patient to the best of their ability and this is done certainly by involving carers as part of the team.* (Carer 14)

All carers were concerned with communication between all parties as a key strategy in information sharing practices. Some interviewees explored the possibility of carers having individual discussion time with the professionals. This provided the chance for carers to discuss general concerns that may not be appropriate to share in front of the service user. In practice, however many carers noted a lack of communication between staff and carers and the detrimental impact this has on both service user and carer well-being

> *Another time I visited my son after a day of him being in hospital. He looked awfully strange you know. I thought what is happening, has he got the flu? I went home very worried and no one told me what was going on. It was only later that my son told me that they were giving him injections. They should have told me then and there when I first went into hospital, they caused me so many unnecessary anxieties.*
> (Carer 13)

Carers noted the importance of staff communicating effectively with one another but in particular, carers noted the importance of all stakeholders communicating and working together. Carers felt that interaction between all stakeholders would allow the opportunity to explore current situations and possible problems together.

Professionals providing both carers and service users with explanations for decision-making was explored as a strategy. Carers felt that the communication between professionals and the service user/carers should be comprehensible and thorough. In addition, one carer noted the potential language difficulties that BME carers face and how this should be instated as part of the communication strategy.

> *Black carers also find it difficult to understand the information which they are given.* (Carer 12)

Most carers recognised the need for professional support as a key strategy in information sharing practices. These carers acknowledged the need for emotional and practical support for the service user but in particular they emphasised the need for support for themselves. They requested immediate responses to concerns, referral to network groups, referral to information sources, advice, assistance, guidance and comfort. Such support would make carers feel valued and encourage them to participate in information sharing processes. Carers did not explore the idea of dedicated staff for themselves such as CSWs. Only one interviewee noted the need to publicise services and support contacts.

Strategies: professionals in adult services

Professionals considered that an assessment of the carer and service user's circumstances was a vital part of information sharing with carers. In so doing it was also important to understand the difference between general and sensitive personal information. The sensitivity of information would vary according to what the carer or service user already knew and the different perspectives of the carer and service user could vary over time. If the carer already knew the position, general information about the issue could be safely shared. If the carer were unaware, any information would immediately be sensitive because the professional would be providing new information. General information might also be highly sensitive where for example the carers held deeply religious views but the service user did not. However, notwithstanding the particular idiosyncrasies of individual circumstances, religious persuasion, sexual orientation and sexual activities were generally considered to be potentially sensitive issues whereas information about services, contact points mental illness, medication, side effects and welfare benefits was potentially safe.

> *You can talk in general terms. Sometimes it's a way round specific issues.* (GP)

> *…It would be good practice anyway to explain the alternatives – a life-line for carers, certain telephone numbers of who to contact. It would also be an information-giving role, yes, rather on the general side of information. But I would also give information about which professionals might be engaged, risk and relapse concerns, midway between general and confidential information.* (ASW/CPA manager)

Professional responses identified a number of factors to guide appropriate information sharing:

- assessing the context, the quality and nature of the relationship between the service user and carer i.e. the rapport between the two parties and position in relation to one another e.g. parent, partner
- assessing the level of risk and the vulnerability of the family
- assessing the service user's capacity to give consent and reviewing consent
- highlighting the benefits of sharing information of which the service user might not be aware, for example alternatives to hospital
- assessing the ability of the carer to understand the information
- assessing the carer's commitment, ability and willingness to provide care
- identifying the objectives of sharing information
- assessing the amount of information necessary to fit and focus on the purpose
- recognising sensitive information disclosed in one-to-one therapy, for example sexual abuse

- encouraging honesty between parties where possible
- recognising particular contexts and the timeliness or otherwise of disclosure, for example about an extra-marital affair, sexuality or religious persuasion.

Most of the professionals who were interviewed highlighted the benefits of bringing stakeholders together to discuss care plans and treatment. The CPA was frequently identified as a helpful vehicle although the CSW from the voluntary agency advised that service users were often very anxious about the process. The GP in particular considered that he worked far more effectively when his position was not compromised by secrets that from his perspective were unnecessary. By bringing stakeholders together progress could be achieved.

> *The direction I'm coming from is to share information. This concerns other disabilities too – cancer. The charade when partners don't want each other to know. I get into a mess. I feel trapped. Therefore I think it's better to start from information sharing, ideally in front of both parties. It's tricky when you can't do that.* (GP)

The community-based professionals were particularly conscious of the importance of spending separate time with the carer and service user. It was necessary to give clear explanations to the carer about, for example the effects of mental illness on dangerous behaviour. This could take up time because of the stress the carers were under. Explanations had to be very clear otherwise the carer might miss the point.

The majority of the professionals adopted a broad, family-centred approach although the nature of the forensic setting, its remoteness from the local community and remedial focus fostered more patient-orientated work. All the community-based professionals supported the need for training on carer issues. In one case at least this was already happening:

> *I organise a lot of workshops for carers, yes professionals also attend, they do some of the training. I've got someone coming from the Maudsley hospital. ... I have involved carers in training professionals.* (CSW)

> *Build trust between everyone involved. It's important to give carers information to enable, empower and support their relatives, and for carers to feel part of the team.* (CSW)

Four professionals considered that advance agreements would be helpful in clarifying the service user's wishes in advance of mental health difficulties. These should contain appropriate safeguards to enable professionals to override these if necessary, and also to prevent service user exploitation, However, participants had little experience of their implementation.

Two ASWs and one CSW emphasised the importance of taking account of diverse needs such as a carer wishing to speak to someone of the same gender, and ethnic considerations such as culturally sensitive services.

> *BME families are very distrusting of services. Having been in mental health for so long I can understand why. Sometimes they don't engage easily because they like testing our commitment - how interested one is in them. And their distrust of services is in some cases very real. And there's something about stigma. They are frightened to share information in case they're pre-judged, because of where they're from and what they've experienced of psychiatric services in the past. From my experience of engaging and trying to work with BME families, my approach has been about acknowledging their anger and distrust and not being defensive of the services we offer.* (CSW)

6.2 Interviews with stakeholders working with older adults

6.2.1 Good practice principles

Principles: carers for older adults

Carers supporting older individuals focused on mutual recognition between stakeholders as the key principle for professionals sharing information with carers, followed by the context in which care is provided, acknowledgement of the incapacitated service user and thus involvement of the carers. They were least concerned with patient confidentiality as a principle.

Carers supporting individuals with dementia were foremost concerned with the development of mutual recognition and respect between all stakeholder groups. An appreciation and empathic understanding of each other's roles and needs seems key in the process of information sharing. In particular, carers acknowledged the importance of promoting a trusting, honest and collaborative relationship between the carer and professional which should lay the foundation for good information sharing practices.

This group of carers reported a lack of respect from professionals towards the service user in information sharing and told of instances in which professionals would dismiss the service user altogether.

> *When my mother and I both attend meetings the professionals always ask me the questions – 'does she do so and so?' and so I have to turn back to mum and say 'do you?' - Its common politeness that the professional should address the patient even if they know they may not get any sense from the patient.* (Carer 7)

Carers also commented on a lack of respect from professionals towards the carer and stated that they were not listened to or recognised for their role. This appears to be the case particularly for carers who are older and sometimes less assertive:

> *They treat carers who are older awfully you know. There are lots of carers who wouldn't speak up for themselves unlike me, you know they are so meek and mild.* (Carer 6)

The context in which care is provided also emerged as a key factor to be considered in information sharing practices. In particular, carers highlighted the need for professionals to understand the specific characteristics and features of the dementia and the physical and emotional demands that are subsequently placed on both the service user and carer. The interviewees placed additional emphasis on the different needs of elderly carers. These carers tended to be spouses who lived with the service user and therefore required different information as well as support by professionals

> *You know a lot of carers are old. Some are in their late eighties - they can't cope with finding out all this information for themselves.* (Carer 6)

As a result of the incapacitating nature of dementia and thus the service user's dependency on the carer for both care and advocacy, carers highlighted 'carer involvement' as a high level principle. These interviewees noted the role of the carer in tending to the service user's needs and how carer involvement is central to this:

> *Carers need general information given that it is a condition which relies so heavily on carers.* (Carer 7)

Patient confidentiality or service users withholding consent was not suggested as a hindrance to information sharing. Carers implicitly relate this to the incapacitated individual who firstly is unable to provide consent, and who secondly requires such an extensive level of care that key information is a necessity for the carer to provide assistance and act on behalf of the service user:

> *Mother always said very clearly that she wanted all information to be shared with me as she wouldn't remember what has been said so there has never been a problem.* (Carer 7)

Carers noted their difficulties in recognising and accessing older adult mental health and how services were often inappropriate. This therefore suggests that the process of information sharing is not reached because of under-funded services and lack of human resources, which in effect mean professionals simply do not have enough time to engage with carers, provide the necessary information or establish continuity in their relationship. This prevents the exchange of information sharing as individuals are stopped from engaging in the services in the first place. Not surprisingly, all interviewees stated how they themselves have an inaccurate knowledge of the services available to them.

Principles: professionals in services for older people

The professionals were most concerned to be discerning in their judgements about sharing information with carers, addressing the principles of confidentiality and understanding the context of the particular care situation. The CSW promoted the need for clear information about information sharing and strategic carer involvement but the other participants did not highlight these as key issues. The majority of the interviewees identified the need to be aware of risk factors such as the side effects of medication and carer and public safety.

> *The capacity of the patient to make decisions is the key factor in determining what information is shared with others. Primarily the patient has to choose but when there is risk to others, lack of insight, unstable mental state or cognitive impairment, the views of the carers are very important. But there is sometimes a real problem in assessing the motives of carers. There are cases where family members want to preserve their inheritance by preventing an older relative being admitted to residential care. The family say they are taking carer of the carers in their own home, when they are in fact neglecting them and using their attendance allowance for their own purposes.* (Consultant psychiatrist)

The allied principles and procedures underpinning professional duties in appropriately sharing information with the carer and safeguarding patient confidentiality were variously identified as:

- taking a ‘non-judgemental’, balanced approach
- identifying carer and service users issues
- consulting a senior colleague in difficult situations
- following departmental procedures, for example protecting files
- flexible application of procedures and informed imagination to take account of particular needs
- not talking about carer or service user issues in front of other clients.

The service user’s capacity and the care context were key factors to be taken into account in information sharing. This is particularly relevant where the service user was incapacitated, dependent on the carer and very much in need of care. Therefore information had to be shared with the carer not only to enable them to care but also to enable them to speak on the service user’s behalf. Even so there was still a need to involve the person cared for in the care plans and have regard to the person’s autonomy:

> *The difficulty with older adults is that many clients wouldn’t be aware of many issues. When the client lacks capacity then I imagine that the carer receives all the information because they have to. It’s a completely different ball game. Likewise the acute wards which are very disturbed places are completely different to this.* (Manager hospital day unit)

> *The core issue for the old or young is they still want to feel in control as much as possible. Sharing information can potentially threaten that. Professional carer partnerships can be very threatening if they are managed in a way that takes away patient choice and autonomy. But for people with psychotic/paranoid illness you are immediately in trouble.* (Psychiatrist)

The psychiatrist indicated that he used his discretion as to when not to share information with the carer and provided as an example the paranoid, mistrustful situation where the person concerned would clearly object to the carer receiving information. However, the need for a flexible approach to service user consent was highlighted by the CSW in a negative example of carer/professional interaction:

> *Someone rang me the other day who wanted to get a wheelchair for their father-in-law as he had trouble getting round the house. I said 'why don't they contact the GP?' They did this but the GP could only respond if the client themselves had requested the wheelchair. This was ridiculous as the client didn't have the ability to know the wheelchair would be best for them'* (CSW)

The professionals were acutely aware of the emotional and physical demands of caring and also the diversity of care scenarios, such as the high needs of elderly carers supporting partners, their ability to comprehend information, and different cultural perspectives. Professionals also emphasised that it was also important to recognise diversity within diversity.

6.2.2 Good practice strategies when supporting people with dementia

Strategies: carers of older age adults

Carers supporting older individuals focused on communication and the need to be proactive as the key strategies, followed by the need for training. They were least concerned with dedicated staff to support carers.

Carers stated strongly that effective communication between stakeholder groups is a vital strategy in information sharing. These carers are primarily referring to staff and carers being well informed and informing one another on both general and specific issues relating to the individual client. Carers expanded on 'general' information to include meaning of diagnosis, side effects of medication, availability of facilities and identifiable services/professional roles. Carers suggested this information should be provided through leaflets and information packs as well as regular coming together of all stakeholders.

Carers also highlighted the importance of 'communication between staff' (carer 10) in both voluntary and statuary organisations. This ensures information is recognised and not misconstrued. Significantly, carers highlighted the importance of having individual discussion time with the professional. Carers particularly welcomed individual discussion time with professionals to safeguard the service user's dignity and avoid distress.

> *I think that it is easier to talk and ask questions regarding my mother when she actually isn't there. For example in the early stages when my mother was very much alert I didn't want to ask questions like what will*

> *be the outcome of this disease be or that would have upset her.*
> (Carer 7)

Carers' persistence to gain information and use their professional knowledge appears necessary in information sharing. They note however that such assertiveness is more demanding for those carers who are elderly. These carers appeared particularly proactive. This was shown in their membership to voluntary groups such as the Alzheimer's society and their determination to gain information.

The majority of interviewees addressed a need for education, training and guidance in effective information sharing They suggested the use of seminars, workshops and training programmes as ways to instruct and inform all stakeholders on effective information sharing and the issues that might obstruct it:

> *Workshops between professionals, carers and service users around the issues involved in information sharing.* (Carer 9)

This group suggested that information packs be formulated and presented in training sessions to provide carers with all the essential information:

> *Right at the beginning carers should be given a list.... the list should contain a name of all the organisations which may be of help.* (Carer 8)

Older carers also highlighted the seclusion and isolation they felt in their caring role: 'A lot of older carers feel very much alone' (carer 6) and yet no interviewee identified dedicated staff such as CSWs as a strategy to support and encourage carers. This may be as a result of their lack of knowledge in the services.

Strategies: professionals working with older service users

Assessment of the service user and carer's position was a prime professional concern in the process of sharing information and involving carers in care plans. Information about services, care and treatment options, medication and diagnosis were clearly regarded as general and essential carer information. There was no reason for it to be otherwise as the service users in most cases were mentally incapacitated and the condition was already known to the carer. The factors to be weighed in assessing the carer and service user position included:

- assessing the nature of the service user/carer relationship and level of commitment
- assessing the competence of the carer and his/her ability to disseminate information
- trying to understand the service user's feelings
- trying to understand the position and feelings of the carer, for example anger, guilt also physical ability and within these contexts the level of carer commitment
- understanding the pressures placed on the carer from critical family members.

Examples of the goals of information sharing included:

- to enable carers to care effectively and support them in their role
- to safeguard the service user's well-being in respect of medication and side effects
- to keep the carer up to date with problems
- to enable carers to access welfare benefits
- to prevent harm to the carer and general public
- to provide the carer with a 'testimonial' describing the care context and validating the care provided to keep critical family members at bay.

> *I was coming from the position of keeping people in the community for as long as possible and this depended on supporting the carer.*
> (Social worker)

> *My mindset in my training is, if you're making an assessment, when you pull it together do you feel that you have adequately put yourself in the position of the patient, have you also thought what it must be like to be the guilty daughter, the punitive husband, the anxious wife etc? What it's like for them? Capturing their anger and commitment. Put [on] the thinking cap of the other players involved – what their response would be.*
> (Psychiatrist)

> *Just one example where I'm often in touch with the key carer where the patient lives. The other relatives within the family nag the carer about whether they're doing the right thing. One thing I've found very valuable is writing letters to the carer explaining the patient situation and the carer's positive contribution to care, commending the contribution and making suggestions.* (Psychiatrist)

Strategies to keep people informed were clearly viewed to be an important part of professional practice. All of the participants recognised the importance of the carer being offered separate time with the professional. There was also substantial support for good multi-disciplinary communication and involvement of the carer in care planning, case conferences and the CPA. Unsurprisingly, given the prevailing issue of incapacity, the service user's position in such meetings was not so prominent. However, the need to talk to the service user about the care plans and involve them as far as possible was acknowledged:

> *When the client is particularly aggressive and violent sometimes carers are scared to share information. This makes it difficult to share information between the carer and professional in front of the carer. The carer needs individual time with the consultant. This would avoid the violence and the carers being scared. Also it would (a) stop the client being emotionally hurt and (b) stop the client losing their dignity – that is, it avoids the carer and professionals talking about the client as if they are not there.* (CSW)

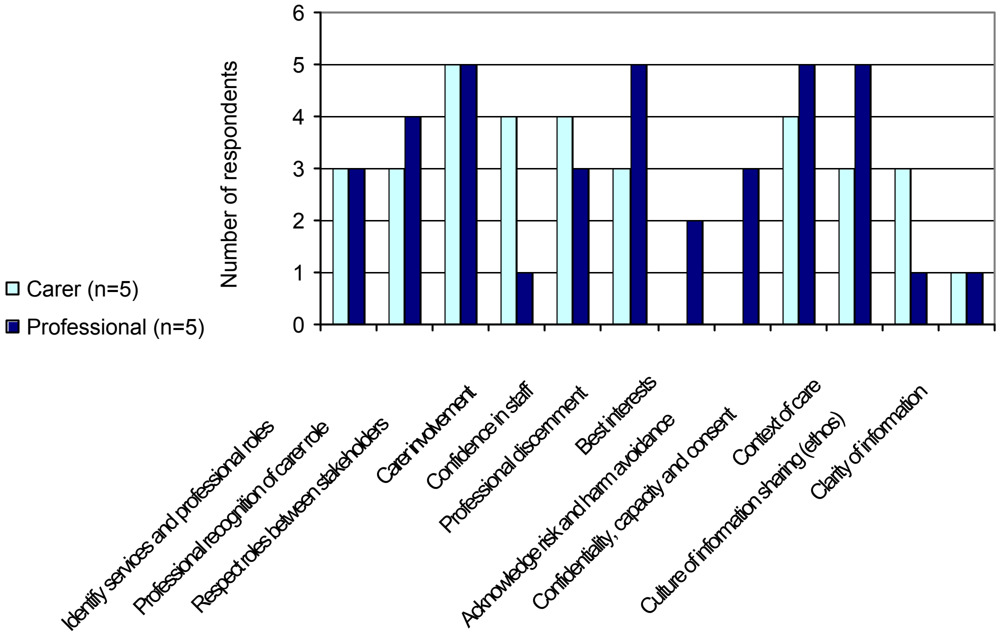
Effective partnership working with carers was also identified as an important element of practice. Identifying key and peripheral carers was raised as an issue in terms of the nature of the information to be shared. There was substantial support for thorough explanations to carers about care and treatment plans and options using accessible language. Although implicitly a likely consequence of carer-dedicated sessions, only one respondent spelt out the need to use the carer as an important information source.

> *My letters, the problems are described, the actions are described, they are more user-friendly than they were. They're not patronising I hope. They are written for professionals but I hope the carer will be able to understand them. I do sometimes write separate letters to the carer where there are technical issues, for example on behavioural interventions. The shorter version will focus on what the problem is and what the options might be.* (Psychiatrist)
>
> *Explain clearly, repeat over and over, carers are older themselves and likely to forget.* (CSW)
>
> *If someone is very ill or coming to us at a difficult time it is sometimes a very difficult time, it is sometimes very difficult to get information straight away. But we do everything we can to get basic information. With carers we make it our business to talk to carers when people start here. Therefore we develop a good relationship with carers and often encourage them to get in touch when a difficulty may arise. We try to include carers in all angles and this usually works well.*
> (Manager hospital day unit)

6.3 Comparing stakeholder views

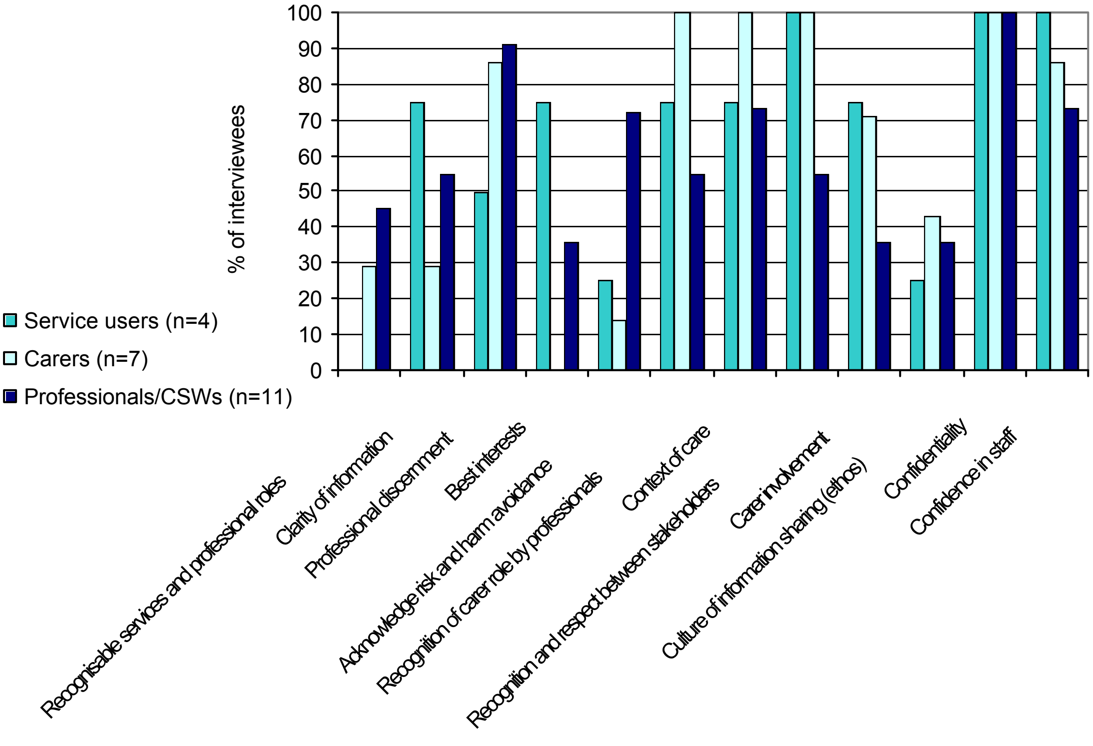
The four graphs presented below summarise the data themes presented in this chapter. They are provided to illustrate the variation and similarity in viewpoints between stakeholder groups.

Figure 2 Principles and values governing information sharing in services for older adults



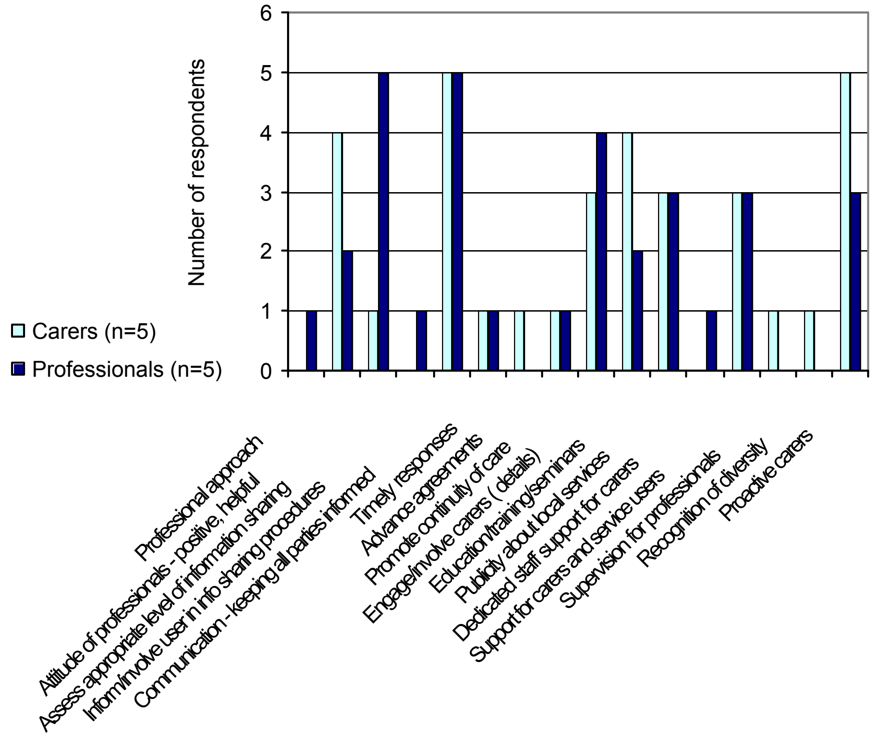
In older adult services, professionals and carers both agreed that respect for each other's roles was an important principle governing information sharing practices. These stakeholder groups also agreed that identification of services/professional roles and clarity of information are fundamental principles to be valued in information sharing. Carer involvement was highlighted as a crucial principle in information sharing for carers but not for professionals. For professionals, consideration of best interests was identified as a key principle. These stakeholder perspectives' differed greatly when considering the importance of acknowledging the risk and harm to be avoided as a principle to govern information sharing in older adult mental health services.

Figure 3 Principles and values governing information sharing in adult mental health services



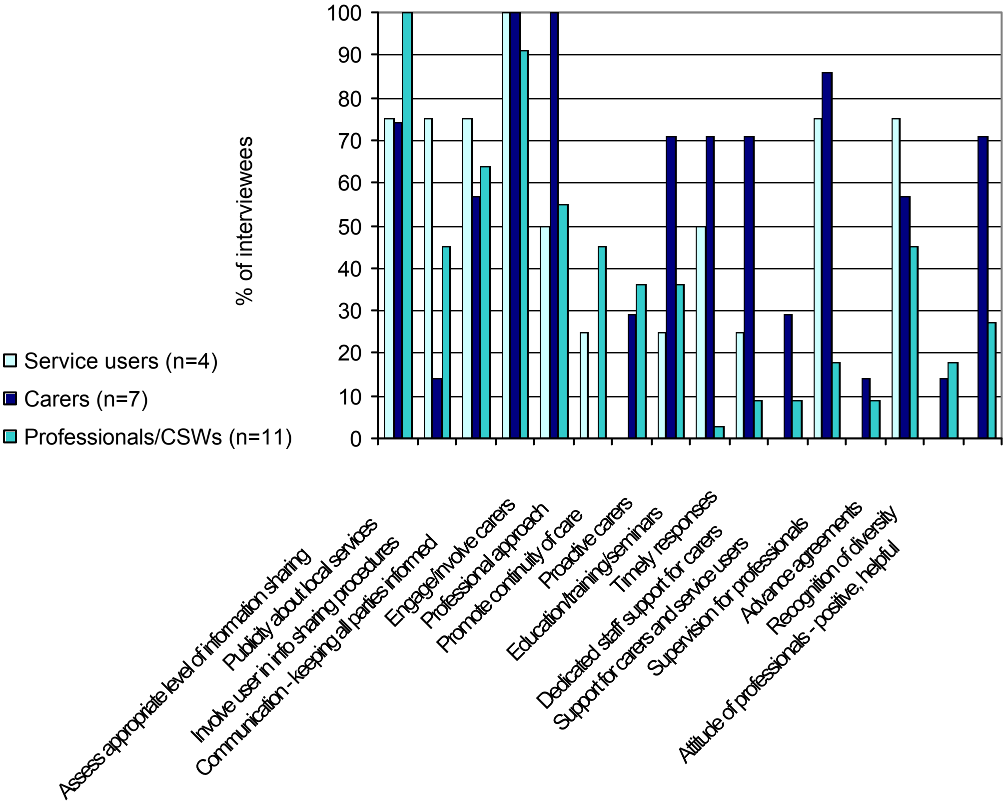
Service users, professionals and carers all agreed that confidentiality was an important principle in governing effective information sharing practices in the adult sample. Interestingly, only services users and carers highlighted recognition and respect between stakeholders as a fundamental principle in information sharing. Both the service user sample and the professional sample suggested 'best interests' should be taken into consideration when information sharing, carers did not consider this. Acknowledging risk and harm avoidance was a priority principle for professionals but not for the service users or carers. Stakeholders' perspectives differed greatly when considering the importance of clarity of information as a principle to govern information sharing in adult mental health services.

Figure 4 Strategies and actions taken to promote good practice information sharing in older adult services



Considering the strategies described in older adult services, carers and professionals both agreed that communication is an important strategy in promoting good information sharing practices. These stakeholders also agreed that a timely response to enquiries and appointments as well as promoting continuity of care are necessary strategies in information sharing practices. For carers, supervision for professionals, recognition of diversity and the use of advance agreements were suggested as actions to promote good information sharing. Professionals, however, did not share this view. Professionals suggested dedicated staff to support carers, but interestingly carers did not consider this action. These stakeholder perspectives differed greatly when considering the need to assess appropriate levels of information sharing to promote good practice in information sharing in services for older people.

Figure 5 Strategies and actions taken to promote good practice information sharing in adult services



Service users, professionals and carers in adult services showed similarities in their perspective that effective communication between stakeholders is an essential strategy in information sharing. For service users, publicity about local services was of great importance but not for professionals. Professionals and carers were concerned with promoting continuity of care, provision of dedicated staff to support carers, supervision for professionals and recognition of diversity. Service users did not consider any of these strategies. These stakeholder perspectives differed greatly when considering the importance of professional attitudes as a strategy to promote good practice in information sharing in adult services.

6.4 Summary

In this section, qualitative data derived from 34 stakeholder interviews has been presented. The data specifically centres on good practice with a particular focus on the good practice principles and good practice strategies that achieve effective information sharing in mental health. In this section the data has been presented thematically for stakeholders involved with mental illness among adults of working age and older adults with dementia. It is worth noting that the information gathered in the interviews confirms the survey findings presented in Section 5.

Adults of working age

Throughout the interviews, service users focused on the overriding importance of professionals obtaining service user consent before their personal information is shared with carers. Service users wanted professionals and carers to respect and adhere to their wishes. They stressed service user involvement and notification at every level of information sharing. Service users felt 'patient autonomy' and empowerment should be at the heart of information sharing practices between professionals and carers.

Carers felt undervalued, unrecognised and unsupported in their caring role. This they sensed impinged on information sharing with professionals. Carers acknowledged the service user's right to restrict certain information, but suggested that all stakeholders are disadvantaged if relevant and necessary information is concealed. Carers were acutely aware of the risk involved in not knowing vital information and thus emphasised their 'need to know'. They viewed carer engagement and the partnership objective essential to good information sharing practice.

Professionals acknowledged the importance of service user consent but were also concerned to address the care context and type and quality of the relationship between the carer and service user. Sensitive management of personal information where information was in the public domain and would reach the carer by default was an issue for forensic services. Some professionals already used strategies such as involving both parties in referral letters to support the carer wherever possible, while appropriately safeguarding the service user's privacy. Although professional and agency codes were respected these professionals highlighted the importance of working flexibly and creatively.

Adults of older age

Carers felt particularly constrained by inappropriate services and staff who were unfamiliar with the complexities of dementia. They felt a lack of specialist services encroached on information sharing, as services were not fully accessed. Carers noted the importance of carer engagement because of the incapacitating nature of dementia, which leaves the service user dependent on the carer for both care and advocacy. They suggested professionals should respect, and be sensitive towards the carer and service user while sharing information. Carers particularly welcomed individual discussion time with the professional to safeguard the service user's dignity and avoid unnecessary distress.

Professionals were concerned with the care context and understanding and assessing the service user and carer's position. This included weighing up the competence of the carer and his/her ability to disseminate information. Professionals felt carers should be involved in care plans and provided with comprehensible information about services, care and treatment options, medication and diagnosis. This they felt was essential as in most cases the service user was mentally incapacitated and reliant on the carer. Thus the carer already knew the condition of the service user. Professionals also recognised the importance of the carer being offered separate time with the professional. Nonetheless, the need to talk to the service user and involve them as far as possible was crucial for professionals in sharing information with carers.

Section 7 Stakeholder groups

The importance of integrated, supportive services resonated throughout the group discussions as important components of good information sharing practice. Group identity and outcomes are summarised in Table 33. The key areas addressed were:

- professional attitudes and approach
- communication and actions
- quality of mental health services
- training.

7.1 Attitudes and approach

Carers in Alzheimer's group 1, the Asian carer group and the service user group highlighted the importance of respecting and valuing the carer role. Alzheimer group 2 stated the importance of carers recognising the significance of their own role especially as the spokesperson for the person with dementia. Other themes included the need for compassion for the service user and carer. The Asian carers uniquely identified the importance of sensitivity to cultural and religious issues. Service users wanted services to respect and promote their right to privacy and empowerment.

7.2 Communication and actions

All groups registered the importance of improved communication between professionals and professionals supporting and engaging carers in the care and treatment plans of the person for whom they were caring. The Alzheimer group 2 suggested that professionals should identify one person in the family with whom to communicate. This might be an adult child with professional standing who was considered to be better equipped than they themselves to negotiate with mental health professionals. In similar vein the Asian carers saw the need for improved carer assertiveness. They also wanted professionals to understand the nature of family relationships and the importance of the wider family network. For service users, the prime carer issue rested on the quality of the caring relationship. A thorough assessment of the quality of care and relationships was fundamental to good information sharing practice.

Participants wanted clear and timely information about treatment and diagnosis. Although advocacy and support were common themes across all groups, the service users wanted information about their rights and entitlements for themselves and their families. Two of the carer groups (Alzheimer's group 1 and the Asian carer group) suggested that professionals should arrange to see the carer independently of the service user. The service users spelt out the need for professionals to weigh up the process of information sharing taking the 'who, why, what, when' factors into consideration. They also advocated that a clear explanation of information sharing practice should be provided to both themselves and their families (carers). Both Alzheimer groups highlighted the need for professionals to understand the complexities of dementia and failing capacity. Capacity was also an issue raised by the Asian carers:

> *[She] was not fit to speak alone, she was isolated and vulnerable ... it was unfair to impose consent on her. ... The person giving consent in that mental state is funny.* (Carer, Asian carer group)

7.3 Services

The need for service improvements including better carer and service user support was echoed across all groups. The service users wanted more integrated, consistent, accessible and accountable services. They made a particular point about the importance of correct recording and interpretation of personal information and facilities to rectify mistakes. Alzheimer's group 2 highlighted the difficulties posed by a lack of staff consistency. The Alzheimer's and Asian carer groups pointed to the communication barriers created by inappropriate services. The Alzheimer's groups wanted specialist services for people with dementia and themselves because they perceived the complexities of dementia to be different from other mental illnesses:

> *With other conditions people get progressively better and move on, but not with dementia.* (Carer, Alzheimer's group 1)

The Asian carers stated that they felt alienated by services because their cultural needs were not addressed. Their needs for a dedicated place for prayer and washing facilities, halal food and gender specific services were not being met. Even relatively straightforward services such as domestic help and meals were unacceptable because cultural requirements were being ignored. Services needed to recognise their cultural needs before real communication could even begin to start. The absence of interpreters was also an issue that prevented communication and proper interpreting arrangements needed to be instituted.

7.4 Training

Training was universally heralded as an important facet of information sharing across all groups. The carer groups wanted professionals to receive training on dementia issues and carer support services (groups 1 and 2) and cultural issues (group 3). The service users uniquely wanted training for families on mental health issues. They were also concerned about the need for the general public to be educated about mental illness to reduce the stigma surrounding the condition.

Section 7.5 Summary

There was general agreement across all stakeholder groups about the importance of communication between carers and professionals. Carers and service users alike were seeking a shift in professional attitudes and improved services and professional standards to facilitate appropriate information sharing. The identity of the carer, assessment of the quality of care and relationship contexts, and the mental state of the service user were crucial factors to be considered as part of the process. Specialist services to meet the needs of people with dementia and their carers and ethnic minority groups were also identified as vital conduits to facilitate information sharing between carers and professionals.

Table 33 Summary comparison of group responses regarding the factors involved in good information sharing practice between professionals and carers

Broad themes	Alzheimer's group 1	Alzheimer's group 2	Asian carers (group 3)	Service users (group 4)
Attitudes/ approaches	Understand, respect, and value the carer role Honesty and openness Trust carers Compassion for service user	Carer recognition of own role	Understand and respect the carer role Be sensitive to cultural and religious issues	Respect service user privacy and status Empower service users Sympathise with service user and carer roles
Actions	Professionals: - communicate with one another - understand the complexities of dementia - engage with carers - provide emotional support for carers - provide carer friendly information	Professionals: - communicate with one another - identify one person with whom to communicate - recognise the role of distant carers and adult children - provide early information about the diagnosis using plain language - assess service user capacity - provide a separate session for the carer	Professionals: - communicate, engage with and listen to carers - assess and understand the implications of service user incapacity - provide feedback where the family is not present at a meeting - provide verbal information - understand the nature of family relationships Carers: to be assertive	Professionals: - promote better communication between all parties - recognise the range of carers - support carers and families - give carers general information about mental illness - inform service users and families of their rights - assess the quality of care and relationships - weigh up information sharing – 'who, what why, when'. - provide a clear explanation of information sharing

Services	Improve standards of carer Provide more resources Provide support and advice through Alzheimer's group	Provide specialist dementia services Provide accessible support groups Improve staff consistency	Provide independent advocacy Provide culturally sensitive services – prayer, food, and gender issues Interpreters	Provide independent advocacy Provide better access to services Improve inter-agency working Provide consistent policies Improve professional accountability Improve accuracy in information sharing and opportunities to rectify mistakes
Training	Provide specialist training on diagnosis of dementia and information sharing for professionals	Ensure professionals know about carer support groups	Provide professional training on cultural issues	Provide training for families Promote education for the general public on mental health problems

Section 8 Workshops

Two NHS Trust areas were identified as having information that provided a framework to promote information sharing between professionals and carers. One area had produced an accessible information leaflet and the other a more substantial policy. Both had been produced in consultation with carers. The first area issued their leaflet in November 2003, whereas the second area's leaflet dated from March 2001 prior to a major reorganisation of services (merging of two adjacent Trusts).

8.1 Workshop feedback: pro forma

8.1.1 Area 1 outcomes:

Attendees were asked to describe how mental health carers were supported in the locality (n=14). Carer groups were mentioned most (10), followed by information packs (6), holiday breaks (3), the carer's assessment (3), training (2) and individual examples of general service support and family work. Most thought that carers' services had improved in the last three years (see Table 34). Examples comprised better carer support, information, training and carer involvement and the introduction of the carer's assessment. Half of the attendees knew that there was a specific Trust strategy on how to deliver support to carers.

Table 34 also describes attendees' knowledge of and use of local carer policies. Responses were generally very favourable: it was clear, informative, concise and potentially useful. Individual negative comments on presentation, raising expectations while resources were limited and the need (highlighted by the nurse) for more information on caring for older people were also stated. Given the leaflet's very recent arrival, understandably only a few people (4) said it was being implemented, five said it was not being used and six were unsure. Respondents were circumspect about its potential to make a difference: only one person said 'yes' - the majority (9) indicated 'possibly'.

The main changes to improve carer services were identified as the need for: more CSWs; more carer involvement; more carer support groups and the implementation of the carer's assessment.

Changes to promote good information sharing practices to take into account the positions of service users, carers and professionals largely included issues to support the carer role. The specific recommendations relating to information sharing are identified below:

- implementation of the leaflet
- clear explanation on confidentiality to the carer and service user
- breakdown the barriers of confidentiality
- clinicians to listen to carers
- stakeholders discuss confidentiality together.

8.1.2 Area 2 outcomes

Sixteen attendees provided feedback in Area 2. The local carers' forum (8), locality support groups (5), information packs (3), CSWs and services (4) and family education and training were cited as local carer support arrangements. Half of the participants (8) considered that there had been improvements in supporting carers in the last three years. These reflected the carer support arrangements: carer groups (5), the carers' forum (3), information and support (2), family education (2), implementation of the NSFs (2).

When addressing the views on local policies for carers (see table 34) only a quarter of respondents stated that they were aware of a local carer support strategy. With reference to the policy, only two respondents, one of the mental health advocates and one of the CSWs had seen it prior to the workshop. Five respondents viewed the document to be potentially useful, while the majority (9) were unsure or declined to comment. Two participants viewed it to be out of date and one person stated a simpler version was necessary.

The main changes needed to improve carer support services were identified as: improvements in carer involvement and communication; changes in professional attitudes towards carers; education for professionals on carer issues and the implementation of regular carers' assessments.

Recommendation for change to improve information sharing, as in the case of area one, were also concentrated on support for the carer role. Specific recommendations to improve information sharing concerned:

- implementation of the advance directive
- clarification on the boundaries of information sharing
- clarification of what information is held by whom and how decisions are made
- clear explanation to carers and service users about confidentiality at the point of entry into services
- tailoring of information to carers taking into account the individual context of care

- ensuring carers were made aware where there were risks of dangerous behaviour.

Table 34 Workshop feedback on the implementation of carer information sharing policy in two sites

Participants' views/knowledge base	**Area 1 (n=14)**	**Area 2 (n=16)**
Carer services have improved over last 3 years	9 (64%)	8 (50%)
Know that a Trust strategy for carers exists	7 (50%)	4 (25%)
Have seen Trust policy/leaflet before workshop	11 (79%)	2 (13%)
Consider policy/leaflet is useful	10 (71%)	5 (31%)
Think the policy is being implemented	4 (29%)	1 (6%)
Policy would 'possibly' make a difference	9 (64%)	8 (50%)
Would recommend other Trusts produce a policy	12 (86%)	12 (75%)

8.2 Case vignettes

The outcomes of the case vignettes of both areas (Tables 35 and 36*)* also highlighted the importance of many tangential areas in supporting good practice in information sharing between professionals and carers. Understanding the feelings of carers and service users and a sensitive response to the situations resonated throughout. Participants viewed that carers should be given general information about mental illness and carer services, and where appropriate, invited to attend care planning. The idea of separate and joint meetings for the service user and carer was popular and the relevance of the carer's assessment was highlighted particularly by Area 2, although the need for carer support was universally recognised. The outcomes highlight the importance of mediation, conciliation and working with carers and service users to achieve appropriate information sharing. A carer could be supported without breaching confidentiality and in addition, the service user's perceptions and position on consent could change over time. A carer should also be supported during the service user's transition to independence. While the service user's needs and wishes for independence should be respected, in only one instance where the person was in therapy was there unanimous support for the strict observance of service user confidentiality. Thus differences between highly sensitive and general information about mental health information were clearly recognised.

Unique approaches should be invoked when services are working with service users and carers from BME communities. Cultural traditions should be respected although not assumed. Professionals should also have the courage of their own convictions to challenge customs that unhelpfully excluded the rightful carer from his or her entitlements. Specialist services for BME carers and service users should be made available if appropriate. The issue of consent was not an issue where the service user suffered from dementia, although the relevance of the advance directive and court of protection was mentioned. Several of the responses identified the need for the wider family, for example children and siblings, to be supported.

Table 35 Workshop attendees' perceptions of good professional practice (Area 1)

Case vignette 3	Case vignette 2	Case vignette 4	Case vignette 5
Asian carer; wife caring for elderly relative. Husband and GP in communication; wife is excluded.	Young schizophrenic man admitted to hospital under section. He does not want parental involvement at any stage or to return home on discharge.	Young man in recovery seeking independence from carer	Young woman with eating disorder discharged home without care plan.
Consider feelings/expectations of all involved	Consider feelings of all involved and need to voice views/concerns	Help mother through grieving process	Consider carer's feelings/disorientation
Provide information about service user	Two-way communication; attempt conciliation	Professional bridging role between mother and son	Liaison between ward and community
Provide information about treatment options	Separate and joint meetings with professionals	Help both sides to view distance as positive	Hold pre-discharge planning meeting
Register with carer support services	Support for parents	Support carer; help her to adjust to changes	Support carer
Enter wife on carer register	Consider safety issues	Enable both sides to air concerns	Provide contact details for queries/ concerns
Inform about legal rights	Give general information	Keep all parties informed	Provide information for main carer; skills fact sheet; carer groups
Also consider needs of children	Support for sister	Value carer contribution	Help brother to understand the situation
Cultural sensitivity; language issues; perceptions of role	Advocacy for son; acknowledge views may change over time	Support son; encourage independence	Clarify roles
Seek culturally appropriate service/organisation	Seek independent accommodation for son and help for addiction	Monitor for change and review	
Sensitively challenge cultural 'norms' e.g. wife's position			

Table 36 Workshop attendees' perceptions of good professional practice (Area 2)

Case vignette 3	Case vignette 7	Case vignette 6	Case vignette 1
Asian carer; wife caring for elderly relative. Husband and GP in communication; wife is excluded	Psychotherapy reveals mother's abusive character. Daughter is very uncomfortable with mother's involvement in her mental health care but remains living at home	Mother attends CPA with son's agreement. Team ask her to leave; son wants her to stay	Husband is caring for wife who has dementia
Acknowledge wife's carer needs	Help mother understand mental health problems	Understand carer and service user stress about attending meetings	Understand husband's need for emotional support
Consider service user's needs	Psychotherapist observes patient confidentiality	Trust would be completely destroyed	Address incapacity and implications
Involve wife in discussions and help service user understand benefits	Information sharing on alternatives and steps to take in a crisis	Private issues should be discussed outside big team meeting	Provide mental health and financial information
Help husband understand wife's carer needs	Mediation to resolve issues between both parties	Team meetings: decide how much should be shared	Act on advance directives, court of protection issues
Arrange meeting of all parties concerned	Invite mother to CPA	Aim for partnership	Invite husband to reviews
Carer's assessment	Carer's assessment	Acknowledge carer knowledge of person	Carer's assessment
Clarify professional roles and responsibilities	Provide CESP training for mother	Respect carer and son's wishes	Carer support groups
GP and psychiatrist liaison	Co-ordination of mental health services		Service consistency/combat ageism
	Seek alternative accommodation for service user		

8.3 Good practice implementation and recommendations

Analysis of the vignettes and the group discussion revealed virtually identical agreement about the value of accessible policy information to promote good practice in information sharing between professionals and carers. Whereas the policy in Area 1, although relatively new, was well-known, the absence of knowledge about the older policy in Area 2 may in part be due to the recent amalgamation of two Trusts and the ensuing changes in service and policy configuration. However, these differences apart, policy information needed to be supported by dedicated carer services, a positive professional attitude towards carers and training for stakeholders on information sharing issues. In addition, professionals needed to balance service user autonomy with the carer's need to know. Professionals should carefully explain policies on confidentiality and information sharing to both the service user and carer and also why and how information would be used. The service user's consent should be respected and regularly reviewed and carers should be involved and provided with information where consent was forthcoming. It was important to distinguish between general and sensitive information in particular scenarios and professionals should be discerning in this regard. Professional standards needed to improve in respect of accurate recording and interpretation of information, and consistent approaches to carer involvement. Policies needed to be clear and unambiguous and provide a framework to ensure carers were given sufficient information to enable them to care without the service user's right to privacy being infringed.

The carer's assessment was viewed to be important not only in meeting carer needs but also providing a means of appropriate information sharing to support their caring role. Carers should be respected and professionals should also recognise the importance of their knowledge about the service user to inform assessment and care plans. There was also general support for service user advocacy and the advance directive to safeguard the service users' interests.

8.4 Summary

Despite the methodological weakness inherent within the workshop component (due to time constraints as a result of the procedures for gaining local and ethical approvals), the data generated within the two sessions was consistent with information emerging through the other parts of the study. In addition, the workshops provided an opportunity to look at how policies were influencing practice on the ground and mixed feedback was provided. These samples are not large enough to draw definitive conclusions, but they warn that the development of carer-focused policies are only one stage. Implementation of these policies requires resources including on-going staff training to work with carers and the systematic use of carers' assessments. In terms of policy development the workshops recommended that guidance and policy documents needed to be clear, unambiguous and provide a framework to ensure carers were given sufficient information to enable them to care without the service user's right to privacy being infringed.

Section 9 Effective information sharing

This section reviews the data presented throughout the report and provides a framework for 'good practice' information sharing in mental health, with a particular focus on how professionals can work more effectively with carers.

The research study has gathered information from a variety of sources to develop the framework and a crucial aspect of effective information sharing is the uniqueness of each individual 'solution'. There is no one blueprint for information sharing in mental health. Relationships between professional/service user/carer will vary and change over time, thus methods of information sharing must also reflect the different needs of all parties. This does not mean that core principles and effective strategies are not identifiable. The research provides a substantial framework for governing decisions for effective information sharing in mental health.

The principle responsibility for implementing good practice rests with professionals and the mental health service. However, effective information sharing relies on key principles of collaboration between all stakeholders (service user, carer and professional in particular), better communication and an information sharing culture built upon openness and honesty. None of the recommendations listed in this section will be possible without a culture shift in services to recognise the role of the carer and promote carer empowerment alongside service user empowerment. This will require professionals and services to address current attitudes towards working with families and carers who are significant others.

The reason effective information sharing is so important in mental health is because of the enormous resource that carers provide to statutory and voluntary services. Caring however takes its toll on the health of carers, many of whom are themselves elderly or have other family responsibilities, and thus the implementation of these recommendations is crucial for both recovery outcomes for the service user and the health of mental health carers.

9.1 Overview: comparing and contrasting stakeholder views

The research featured in this report is based on findings from a multi-method study exploring policy and research literature, a survey of stakeholder views, in-depth interviews with key stakeholders, workshops to assess links between policy and practice and supplementary information through workshop group sessions. The data presented in Sections 4 to 8 illustrate key themes for building best practice recommendations for information sharing in mental health. The project has generated large data sets, and these have been presented through descriptive statistics and content analysis of qualitative data. More critical analysis has not been possible within the project timescale.

In this section, we address contrasts and consensus within the data set before setting out an emerging conceptual framework for 'good practice'. Underpinning this entire project have been several guiding principles:

- Establish a balance of perspectives on the issue from different stakeholder groups – professionals, carers and service users.
- Consider different types of information in mental health – general information, personal information and sensitive personal information. The principles regarding the sharing of information will vary dependent on information type as well as context.
- Consider the context of care: type and length of relationships, level of disability, residential setting, advance statements.
- Emphasise the importance of process and time in relation to information sharing, for example collecting patient consent is not an event but a process within the context of a relationship based upon knowledge, trust and expertise.
- Acknowledge the role of subjective judgements in decision-making, influencing the process of collecting consent, sharing information, requests for information, protecting personal privacy, building trust.

This study has a number of methodological weaknesses that have been highlighted throughout the report. However, to counteract these limitations, triangulation of the data set was employed to strengthen the emerging evidence base. Clear emphasis has also been placed on describing the depth of experiences across the sample. Most notably, synergy between the national survey and in-depth interview findings are reported. When considering evidence across the study, intra-group and inter-group comparisons are also explored and it is important to emphasise that not only do the views of professionals, service users and carers as distinctive groups vary on a number of issues, so do opinions within specific groups. For example, 31% of service users feel information should never be shared without their consent compared to

69% who report context specific justifications. Another example involves carers, where 21% feel they do not need access to personal information about the service user in order to be proficient in their carer role compared to 79% who believe such access is vital. Across this report, emphasis is placed upon context-specific solutions developed in consultation with all relevant stakeholders.

Unsurprisingly, solutions to problems are unique to each context and person; recommendations are also diverse and cover a large number of often contradictory pathways. In each of the data sections the range of responses provided to the open-ended questions is one indication of the breath of views held. For example, it is important to note that for some service users, solutions are not needed for information sharing 'problems' between professionals and carers, because they do not want information shared with carers under any circumstances and thus the solution is preserving service user confidentiality at all times. Greater consensus emerged across the carer and professional surveys and interview samples, with solutions relating to professional actions and systems changes being highlighted. Once structural reforms impact locally, individual carers and professionals may then seek out more personalised solutions to context specific issues.

9.1.1 Consensus areas across the data set

Professionals, carers and service users all highlighted confidentiality as an important principle governing the delivering of effective mental health services. These stakeholder groups also identified the importance of appropriate information sharing that is built upon decisions that take into account the context of care and the views and wishes of the service user (see Section 6.3). Communication is a theme that repeatedly emerges to govern good information sharing practices whereby all parties are kept informed of decisions or current situations. This does not necessarily lead to the sharing of confidential information, but the establishment of a dialogue between parties so that stakeholders are kept informed of decisions and understand these actions. Greater emphasis on professional responsibility for supporting carers, and engaging with carers, was also highlighted as a good practice strategy by all stakeholders (see Table 32).

In the national survey, the stakeholder groups were asked to indicate from a range of approaches to overcome information sharing problems in mental health, which solutions were most appropriate in their opinion. From a list of 16 options, the least favourite solution for all groups was 'share information with carer on a hypothetical basis' while a popular suggestion for all stakeholders was 'discuss issue of confidentiality with service user and carer together'. The remaining 14 options provided more contrasts in ratings illustrating greater divergence in opinions than consensus for ways forward in addressing problems related to poor information sharing in mental health.

9.1.2 Contrasting perspectives

The data sets reveal far more differences than concordance in views between stakeholders leading the research team to a strong conclusion that there are no blueprint solutions for good practice in information sharing in mental health. Below are a few examples to illustrate the range of contrasting perspectives uncovered in the course of this project.

- Carers' views were found to vary, explained in part by relationship type (parents supporting a child with an SMI held different views on information sharing than carers who were also partners) and living arrangements. For carers, if the service user lived with them, access to confidential information was rated as a greater priority compared to where support was provided 'at a distance'. However, three in four professionals and service users did not view 'living in the same house' a good reason for breaking confidentiality whereas one in two CSWs encouraged information sharing based on living arrangements, providing a proxy indicator for carers' rights in terms of 'need to know'.
- The reasons why personal information, and in some cases general information, is not shared between professionals and carers was explored in the study. For professionals a key reason – acknowledged by 81% of the national survey sample is the withholding of consent by the service user. However, this was only an explanation for 21% of the carer sample. Differences in the proportions of carers and professionals identifying service users not being asked for consent was also noted – 44% of professionals provided this reason compared to 19% of carers. When service users were asked about the routine collection of consent, 24% said they were rarely asked and 18% reported never being asked.
- As reported above there are divisions in opinion over whether there are any circumstances in which patient confidentiality should be broken, as reported by the service user sample. When the views of professionals and service users are compared another contrast emerges as 97% of professionals acknowledge circumstances where patient confidences can be broken whereas for service users only 69% identify such circumstances.
- An important contrast of opinion across the data set concerns the involvement of carers in clinical meetings and CPA reviews, as well as carers having time alone with professionals. In the sample, 32% of service users did not feel carers should be offered separate time with professionals to discuss their concerns regarding the user's mental health, treatment and care. All respondents were asked to rate approaches to overcoming information sharing problems in mental health, one option provided was for carers to attend care planning meeting. Only 43% of service users rated this option, compared to 70% of carers and 80% of professionals.

- In addressing key solutions to overcome barriers to information sharing (see Table 28) the following differences in rankings were reported:
    - overall, service users rated professional actions as the most important solutions
    - overall, carers rated their own actions as the most important solutions
    - overall, professionals rated their own actions as the most important solutions
    - overall, CSWs rated support for service user and carer as the most important solutions

The study also considered different caring treatment contexts, in particular the needs of carers supporting a person with an eating disorder, dementia or SMI, as well as the particular information needs of young carers. When the in-depth interview data was compared through strength of theme (see Section 6.3) differences between stakeholders for both older adult and adult services emerged. The most striking contrasts in terms of the principles theme are listed below:

- Professionals working in older adult services described principles relating to ‘best interests’, ‘acknowledging risk’ and ‘harm avoidance’ which were not mentioned by carers.
- Carers supporting a relative with dementia emphasised the principles of carer involvement and a culture of information sharing to support better practices, though these were not described by many professionals.
- In adult services professionals again cited best interests as an important principle, as did service users, though no carers framed their response through the ‘best interest’ perspective. Professional discernment was an important principle for professionals and service users, but not carers.
- Service users prioritised clarity of information and carers emphasised recognition of the carer role.

The interview sample is small but provides information that mirrors to some extent recommendations and experiences emerging from the national survey data set. Intra-group and inter-group contrasts are important to emphasise in this study because they impact directly upon the development of models of good practice for effective information sharing in mental health. There is no consensus position and thus future initiatives must focus upon strong policy development and training programmes to build capacity locally to develop overcome noted barriers to information sharing. Differences in opinion must be reconciled through the strongly emphasised recommendation to communicate and keep everyone informed - both in terms of strategy development and through practical solutions. The following section describes a framework that the research team have devised based upon the data collected in this study. It considers both the consensus and contrasting perspectives revealed in the data to conceptualise how good practice information sharing protocols could evolve to improve the experience of carers and service users in contact with mental health services in England.

9.2 A basic framework

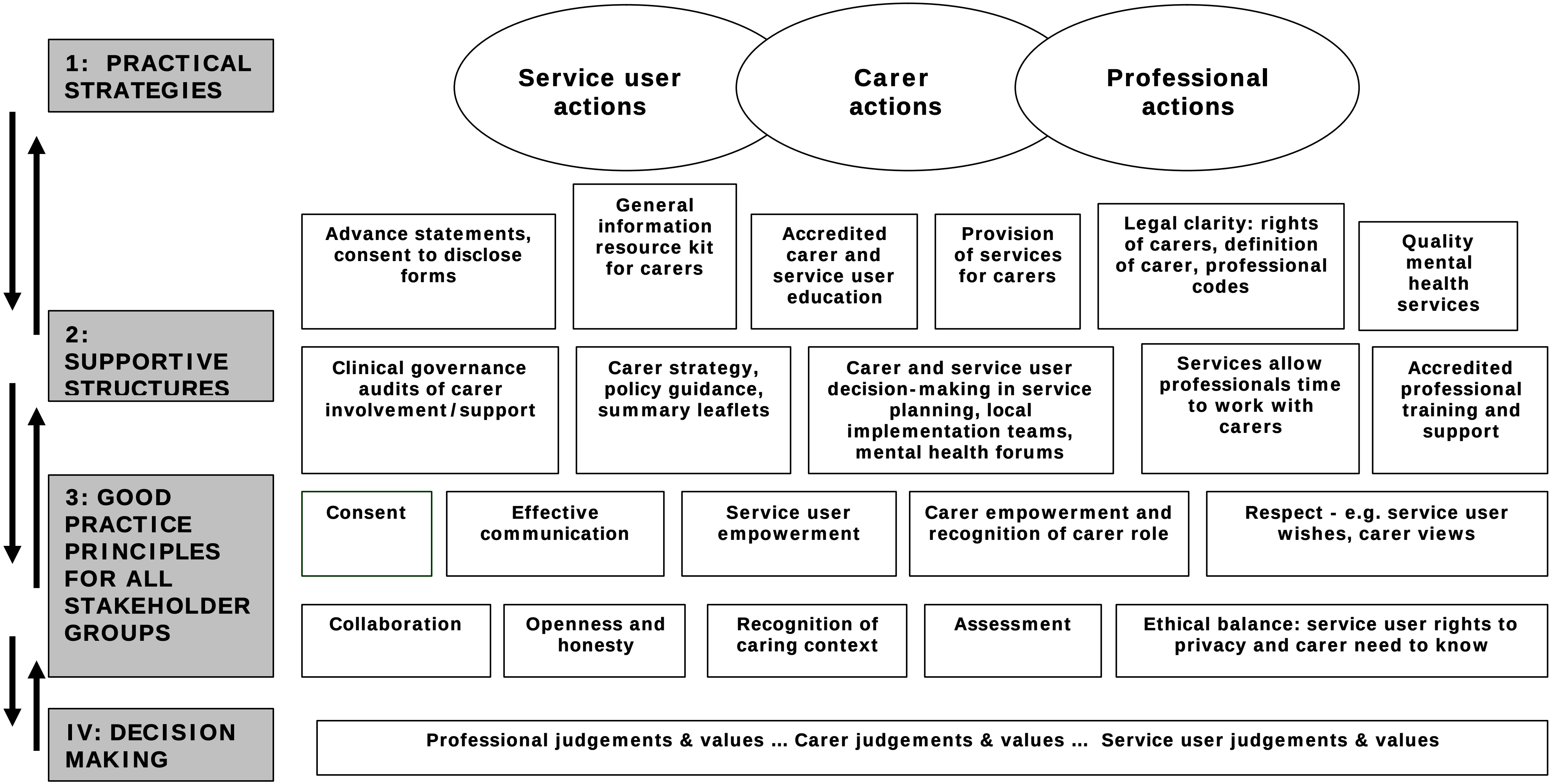
The focus of this study is the promotion of carer involvement and 'empowerment' in information sharing. The framework provided in Figure 6 emphasises the role of carers within the mental health service, while acknowledging difficulties with the definition of 'carer' in practice. The framework does not specifically consider all information sharing contexts though many of the principles apply to other situations, for example service users sharing information with carers or professionals.

In developing the framework, material from Sections 4 to 8 have been assembled. It is important to emphasise that the framework is a 'menu' of considerations and the relative importance of each component will be dependent upon individual contexts, and these will change over time. Relationships in the context of information sharing are of vital importance where trust and understanding are built over time, reinforcing the importance of continuity of care in mental health. The data revealed a number of consensus points and far more contrasts in opinion. The differences between carers, service users and professional viewpoints must be acknowledged, with open and honest dialogue promoted to find agreed levels of information sharing and support for all parties. In the report emphasis is placed on the importance of different types of information – general, personal and personal sensitive. Not all information sharing to support carers leads to breaking 'patient confidentiality', and more support and training of all stakeholder groups is required to reinforce this message.

The conceptual framework developed by the research study is provided in Figure 6. The framework first acknowledges the importance of practical strategies or 'actions' though these are not detailed in Figure 6 itself, but are explored at length in this section (level 1). These actions will mostly be led by mental health professionals, though service users and carers will also have an influence through selected strategies such as being proactive. Underpinning specific actions are structural elements of the mental health service that shape effective clinical governance (level 2). This includes policies, procedures, model documentation, professional codes and the implementation of these through training programmes. Level 3 involves the application of principles for effective information sharing. The two most important principles identified by service users and professionals in the study were 'establishing effective dialogue and communication between all stakeholders' and 'the principle of consent'. For carers the principles of carer empowerment and being proactive, together with professionals recognising the carer role and their expertise were most important. The development of open and honest relationships between all stakeholders was also a repeated theme across each stakeholder group. The whole framework is underpinned by level 4, which describes the key characteristic of decision-making in mental health, both in relation to individual judgement and values-based practice. Professionals make clinical decisions based upon their professional expertise, training, codes of practice, local guidance, relevant information and assessment. Equally service users and carers also make a series of judgements before deciding what information to disclose, or who to ask for, when and to whom. As one research participant noted, the key to information sharing for service users is that once information is shared one can not take it back, so one has to be sure it is in one’s best interests to share having considered the impact it may have on others. People’s views and the decisions they make change on the basis of information received. Where professionals and ‘nearest relative’ carers have the power to detain a service user against their own wishes under the Mental Health Act 1983, these decisions by service users to share information cannot be taken lightly. With carers, receiving information is only one stage of the support process. Professionals have to be aware of the impact of appropriate information sharing on carers, and where staff judge that a carer requires additional support from statutory services or signposting to other sources should be available to support carers in this way.

The basic framework provided in Figure 6 provides an overview of key considerations to support all carers of people with mental health problems. This framework is explored in more detail in the subsequent parts of this section. It has been developed using the data collected within Sections 4 to 8 of this report but there are no references to individual links between data and framework items in this section.

Figure 6 Framework for effective information sharing with carers in mental health



9.3 General principles and attitudes towards carer empowerment

The research has highlighted from both a professional and carer perspective in particular, that in order for carers to be effectively supported and meaningfully involved in the mental health care 'team' a cultural shift is needed within the mental health system, a position required in recognition of the vital role that carers play in many service users' lives. Standard 6 of the NSF for Mental Health outlines the government's commitment to carers. Since 1999, there has been an increasing number of CSWs in post across the country, greater provision for respite breaks and networks of formal and informal support structures for carers including education programmes, peer support groups, carer conferences and places on local advisory forums. However, our policy analysis revealed that the development of carer strategies to underpin and strengthen these developments at a local level is under developed on a national scale. There are excellent examples of policies structuring work with carers but these are few, and as shown from our workshops, are difficult to access on the ground even in the same location that they were developed. Too many policies lack advice on how to apply regulations in practice and accentuate the negative rather than the positive effects of information sharing with carers.

It is also particularly important to note that carer involvement and 'empowerment' is opposed by some service users, particularly those who have to manage difficult relationships with family members or where relatives are viewed not as carers but as equal partners in a family or friendship. Thus, while the mental health system must address its attitudes to working with carers this should not be done uncritically, and must be based on a clear understanding of the context of care, the long term relationship between the service user and carer, the service user's wishes and the needs of the carer.

In general, the practice of carer empowerment needs to be based on the following approach:

- **Recognition of the carer and their role** (including identifying the relevant carer through discussion with service user and family) from the outset of any service contact. This will involve in many cases the carer being viewed as an active participant in the community care team. However, there will also be occasions where the service user does not want any involvement from the family and these wishes must be respected and alternative ways of supporting the family sought.
- **Services and professionals that are positive and inclusive** towards working with carers. The current reluctance of many

professionals to engage with carers must be replaced with supportive approaches.

- Effective dialogue and **better communication** between all parties in mental health.
- **Professional judgement and assessment** used in weighing up particular factors in each individual care context regarding appropriate involvement of carers. For example:
  - what is the nature/quality of the relationship between service user and carer?
  - what are the living arrangements – do they live in the same house and are living arrangements relevant to the current context of information sharing?
  - what are the service user's wishes regarding the involvement of the carer?
- **Service user involvement** in discussions about the involvement of carers, and decisions relating to carer empowerment. Where service users are reluctant for carers to be involved, professionals should seek to understand this decision and work with service users, where appropriate, to emphasise why carers may need to be involved for their benefit.
- A recognition and understanding of **the rights of the service user to confidentiality** together with the circumstances under which such rights may be breached. **Consent** should be sought before disclosure of **personal information**, and when confidentiality is breached this should ordinarily be explained to service user and carer as part of a **joint collaborative approach** to addressing the needs of both parties.
- **Sensitivity in information sharing** practice and professional empathy in order to **balance the individual needs** of service users and carers.:
  - assessment to understand the importance of the current/potential contribution of carers in addressing the needs of the service user from the outset
  - assessment to understand the needs of the carer to support them in their caring role – the 'need to know' principle in terms of personal information and the provision of resources to support their 'general' information and support requirements
  - sensitivity in working with carers supporting people with dementia
  - sensitivity in addressing cultural issues
  - proactive engagement with young carers.
- **Openness** wherever possible. Thus the need for confidentiality will be reduced as information is shared more readily between all parties together. **Honesty** is another important principle, explaining to carers why information can't be shared rather than just offering the 'no' response where confidentiality is perceived as a block rather than a justified reason.

- **Flexible and imaginative** practice that addresses ethical issues relating to involved stakeholders within the bounds of the law and professional codes. Practice that upholds the therapeutic alliance, service user privacy and autonomy, and carer rights to confidentiality.

9.4 Service structures that support good practice

While moving closer to specific strategies for informing good practice, in this section the supporting structures to frame effective clinical practice are documented. The research data highlighted the importance of policies. Where these were in place, 20% of professionals found them very helpful and 62% quite helpful. Other structures include resources for carers both in terms of information and services and improvements in the quality of mental health services more broadly, particularly for dementia services and BME communities. The crucial role of training and education is also highlighted. Figure 6 (level 2) listed the main elements of supportive information sharing structures. These are also described in more detail below:

- **Carer strategies** based on government policy such as Standard 6 of the NSF for Mental Health that are written with the involvement of carers.
- The development of **clear confidentiality and related policies** in collaboration with service users and carers in reference documentation and also user-friendly formats which use plain English, for example information guides, leaflets and videos specifically for carers. Policies relating to carers should also be cross-referenced in other mental health policy documentation for example the CPA. Model confidentiality policy documentation should be:
    - written in collaboration with carers
    - jargon-free and easily located
    - identify and explain rights and responsibilities of users and carers
    - outline professional roles and responsibilities with regard to patient confidentiality and the central role of consent
    - provide helpful contact points
    - outline carer entitlements for example carers’ assessments
    - include summaries of the law and government policy on carer issues
    - provide examples of situations where information may be shared without the service user’s consent, for example in cases of risk.
- **Information** on confidentiality should be **accessible** to all stakeholders using community settings such as Citizens Advice Bureaux and GP surgeries as well as dissemination routes through mental health professionals.

- **Advance directive and consent to disclose forms** should be readily available in all health and social care settings for service users and carers to access. Where agreements are developed between the service user and carer these should be independently witnessed.
- An **information resource kit for carers** should be produced for each locality providing carers with **general information** about mental health problems, diagnosis, assessment and treatments. The kit should also sign post to specific carer services and resources, and list contact details for local mental health facilities. This kit should be regularly updated.
- Professionals identified a number of practical barriers to working with carers. The **mental health system must recognise the current capacity constraints** for example staff experience, particularly in terms of having insufficient time in their job role to work effectively with families. The research identified that professionals require various types of supports to work effectively with carers including capacity in job role, training, and supervision.
- **Professional training** is discussed in more detail below under 'professional actions'. However it is also included as a structure because professionals require on-going training for working with carers. This accredited training should be embedded within clinical governance frameworks, with ongoing commitments to staff development including training on working with carers both through placements with carers, structured education sessions and professional supervision. The taught training could be part of an individual's professional development programme and contribute to professional development accreditation points.
- **Clinical governance systems** should require service audits to include indicators of carer participation. There should be a carers' register naming all local carers supporting service users on CPA and supporting documentation identifying their own health and social care needs. The clinical governance system should also audit carer involvement in mental health forums, local implementation teams and service review groups.
- **Specific carer services** should be established. Where support groups are held these will need to be for specific groups, for example people supporting a person with psychosis, dementia, eating disorders or dual diagnosis. Other services include: respite breaks, family therapy, carer education, counselling for carers and CSWs.
- **Carer education**, as with professional training, is also described under 'actions'. The structural element of providing carer education is a financial commitment by primary care trusts to fund carers to attend training courses and to ensure that these courses are accredited to guarantee quality.

- **Clarity about the law, policy and codes** is essential for guiding good practice. Both service users and carers need to understand the parameters of confidentiality. The law needs to be strengthened to enhance the rights of carers, for example the right to advocacy. The law also needs to be strengthened to enable service users to evoke an advance statement of their wishes. Professional codes should be updated regularly and allow for practical application to individual situations using flexible decision-making based upon professional judgements.
- Mental health service structures to deliver **quality services** to improve the recovery journey for people with mental health problems across England. Both carers and service users noted that if standards of mental health care improved, carers would require less information and support as their caring roles would have been made easier by the recovery of service users' mental health. This is of particular importance for **carers from BME communities** who recognise that the provision of services are often culturally insensitive and do not meet the needs of their relatives.
- **Carer and service user decision-making in service planning** ensures that the priorities of both service users and carers are considered as new services are commissioned and current services are reviewed.

9.5 Good practice strategies

In this final section we address in detail the 'actions' that various stakeholder groups can take to build the effective, and appropriate, involvement of carers in information sharing. These are strategies that have been generated through the research, and they represent both practical grounded solutions and individual ideas. A thorough examination of the impact of these strategies requires further investigation through an implementation assessment exercise. It is also important to emphasise again that there are no blueprint solutions for effective involvement of carers in information sharing. The appropriateness of each individual action will depend on the current context of care and the service user's wish. The good practice strategies are organised thematically.

9.5.1 Good practice in assessment

The actual practice of involving the carer could be affected by a number of often coincidentally-occurring factors. These included the nature of the mental illness and its effects on mental capacity, the quality and nature of the service user/carer relationship and how, when and where the service user and carer came into contact with services, for example whether they were together or apart at the first crisis or appointment, or whether they were presented at primary or secondary stages. The data analysis identified a range of good practice strategies that underpin the assessment process that informs professional judgements in decision making.

- **Holistic assessment of caring context** including: carer's motives; the quality of the service user and carer relationship in the longer-term; the amount of caring provided and the carer's context – do carer and service user live together?
- **Assess the capacity of the service user and carer to understand the shared information** or the explanation surrounding information sharing policies: take into account the nature and likely duration and stage of the service user's incapacity and the possibility that the carer's understanding and retention of information may be limited by stress as well as other factors, including cultural and language issues.
- **Assess carer's needs and their ability to use and manage the information provided.** Carers may require additional supports after information has been shared and this should be discussed with the service user and carer collaboratively where possible. The requirement for additional support should not be used as a reason for excluding carers from the information sharing process.
- **Undertake a thorough risk assessment** of both service user and carer circumstances to assess carer's 'need to know' and the likely risks to carer (carer protection policy). Carers in the study did not want to know 'everything', only that which was pertinent to their role in supporting the service user effectively;
- To incorporate **carer assessments** into routine practice.

9.5.2 Consent

The research highlighted that information sharing was principally governed by consent (which is informed, written, voluntary, recent and competent) although professionals were also using a range of strategies to involve carers and bridge situations where consent was withheld or not clearly forthcoming. This suggests that professionals, while adhering to core principles, were responding creatively to the care context beyond the guidance of prescriptive professional and agency codes. Their main considerations were to ascertain:

- the status of the service user's consent and capacity to give consent
- any known advance wishes
- the identity of the main carer and significant others who may be supporting or liaising on behalf of the carer
- the role of the identified carer where the service user's judgement is impaired either permanently or temporarily
- the nature and extent of information necessary to support the particular care context
- the risks involved in disclosing or not disclosing information

- duties under the law, courts and tribunals
- responsibilities where there are known risks regarding the health and/or safety of the service user and others.

If confidences are to be broken, a written explanation in the case notes should be made of the decision and whom it was discussed with, and this decision should be ordinarily discussed with both the service user and the carer. Service users should also be informed of the decision even where their capacity to provide consent was absent though the timing of this discussion would be based on clinical judgement.

Good practice in the collection of consent would involve the routine use of disclosure to consent forms or advance statements. These should be available in all clinical settings and service users should be supported to complete these forms to ensure that their wishes are well-documented and regularly reviewed. When the service user fills in an advance consent form privately with the carer this would need to be independently witnessed such as by a solicitor, advocate or advice worker.

It is also important to emphasise that the collection of consent is not an isolated event. The collection of consent can be viewed as a *process* built upon trust, experience and knowledge of both a particular context and relevant policies and procedures. This point relates to continuity of care in the mental health community that is crucial for the development of effective therapeutic relationships.

9.5.3 The disclosure process

Considering the recommendations outlined above governing the giving of consent or decisions to break patient confidentiality, the following recommendations are provided to structure the process of information sharing:

- To differentiate between general, personal and sensitive personal information in the particular care context based on an assessment of how much the carer already knows about the service user’s situation, and how closely the carer is involved with the service user’s care.
- To recognise the different professional and informal care responsibilities deriving from different relationships, for example parental, partner, young carer or adult child caring for an elderly parent.
- To provide a thorough explanation to the service user and carer as early as possible about the agency protocol on confidentiality, the potential benefits of information sharing and how personal information might be used in relation to the actual situation. Discussion with service user and carer jointly should take into account the consent parameters listed in Section 9.4.2.

- To consider the appropriateness of separate and joint sessions with the service user and carer and the appropriate sequence of any such arrangements. Where service users are reluctant for carers to have time alone with professionals, service users may need support to understand why time alone for the carer can be appropriate and supportive to the carer's own needs.
- (Where a service user deemed to have capacity withholds consent) to continue to negotiate with the service user, try to discover why consent is withheld (for example carer/service user relationship problems, paranoia caused by mental illness, shame of mental illness, not wanting to distress the carer) and where appropriate explain to the service user the carer's 'need to know' certain information about their care and treatment.
- To keep the service user informed about how his or her information is being used, even where information is being disclosed without consent, unless this would compromise personal safety.
- To respect the dignity of the service user who has lost or is losing capacity and involve him or her in decision-making as far as possible. This is particularly important for people with dementia, but is also relevant for adults with psychosis.
- To review consent regularly about what may and may not be shared and keep a written agreement of the service user's decision.
- To provide general information to inform carers about mental health services, mental health problems, treatments, service and carer contact points, websites, carer groups and carer entitlements.
- To consider with the service user the inclusion of the carer in written correspondence – copying of correspondence to carers is said to be desirable by some service users, professionals and carers. Letter writing is another way for professionals to share information (general and personal) with carers.

9.5.4 Carer and service user responsibilities

Carers found they could obtain information about the person for whom they were providing care by being assertive. While they perceived this approach to be necessary, it is to be hoped that as services become more proactively engaged in the ethical dimensions of involving carers while safeguarding service users' privacy, carers will find more satisfying ways of successfully channelling their energies. In this regard, and in tune with consensus on good practice models it is to be hoped that carers will take up offers of carer support initiatives as these become available. These include:

- carer assessments
- carer advocacy

- training forums and educational courses
- contributing to service evaluation and monitoring on the protection and use of information and CPA.

Service users identified the importance of professionals seeking their consent before disclosures of personal information to their carers were made. However, while professionals and carers upheld the centrality of this perspective, occasions were also cited where confidentiality had, out of necessity, been breached without the service user's consent. Service users should be deeply engaged in all debates surrounding the sharing of information. It is to be hoped that service users will contribute to good practice by:

- coming together to the debate their position
- identifying core principles and promote these within local mental health forums
- taking part in educational sessions delivered to professionals and attending sessions specifically for service users identifying core principles of information sharing in mental health
- participating in service evaluation and monitoring on the protection and use of information and CPA.

9.5.5 Training and education

Training for service users, carers and professionals on confidentiality, information sharing and the involvement of carers is essential for building effective communication and collaboration in mental health. There are conflicting perspectives on information sharing and these will not be resolved without some consideration and respect for other peoples' perspectives. Training offers a vehicle for the development of empathic understanding of other positions and the opportunity to learn about the ethical boundaries and application of confidentiality policies.

Professionals, service users and carers all highlighted that staff members do not know or lack the confidence to work effectively with carers. At the heart of any training on carers and confidentiality should be carer trainers. It was also suggested that training placements with carers could offer professionals valuable insight into carer roles and responsibilities. Ensuring that professionals can access training on working with carers needs careful planning and accreditation to guarantee attendance. A modular approach, such as the one offered by the Sainsbury Centre for Mental Health provides one possible model. This training would include specific sessions on:

- ethical practice
- professional codes, government guidance, confidentiality policies
- the role of carers in mental health care
- the rights and responsibilities of professionals, service users and carers, and recognition of other perspectives

- assessment including identification of carers (including those who may be abusive), caring context and relationship with service user
- information sharing including the difference between personal, sensitive personal and general information, application of confidentiality policies and alternative ways of supporting carers without breaking patient confidentiality
- support for carers including carers' assessments
- service evaluation techniques to support professionals who need to audit their current practice with carers.

Carer education is also essential to support carers across the whole caring experience including the developing of skills to support them in their caring role and an understanding of carer rights and responsibilities. When service users are unwilling for carers to be party to aspects of personal information, carers need support to understand this exclusion and offered alternative ways of meeting their information needs. Carers who are parents of children with long standing mental health problems may over time feel more and more excluded (as the service user gains independence through recovery) but their own anxieties and involvement may not diminish. Alternative methods to support carers in this position must be sought. Materials to support a training programme for carers would include the carer's information resource kit. Carers need access to a range of information sources including: books, leaflets, websites and contact telephone numbers, including carer support groups.

Carer education can take various forms including those described in Section 2 (CESP and Meriden). Professionals also suggested that carer drop-in clinics could be run by hospital wards or the CMHTs where carers could come along and receive general information and support. Carer support groups, which are very popular among carers, also provide education through shared experience and peer support networking.

9.5.6 Meetings

There are a number of meetings that provide professionals with opportunities to share information with carers. One of these is the CPA review. In practice carers can be:

- asked to attend the whole meeting (with the agreement of or at the instigation of the service user)
- asked to attend for specific items on the agenda and only for those specific items
- not invited to attend but given feedback of the outcomes with the agreement of the service user
- not invited and no feedback provided.

Decisions to involve carers in meetings, such as CPA reviews, should be taken jointly with the service user, and where appropriate the carer as well. These decisions should be regularly reviewed and the clinical team should consider the impact of attendance or non-attendance on the carer particularly if they have been providing substantial and regular support to the service user.

All the stakeholders reflected on the use of meetings as a solution for information sharing and it was noted that service users compared to carers might favour different practices. The different options are as follows:

- service user meets professionals alone and does not consent to carers/family members being involved at all
- service user meets professionals alone and also together with carers but does not want carers to be given time alone to meet with professionals to discuss their care and treatment or concerns
- service user meets professionals alone, carer and service user meet professionals jointly and carers meet professionals alone to discuss their concerns.

Service users were mostly opposed to carers having ‘time alone’ with professionals often because they feared their confidences would be broken. Through training it would be important to support service users to understand why carers meeting alone with professionals may be beneficial to the carer, for their own support needs. Service users need to feel confident that no personal information would be shared without their consent, or knowledge of where professionals had decided to breach confidentiality. If the service user is not comfortable with carers having time alone, many carers supporting working age adults (as opposed to older people with dementia) acknowledge the strategy is unworkable because it damages relationships and can fuel distrust.

9.5.7 First points of contact: hospital and GPs

Carers and CSWs noted that settings acting as first points of contact to psychiatry for many carers – the acute hospital ward or a visit to the GP to discuss concerns about a relative, are particularly difficult in terms of information sharing. Carers reported how service users can be discharged from hospital without the carer’s knowledge even when the service user is due to return to the family home. Ward staff acknowledged they do not always have the appropriate physical space to discuss information with families. Conversely, the experience of carers engaged with early intervention services that proactively support carers through support groups and appropriate information sharing, emphasised the high level of support they received from staff on acute wards. Both GPs and ward staff need training to understand the impact of caring on the health of the carer and the importance of carer involvement within hospital and GP settings.

9.6 Strategies for specific groups

The following recommendations emerge from a qualitative analysis of carer responses to both current problems and suggested solutions.

9.6.1 BME carers

- Address culturally insensitive services. Carers felt services did not take into consideration their religious or cultural needs.
- Professionals should recognise and respect ethnic diversity. Professionals should understand cultural norms and the impact these have on family dynamics.
- Address poor communication between professionals and carers. Carers find it difficult to share as well as understand information. Interpreters and independent advocates should be made readily available.

9.6.2 Carers for people with dementia

- Address poor communication in dementia services particularly in hospital services. Carers want access to information about diagnosis and treatment as well as personal information (where appropriate).
- Involve carers of people with dementia in treatment decisions. Carers feel excluded from treatment decisions and this was compounded by lack of both general and personal information.
- Carers should attend specific support groups. Carers acknowledged the enormous level of support provided by Alzheimer's Society support groups.
- Carers should persist in establishing relationships with staff. Carers acknowledged the importance of their own proactivity in approaching mental health professionals but this is not always an easy task.

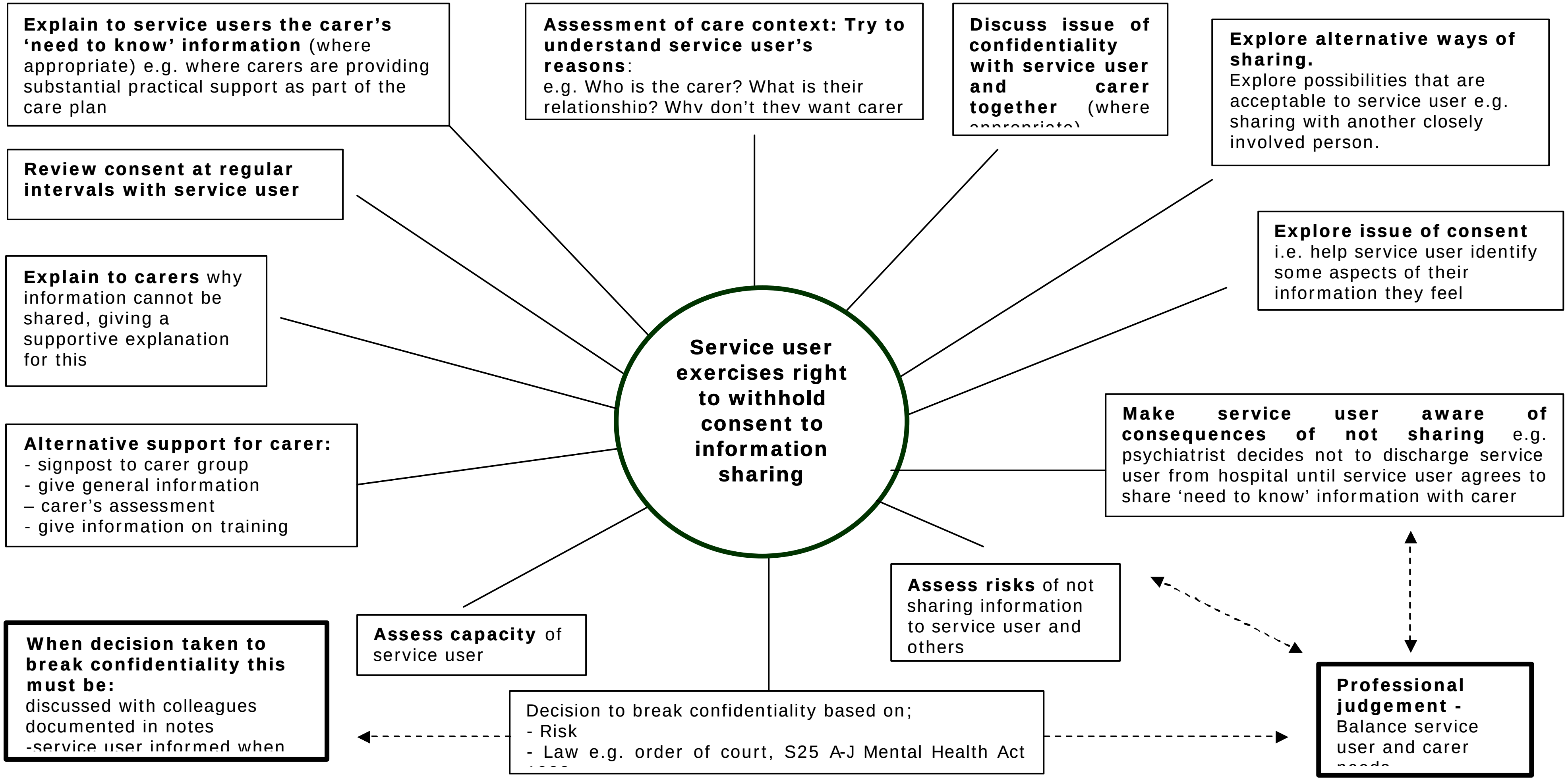
9.6.3 Young carers

- Professionals should not exclude young carers from discussions and better communication should be promoted.
- Young carers need to be proactive in seeking information and involvement.

9.7 Strategies when service users withhold consent to share information

Throughout the project we have been concerned with best practice information sharing solutions and ways to effectively involve carers through information sharing. As has been highlighted throughout the report, the key principle for service users, carers and professionals is consent. Where a service user does not want carers to be involved, or is not asked by professionals whether they want carers involved, information sharing 'blocks' under 'patient confidentiality' values and principles are experienced by carers. Figure 7 outlines a number of the strategies open to professionals when the service user withholds consent to share information. These solutions are not ordered sequentially but they are listed as options to effectively engage with carers even where consent is withheld. Most of the strategies in Figure 7 do not rely upon the breaking of patient confidentiality. In producing this diagram it is important to emphasise that it is the service user's right to withhold information from their carer and many carers acknowledge the fact that they 'do not want to know everything'. This diagram has been constructed to outline strategies for sharing 'need to know' information with carers when the service user, as is their right, has refused to provide consent. It is also important to emphasise that carers need access to generic information to develop a knowledge base to support them on a journey through the mental health system and mental health problems; information not bound by patient confidentiality considerations.

Figure 7 Possible strategies for professionals when service user's exercise their right to withhold consent to share 'need to know' information with carers



Service user exercises right to withhold consent to information sharing

Explain to service users the carer's 'need to know' information (where appropriate) e.g. where carers are providing substantial practical support as part of the care plan

Assessment of care context: Try to understand service user's reasons:
e.g. Who is the carer? What is their relationship? Why don't they want carer

Discuss issue of confidentiality with service user and carer together (where

Explore alternative ways of sharing.
Explore possibilities that are acceptable to service user e.g. sharing with another closely involved person.

Review consent at regular intervals with service user

Explore issue of consent i.e. help service user identify some aspects of their information they feel

Explain to carers why information cannot be shared, giving a supportive explanation for this

Make service user aware of consequences of not sharing e.g. psychiatrist decides not to discharge service user from hospital until service user agrees to share 'need to know' information with carer

Alternative support for carer:
- signpost to carer group
- give general information
– carer's assessment
- give information on training

Assess risks of not sharing information to service user and others

Assess capacity of service user

When decision taken to break confidentiality this must be:
discussed with colleagues
documented in notes
-service user informed when

Decision to break confidentiality based on;
- Risk
- Law e.g. order of court, S25 A-J Mental Health Act

Professional judgement -
Balance service user and carer

9.8 Information sharing – final reflections?

Information sharing in mental health is a hugely controversial area but the research team has found, through the process of carrying out this project (including analysing the data sets and involving the expert panel), that where key differences are addressed, clarity and understanding are generated which could in the longer term lead to improved clinical outcomes. The government is committed to increased service user and carer involvement in mental health, with clinical benefits of these developments documented in the recent mental health clinical governance reports from the Commission for Health Improvement (2003). However, commitment to improved information sharing practices is not enough: practical strategies addressing the legacy of poor information processing are required to develop a positive and inclusive information sharing culture delivering improved outcomes for mental health professionals, carers and service users. These developments cannot proceed without due regard to policy regulation, ethics and professional codes of practice. The central principle of consent (and patient confidentiality) that protects the civil rights of mental health service users does not have to be eroded by more positive and inclusive information sharing practice. The central principles structuring information sharing remain, but in application improved communication must be encouraged to establish meaningful dialogue between all stakeholder groups thus removing confidentiality as a block to engaging with carers.

The public health White Paper (Department of Health, 2004) provides the health and social care landscape with an updated government vision for healthcare in the 21st century. Government policy emphasises the central role of patient choice and the personalisation of healthcare services. In mental health these two concepts have been included within a programme of ongoing reform that started in the early 1990s (Rankin, 2004), but the system is only beginning to generate many of the practical initiatives associated with this vision for example direct payments. Those involving carers have only been introduced in a piecemeal fashion and although the target for CSWs in the NSF for Mental Health is likely to be met by the end of 2004, as this report highlights there is a lot more that needs to be done to bring carers into the mainstream of the mental health support and planning system.

Alongside a proliferation of guidance and policy documents to support professional working in mental health there has also been a large scale review of the Mental Health Act 1983 legislation. The review was set up to assess how ‘fit-for-purpose’ the current law is after a large-scale modernisation programme in mental health has seen the closure of many inpatient hospital beds, advances in treatment (both medications and psychological therapies) and new service configurations such as home treatment teams, early intervention services and crisis resolution teams. There is a tension in government policy between the promotion of carer rights, and the role of carers providing informal support to mental health service users often 24 hours a day, seven days a week, *versus* the proposed weakened rights for carers in the proposed Mental Health Bill 2004. The Mental Health Alliance has highlighted these issues, and is campaigning for changes to the Bill, though this situation provides one clear example of the mixed messages being provided to mental health professionals.

This report started by outlining the different types of information that concern service users, carers and professionals in mental health. Unpacking the different types of information is central to positive and inclusive information sharing practice with carers. Throughout the report, emphasis has been given to professionals providing necessary and appropriate levels of support to carers. This, as many professionals point out, will require structural changes to facilitate this shift in emphasis. When reviewing different types of information the report described three categories:

1. **General information about mental health problems** for example information available on the web, MIND fact sheets, books and journal articles which provide generic information on specialists subjects (ECT, Disability Living Allowance, CPA) or general topics (local contacts database, living with mental illness, caring and coping).
2. **Personal information** describes details that are specific to a particular person (for example diagnosis, type of medication, care plan activities), but which when presented in a depersonalised form can form part of a general information category. For example, schizophrenia or clozaril.
3. **Sensitive personal information** describes knowledge of a person of a particularly sensitive nature shared in confidence with a mental health professional, often within a structured therapeutic meeting. This would include personal information on sexual or emotional abuse, service user's views of family members, HIV status or sexual history.

The stakeholder groups involved in the research (service users, carers, professionals and CSWs) must all be able to distinguish between types of information in order to remove some of the tension from this hugely sensitive area in mental health. Supporting a carer through, for example, the provision of a leaflet, website addresses, a carers' toolkit package or telephone numbers of local support groups is positive and inclusive practice. Sharing personal and in rare occasions sensitive personal information can be supportive in a given context, but firstly patient consent is required and careful consideration should be given to the impact of information disclosure on the carer as well as the service user. Where consent is not given, professionals must consider whether patient confidentiality needs to be broken in the carer's best interests and record any decision taken. Although this process is common sense, it is not happening in practice. As with all aspects of information sharing outlined in the report, professionals, carers and service users all need to develop clear lines of communication which at times, because of the nature of mental health problems and resource pressures within the mental health system, break down.

The research contained in this report provides a series of challenges to mental health services across England. Evaluation of the various strategies undertaken to improve information sharing between professionals and carers, in a local context, is required as little is known about what works, for whom and in which contexts in this important but under-researched area. Through careful monitoring of different initiatives, and the sharing of practice-based knowledge nationally, carers, service users and professionals should all benefit from the potential therapeutic supports afforded by effective information sharing in mental health.

9.9 Summary

A broad measure of agreement emerged about the problems in current practice, and about the potential solutions. In addition, as indicated in the report, there is no one ideal solution, although the need to recognise the diversity of perspectives is a crucial component of any attempt to improve the situation.

What the study revealed about current practice:

- Professional codes as they stand neither explore nor develop the moral ground that lies between a carer's need for information to enable them to care and the service user's need for privacy.
- Policy guidance is both inconsistent and scattered in a range of documentation.
- Professionals are uncertain about what they may share and carers are often unaware of their rights.
- The role of carers needs to be recognised by all practitioners, but currently professionals admit there is reluctance among some staff to work with this group. This reluctance has its roots in structural problems: professionals lack training (and hence confidence) to work with carers; there is insufficient capacity (acknowledged as lack of time) to work effectively with carers as well as the service users on their case loads; and the environment (most notably on wards) is not conducive to sharing information with carers. However the reluctance also stems from stereotypes of carers and family members as being over-involved, difficult and better avoided.

What needs to change for carers:

- A common theme across the stakeholder groups was the importance of effective communication and the basis for information sharing being open, honest and respecting relationships.

- For carers and CSWs, the culture shift required in mental health to place carer issues further up the priority list not only in principle but in practice, underpinned all solutions.
- One vital component of mental health care is access to information, particularly for service users and carers to support informed choice. Developing and embedding sustainable frameworks to promote the flow of appropriate and necessary information should be a priority for care providers.
- The documents that contained positive carer guidance revealed a number of good practice points. A major factor is the importance of introducing a carer strategy to provide a framework for the development of carer services.
- The underpinning principle was the balance of ensuring carers had sufficient information to enable them to provide care and attain their entitlements, while simultaneously upholding service users' autonomy and privacy and the therapeutic relationship.
- Carers acknowledged service users' rights to restrict certain information, but suggested that all stakeholders are disadvantaged if relevant and necessary information is concealed.

What professionals can do:

- Professionals in their daily contact with service users and carers hold the key to balancing the perspectives of the different parties involved, including their employers and professional bodies.
- A range of good practice measures to support appropriate information sharing between professionals and carers was assembled from the analysis of carer-orientated policies. These identified the following professional responsibilities:
  - to provide an explanation of confidentiality and the agency protocol to all parties
  - to seek service user consent to disclosure of personal information to support carer 'need to know'
  - to review consent at regular intervals
  - in the event of the service user withholding consent, persevere with seeking consent, where appropriate, working with service user to help them understand why their carer may 'need to know' specific personal information regarding their care and treatment
  - to assess the capacity of the service user to give consent
  - to ensure information is accurately recorded
  - to assess the nature of the care context and relationships.

The service user's perspective:

- Service users, who in this sample were comfortable with their carer being involved, were keen to have the principle of consent underpinning the sharing of all information with carers.
- Service users also had mixed views on the practice of carers having separate time discussing them with a professional.
- Service users focused on the overriding importance of professionals obtaining service user consent before their personal information is shared with carers. Service users wanted professionals and carers to respect and adhere to their wishes.

The particular instance of dementia:

- Carers felt particularly constrained by inappropriate services and staff who were unfamiliar with the complexities of dementia.
- Carers noted the importance of carer engagement because of the incapacitating nature of dementia, which leaves the service user dependent on the carer for both care and advocacy.
- Professionals were concerned with the care context and understanding and assessing the service user and carer's position. This included weighing up the competence of the carer and his/her ability to disseminate information.
- Professionals felt carers should be involved in care plans and provided with comprehensible information about services, care and treatment options, medication and diagnosis. This they felt was essential as in most cases the service user was mentally incapacitated and reliant on the carer. Thus the carer already knew the condition of the service user.
- Professionals also recognised the importance of the carer being offered separate time with the professional.

The implementation of effective information sharing in mental health on a nation-wide scale will require substantial commitment from all stakeholders across the mental health system in years to come to rectify the widespread current poor information sharing practices. In this research we have reported the many problems that carers, service users and professionals experience with regard to information sharing, primarily based upon poor policy guidance, lack of knowledge and training, no routine collection of service user consent, and an under recognition of the role of carers in the mental health care team.

In order to improve information sharing in mental health improvements are required as outlined in the suggested framework including: practical actions; structural changes; application of good practice principles; and decision-making based upon knowledge, good quality training/support and context.

Section 10 Next steps

> *No matter what recommendations are produced with regard to confidentiality there must be a will on the part of the local authorities and front-line professionals to provide as much information to the carer as possible, and this should be reflected in professional training, because without this positive mindset the care will be disadvantaged.*
>
> (Expert panel member)

In summary, the implementation of effective information sharing in mental health on a nationwide scale will require substantial commitment from all stakeholders across the mental health system in years to come to rectify the widespread current poor information sharing practices. In this research we have reported the many problems that carers, service users and professionals experience with regard to information sharing primarily based upon poor policy guidance, lack of knowledge and specific training opportunities and an under recognition of the role of carers in the mental health care team. The key principle guarding all information sharing in mental health is consent and in this research it has been reported that service user consent to disclose information is not being routinely collected in practice. A number of practical changes to professional practice would make an enormous difference to the way mental health carers are supported and valued.

The research is limited by a number of factors that must be considered when applying the material presented in the report. The most notable limitations in this study are the need for more evidence to explore specific information difficulties experienced by carers from BME communities and young carers. Further research is also needed on the implementation of the strategies to address effective information sharing to understand which solutions work for whom in practice, and why.

In order to improve information sharing in mental health both improvements to professional/service engagement with carers and strategies relating specifically to information sharing are needed. A number of ‘next step’ recommendations are provided below:

- There has to be a culture change in professional attitudes towards working with families and significant others supporting the service user, while the service user’s right to privacy is maintained at the individual case level.
- Carer strategies must be produced and made readily available to professionals, carers and service users.
- Carer strategies must acknowledge diversity both in terms of caring context and strategies for building best practice.
- Comprehensive ongoing training for professionals, involving service users and carers as trainers, must be provided on working with

carers, including modules on information sharing and confidentiality. Trainee professionals could also have the opportunity to have placements with carers as part of their induction courses.

- Trust and SSDs must show a commitment to supporting staff to work with carers through supervision, job descriptions and workload balance.
- Regular carer audits should be carried out as part of clinical governance frameworks to document levels of carer engagement with services over time.
- Service user consent should be routinely collected, ensuring that advance consent forms (or consent to disclose forms) are readily available to all service users.
- Continuity of care problems should be addressed within mental health services, to promote improved therapeutic relationships based on trust, experience and knowledge of an individual that is built over time.
- Comprehensive risk assessments for both service user and carer to inform the ethical balance between a service user's right to privacy and a carer's 'need to know' should be carried out as part of routine clinical practice.
- Routine introduction of carer assessments and care plans for carers to support carers, including the identification of their information needs.
- Clear distinctions between 'general information' and 'personal/personal sensitive information' must be well-known by service users, carers and professionals.
- All stakeholders must consider the position of others – service users, carers and professionals – when making decisions about information sharing and take into consideration the impact of sharing or not sharing information on themselves and other people. Stakeholders may need assistance and support in dealing with the sharing of information.

This report has drawn upon the expertise of a wide group of people to outline good practice information sharing strategies. The next steps outlined here are of crucial importance if changes in the way carers are supported through information sharing are to be realised on the ground. The recommendations in this report should be implemented and evaluated because there is currently not enough information about which combination of strategies will be most effective in removing the information sharing blocks currently hindering the involvement of carers in information sharing. At the heart of the recommendations are training and support for professionals who themselves must be enabled and supported to lead these reforms and achieve best practice in mental health information sharing.

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Appendices

Appendix 1 Expert panel

Jackie Ardley, NIMHE carer lead (joined post during study)

Malcolm Bateman, Nurse, Addiction Services

Sophie Bellringer, Research Assistant, Institute of Psychiatry

Kathy Billington, Department of Health (left post during study)

Eileen Brown, Carer Support Worker (young carers)

Paul Corry, Head of Policy and Campaigns, Rethink

Marva Clarke, Nurse, Mental Health Promotion Specialist

Graham Estop, Voices Forum Coordinator

Moira Fraser, Policy Officer, Mind

Betty Hunter, Carer Support Worker (adults)

Peter Huxley, Professor, Head of Section, Social Work and Social Care, Institute of Psychiatry

Mike Launer, Consultant Psychiatrist (adults)

Joanna Murray, Senior Lecturer, Section of Mental Health and Ageing, Institute of Psychiatry

Mary Nettle, Mental Health User Consultant

Vanessa Pinfold, Rethink Research Manager

Charlotte Platman, Social Worker, Assertive Outreach Team

Joan Rapaport, Lead Researcher

Shula Ramon, Professor, School of Community and Health Studies, Anglia Polytechnic University

Les Sharpe, Chair, CPA Association

Bill Sheldrake, Carer and Chair, East Kent Mental Health Carers' Forum

Marisa Silverman, Consultant Psychiatrist (old age)

Susan St Clair, Carer (Alzheimer's Society)

Virtual network members commenting on final report:

William Bingley, Professor, Mental Health Law and Ethics, University of Central Lancashire

Geoff Lindsay, Rethink Involvement Officer

Janey Antoniou, independent mental health trainer and writer

Assistance in German – English translation: Jens Schulte

Appendix 2 Summary history of carer policy and legislation

Policy/legislation	Summary of significant points
Nearest relative – Mental Health Act 1983	Prioritises carer relative; discretionary powers (civil sections): - to request an assessment of patient for hospital admission – to which social services must respond. ASW must give written reasons if admission is not made - to make the application to detain the patient (if doctors agree) - to object to a treatment or guardianship order - to seek to discharge the patient Rights to information about detention Rights to attend tribunal
NHS & Community Care Act 1990	Introduces term carer Promotes carer involvement in patient care
Care Programme Approach (CPA) and carer policy – Department of Health 1990/95/99	Promotes carer involvement in CPA (Department of Health 1990; 1999c) Introduction of framework to support development of confidentiality policies available to carers and service users (Department of Health, 1995)
Carers (Services & Recognition) Act 1995	Defines carer: person who provides substantial care on a regular basis (excludes employment and voluntary body arrangements). Introduces carer's right to ask the local authority (social services) for an assessment of own needs. Guidance urges local authorities to inform carers about the carer's assessment (SSI, 1996)
NSF for Mental Health Standard 6, 1999	Provides the carer of someone on CPA with: - an annual (at least) assessment of caring physical and mental health needs - his/her written care plan
Caring about Carers 1999b	Injection of funding to local authorities to provide carer respite services.
Carers & Disabled Children's Act 2000	Empowers local authorities to provide: - carer services - short-term break voucher schemes - direct payments to carers - local authorities can charge carers for services received

Proposed legislation

Draft Mental Health Bill (2002b) and explanatory notes, clause 8 (2002c)	Abolishes nearest relative; replaces with two roles- nominated person (NP) and carer that can be vested in one or two people: NP: appointed by patient with approval of approved mental health professional: Can appeal to tribunal on patient's behalf; rights to be consulted about care plans and discharge. Carer: Right to make a request for an assessment for the patient's hospital admission (no comparable local authority duties associated with nearest relative). Rights to be consulted about care plans and discharge Professionals have discretion to exclude carers where consultation is inappropriate or counterproductive
Carers (Equal Opportunities) Bill	Local authority (social services) duties: - to ensure carers know about their rights - to promote strategies to help carers across local authority services Directions will promote local authority and health co-operation to help carers
Mental Capacity Bill	Enables people to appoint a lasting power of attorney (LPA) in advance of incapacity to make health and welfare decisions – thus in some cases carers may be appointed.

Appendix 3 National survey: carers' version

Part 1: About you

The following questions ask you to tell us about yourself. All the information will be treated in confidence.

1.1 Are you: ☐ male ☐ female

1.2 Are you: ☐ Under 18 ☐ 18 – 30 ☐ 1 – 45 ☐ – 60 ☐ +

1.3 Please describe your ethnic origin. If you don't feel that any of the options are appropriate, please tick other and describe in your own words.

☐ White (British, Irish, Other)
☐ Black or Black British (Caribbean, African, Other)
☐ Asian or British Asian (Indian, Pakistani, Bangladeshi, Other)
☐ Mixed (White & Black Caribbean/Black African/Asian)
☐ Chinese
☐ Any other ethnic group (Please specify) ______________________

1.4 The first part of your postcode is: ☐☐☐☐ e.g. LG21, SE1

Part 2: About your role as a mental health carer

2.1 How long have you been a carer? ______ years

2.2 Do you provide care/support to more than one person? Yes ☐ No ☐

For the rest of this section please answer the questions thinking about <u>one</u> person to whom you provide the most support.

2.3 To whom do you provide the most support? (*Tick one only*)

☐ My Son
☐ My Daughter
☐ My Mother
☐ My Father

☐ My Husband
☐ My Wife
☐ My Partner
☐ ther (Please specify)

☐ ther family member
☐ y Friend
☐ y Neighbour ______________

2.4 Are you their <u>main</u> carer? ☐ Yes ☐ No

2.5 What are their current diagnoses? (*Tick all that apply*)

☐ Dementia, Alzheimer's
☐ Clinical Depression
☐ Eating Disorder
☐ Personality Disorder (e.g. Borderline, Paranoid)
☐ Psychosis (e.g. Schizophrenia, Schizoaffective Disorder, Bipolar/Manic Depression)
☐ Anxiety related disorders (e.g. Obsessive Compulsive Disorder, Phobias)
☐ Dual Diagnosis (a mental health problem in conjunction with a substance misuse)
☐ Other (Please specify) ______________________________

☐ Don't know
☐ No diagnosis has been given

2.6 Would you say you have a reasonable understanding of your friend/relative's diagnosis?

☐ Yes ☐ o

2.7 Do they live with you? ☐ Yes ☐ o

2.8 If they do not live with you, on average does it take more than 1 ½ hours to reach him/her?

☐ Yes ☐ o

2.9 Currently, how often are you in contact with the person or people you care for?

	All the time “24/7”	Daily	At least once a week	At least once a month	Less often
A) By telephone	☐	☐	☐	☐	☐
B) Face to face	☐	☐	☐	☐	☐

2.10 We have created different versions of the questionnaire and we are interested to know whether any other roles are also relevant to you. Do you have experience as a:

Mental health service user	☐ Yes	☐ o
Carer Support Worker	☐ es	☐
Mental health professional	☐ Yes	☐ No

Part 3: Information sharing

We are aware that some carers will provide support to more than one person. In this section we are interested in ALL your experiences of providing care for people with mental health problems.

3.1 The government is committed to supporting carers. They say carers should expect that mental health staff will encourage service users to allow their carer to be involved and consulted unless they have clearly expressed an objection. Were you aware of this?

☐ Yes ☐ o

3.2 Do you currently have sufficient general information (leaflets, rights advise, tips on how to cope, etc) to support you in your caring role?

☐ Yes ☐ o

3.3 Where do you get most of your general information from: (*Tick all that apply*)

☐ Haven’t received any
☐ Service users
☐ Other carers
☐ Psychiatrist
☐ Psychologist
☐ Social worker
☐ Carer support worker
☐ Psychiatric nurse
☐ Occupational therapist
☐ Care coordinator (key worker)
☐ Educationalists (e.g. teachers, school welfare)

☐ Carer training course
☐ Carers’ centre
☐ Carer support group
☐ NHS Direct
☐ GP surgery
☐ Libraries
☐ Helplines/Advice lines
☐ Websites
☐ Voluntary organisation (e.g. Alzheimer’s Society, Carers UK, Rethink)

Other (Please specify) ____

3.4 Is this information available in the language of your choice?

☐ Yes ☐ o

3.5 Are interpreters made available to you?

☐ Always ☐ Sometimes ☐ Never ☐ t applicable

3.6 Do you have the opportunity to discuss the information you have come across (from any source) with mental health professionals?

☐ Yes ☐ No

3.7 Do you **feel** you need any **personal (confidential)** information about your friend/relative to enable you to provide care?

☐ Yes ☐ No

If Yes – what **personal (confidential)** do you need? (*Tick all that apply*)

☐ The type of problem(s) my friend/relative suffers from (diagnosis/es)
☐ The likely progress of their mental health problem
☐ How their mental health problems will affect me
☐ Access to their medical notes
☐ What medication they are taking
☐ What treatments they are currently receiving
☐ Possible future treatment options for them
☐ What their Care Plan says
☐ Who to contact in a crisis for my friend/relative
☐ Who to contact for everyday help and support
☐ Early warning signs of possible relapse
☐ Risks associated with my friend/relative's mental health problems
☐ Content of risk assessments (from health/social/voluntary services)
☐ Information for benefit claims (housing, income, disability)
☐ How to attend to my friend/relative's personal affairs (e.g. finances)
☐ Other (Please specify) ____________________________

3.8 What do you think are the main problems with information sharing (general and/or personal) between professionals and carers?

____

____

____

____

____

____

3.9 Is it difficult to get the **personal (confidential)** information you need to support the person(s) you care for in the following situations?
(For each situation please tick the one response that applies to you)

	Not relevant to me	Always difficult	Sometimes difficult	Never difficult
Getting personal Information……….	☐	☐	☐	☐
During hospital stay……………………….…………….	☐	☐	☐	☐
On discharge from hospital…………………….……….	☐	☐	☐	☐
From residential care home……………..…………..….	☐	☐	☐	☐
From supported housing staff………………………….	☐	☐	☐	☐
From Community Mental Health Team……………..….	☐	☐	☐	☐
From Care Programme Approach reviews ………….	☐	☐	☐	☐
From GP Surgery …………………..…………………….	☐	☐	☐	☐
From Day Centre..…………………………...…..…….	☐	☐	☐	☐
From Home Care Services…………………………..….	☐	☐	☐	☐
From Carer Respite Services……………….………...	☐	☐	☐	☐
From Carer Support Services……………..……...….	☐	☐	☐	☐
From Voluntary Sector Services ………………………	☐	☐	☐	☐
When filling in Welfare Benefit forms..………..…..….	☐	☐	☐	☐
When Social Services are involved……………………..	☐	☐	☐	☐
When the Police are involved…………….….…………	☐	☐	☐	☐
In relation to Mental Health Review Tribunal hearing..	☐	☐	☐	☐
In relation to court hearings…………………….…..……	☐	☐	☐	☐
Other (please specify)…………………….…..……..	☐	☐	☐	☐

____

3.10 If you discuss confidential matters with professionals do you expect them to consult you before sharing it with others?

☐ Yes ☐ No ☐ Don't know

If Yes – Are you consulted?

☐ Always ☐ Sometimes ☐ Never ☐ Don't know

3.11 Are there times when you are reluctant to share information about the person you support/care for with mental health professionals?

☐ Yes ☐ No

If Yes – Why is this?

3.12 In the past 12 months have you been provided with **personal (confidential)** information about the condition, treatment or care of the person you support?

☐ Yes ☐ o

If no **personal (confidential)** information has been shared with you, why was this? *(Tick all that apply*

☐ I have not asked for any
☐ Person cared for did not give consent
☐ Person cared for was unable to give consent
☐ Mental health professionals did not ask person cared for if they would give consent
☐ Reason given 'confidentiality' but with supportive explanation
☐ Reason given 'confidentiality' but without further explanation
☐ Don't know
☐ Other (Please specify) ____________________

3.13 In your experience do mental health professionals ask service users for their consent to give information to carers as part of their routine clinical practice?

☐ Always ☐ Sometimes ☐ Rarely ☐ ver ☐ 't know

3.14 Are you offered separate time with mental health professionals to discuss any of your concerns regarding the person or people you support?

☐ Yes ☐ o

3.15 Do you feel that mental health staff value and respect you for the skills and help you provide to the person you support?

All the time ☐ Most of the time ☐ Some of the time ☐ Rarely ☐ Never ☐ ☐

3.16 Do you feel that mental health staff take your opinions into account?

All the time ☐ Most of the time ☐ Some of the time ☐ Rarely ☐ Never ☐ ☐

3.17 Do you feel that mental health staff are sensitive to cultural issues affecting you and the people you support?

All the time ☐ Most of the time ☐ Some of the time ☐ Rarely ☐ Never ☐ ☐

3.18 Are there any occasions when personal (confidential) information should be shared with you about the person or people you care for without their consent? *(Tick all that apply)*

☐ No ☐ Don't know
☐ Yes - When they are very unwell
☐ Yes - When they have agreed in advance
☐ Yes - If people are worried about their safety
☐ Yes - If there are concerns that they might harm other people
☐ Yes – When the carer and service user live together
☐ Yes – Other (Please Specify) ______________________________

Part 4: Resolution

4.1 Please tell us about:

a) Any problems you have experienced as a result of poor information sharing practices.

____
____
____
____
____
____

b) How you think these problems could be avoided in the future.

____
____
____
____
____
____
____

c) Any positive experiences where problems over information sharing have been resolved or any ideas you have on how current practices could be improved.

____
____
____

4.2 When there are problems with sharing **personal (confidential)** information, which of the approaches listed below do you think would be helpful?
(*Tick all those approaches that you agree with*)

Professionals' actions

- ☐ Professionals explain to service user about their carer's 'need to know'
- ☐ Professionals discuss issue of confidentiality with carer and service user together
- ☐ Professionals share information with carer on a general (hypothetical) basis
- ☐ Professionals help service users to identify some aspects of their information that they feel comfortable sharing
- ☐ Professionals consider the long-term relationship between the service user and carer when deciding whether or not to share information
- ☐ Professional explore alternative ways of sharing information that are acceptable to service user (e.g. sharing with another closely involved person)
- ☐ Professionals discuss the issue with service users and have a record of their wishes (e.g. consent to disclose document)[1]
- ☐ Professionals make clear to carers the rules of professional codes by which they are bound
- ☐ In cases of serious disagreement carers, service users and professionals should be able to consult an officially recognised, independent group of people

Support for carers/service users

- ☐ Service user supported by an advocate
- ☐ Carer supported by Carer Support Worker or an advocate
- ☐ Carer supported through a Carer Assessment[2]
- ☐ Carer supported by a carer support network
- ☐ Carer undergoes carer training

Your actions

- ☐ You seek information/support from another mental health professional
- ☐ You persevere in your contact with professionals
- ☐ You attend care planning meetings

If you would like to add any additional comments on information sharing practices please feel free to do so overleaf

Thank you for taking the time to fill in this survey.

---

[1] Consent to disclose form: a form signed by a service user saying he/she agrees (or does not agree) to relevant personal information being shared with identified services or people. These will be correctly numbered in final document

[2] Carer Assessment: Carer's legal right to have an assessment of their own needs to help them to provide care.

Appendix 4 Partnership organisations involved in the study

Afiya Trust

Age Concern

Alzheimer's Society

British Association of Social Workers (BASW)

Carers UK

Derbyshire Mental Health Services NHS Trust

Eating Disorders Association

Mental Health Aftercare Association (MACA)

Mental Health Alliance

Mind

Partners in Care

Princess Royal Trust for Carers

Rethink severe mental illness

Royal College of Psychiatrists

Royal College of Nurses

Social Perspectives Network (SPN)

South London and Maudsley NHS Trust

West Sussex Health and Social Care NHS Trust

Voices Forum

National Black carers and carer worker network

Appendix 5 In-depth interview schedule

Thank you for agreeing to be interviewed for this study. As explained on the information sheet we are carrying out this research to identify factors influencing **good practice** for information sharing in mental health with a particular focus on mental health professionals sharing information with carers. We anticipate that the interview will take about 45 minutes. If at any time there is a question you don't want to answer or if you would like a break please just let me know.

1. What is your involvement in mental health?

Probes: Which roles? How long? Current involvement?

I'd like to hear about your views on confidentiality and information sharing practices.

2. Can you give me an example of how confidentiality and information sharing practices have affected your role(s) as a ________________?

Emphasis: Relationship between professionals and carers

In particular, we are looking for examples of why things work well in practice.

3. In your experience, do you have any examples of where information sharing has worked well?

If yes – could describe what happened to provide you with these positive experiences?

4. What do you think are the important issues in information-sharing for you as a .. ?

Probe: How people relate to one another – are organic relationships between parties more important than procedures?

5. What are the important issues for (deselect role of interviewee) carers, service users and professionals?

6. What do you think would make information sharing work better in practice?

7. How could these ideas be into practice?

Thank you for taking the time to share your views with us.

Appendix 6 Case vignettes used in workshops

Case vignette 1

Mrs Silvia Georgio has dementia and attends a day respite centre two days a month. Her husband Carlos 79, is her main carer and is starting to find being on hand to look after his wife night and day very stressful. Silvia was diagnosed with dementia five years ago and Carlos has struggled to understand the illness and what he should be doing for his wife.

A few weeks ago their son was staying when the social worker visited. Carlos was surprised by the way the social worker talked with their son and answered his questions. Carlos learnt more that day than in his entire five years supporting Silvia. He now wants to find out more but without his son being present. This is because their son visits very infrequently and has a poor relationship with them. Carlos also fears that his son is more worried about his inheritance than their health and happiness.

Case vignette 2

Shaun is 23 years old. He has only a week or so ago been admitted to hospital for the second time under section and currently has a diagnosis of schizophrenia. Previously he was living at home with his parents, Carol and Bob, and his sister Erica who is studying for her A-levels. In the past Shaun has always consented to his parents being involved in his care and discussions with professionals, though information has never been easy to obtain. Shaun has said this time he doesn't want to return home to his parents and he doesn't want them involved. He blames them for his illness, for the break up of a relationship with a girlfriend three years ago and for having to leave university.

Carol and Bob are extremely anxious and worried. They don't know what treatments he is receiving and how plans for his discharge are being made – will he come home or not – although they were very much involved when he was sectioned. They don't feel he could cope living alone, but are also aware of the stress placed on their daughter (particularly when Shaun is unwell and can be aggressive) so they are unsure what is best for Shaun, and the family. They also want mental health professionals to look at both his psychosis and his cannabis use but don't feel that the psychiatrist is listening to their concerns.

They have asked to meet with the ward staff to discuss these issues but no one seems willing to meet them. When they visit the ward none of the staff tell them anything useful.

Case vignette 3

Sonia Singh provides support to her mother-in-law (Bravin) who has depression and has lived with Sonia and her husband all their married life. The depression has only been treated through a GP – the family doctor, and referral to a psychiatrist seen in outpatient appointments, for the past two years. Before this time the family dealt with the issues.

Sonia has three young children, helps her husband run a local business and provides all the day-to-day care for Bravin. However, it is her husband who meets the psychiatrist and the GP in the surgery. Her husband doesn't talk to her about the meetings with the psychiatrist, and Sonia is finding it really hard to cope with no information about Bravin's condition, medication and future. The husband does not think there is any need for Sonia to be included in his discussions about his mother's condition with medical professionals. Bravin seems to cope by expecting Sonia to provide her support.

Both the GP – who knows the whole family and the psychiatrist are aware that Sonia provides most care and support. The GP also knows Sonia is finding it very difficult to manage all her responsibilities.

Case vignette 4

Brenda Black has been providing practical and emotional support to her son Simon who has had a diagnosis of schizophrenia for 20 years. He lived at home until three years ago, but he is currently in supported accommodation and is thriving with this level of independence. Brenda lives 5 miles away and visits about 3 times a week. Brenda is an active member of the local carers' group and has always been included by professionals in planning Simon's care because she is assertive and has had to fight for Simon to get a range of different treatments over the years. Brenda is really pleased that Simon is becoming more independent and has made friends with other residents in the project. He also attends a local resource centre.

Simon told the manager of the project he was uncomfortable with his mother remaining so involved with his care plan and meetings with the psychiatrist, though he didn't want to hurt her feelings. So, Simon and the manager spoke to his CPN about this and it was agreed that they would talk about Brenda's role in the forthcoming care plan review meeting.

Brenda has always made it clear to those involved in Simon's care that she wants to remain very much involved for his benefit. However, in the recent care planning meeting her involvement was discussed and Simon said he didn't want her to come to meetings in the future. Brenda is very upset with the care team and is worried about how she will support Simon in the future.

Case vignette 5

Angela, aged 21, who has anorexia left hospital and went home with her mother (Belinda) without a diet plan. Angela lives at home with her mother and younger brother aged 14. It was the first time that Angela had been in hospital and Belinda wasn't aware of what questions she should be asking of the staff both during her daughter's stay and on discharge. She feels overwhelmed with the severity of Angela's illness and the impact that this is having on her own mental health and relationship with her son.

At the weekend, Angela and her mother went to the supermarket to buy food for the family. Angela wanted to buy low calorie food. Belinda felt that she needed to encourage Angela to eat wholesome food but was aware that managing this was going to be hard. Angela told her mum that she was allowed low-calorie food because that was best for her and reassured her that this is what the ward staff had said. Belinda abided by her daughter's wishes but was unhappy with this decision. When they were got to the checkout Belinda raised the issue again and the situation became very awkward. When they got home a huge argument developed.

Case vignette 6

Robert has had a diagnosis of schizophrenia for a number of years. He attends a local day centre, art group and employment project as well as his psychiatric outpatient appointments. Until very recently he lived with his mother. Although he was living very happily at home partly as a result of his mother's efforts and with his agreement he has recently moved into separate accommodation. With Robert's agreement his mother attends all the care planning meetings. His mother is always updating an agreement signed by Robert because she realises this is important to the care team.

At the most recent care planning meeting attended by Robert, his mother and eight members of the care team, Robert's mother was asked to leave the room before the meeting had ended. Robert's mother did not want to go and Robert wanted her to stay.

Case vignette 7

Olivia is a 25 year-old woman who has Bipolar Disorder. She lives with her mother, Linda. Olivia father sexually abused her a young girl, and neither she nor her mother currently has contact with him. When the abuse came to light there was an issue over whether or nor Linda colluded in the abuse.

Olivia is currently finding it difficult to stay on her medication due to the side effects and is receiving outpatient psychotherapy. She is also exploring alternative combinations of medication with her Psychiatrist and her CPN. A number of issues have come to light in the psychotherapy sessions; during manic episodes Linda locks Olivia in her bedroom and has forcibly removed her money and case cards. On each of these occasions Olivia has struggled getting them.

Olivia does not her mother to know that she has discussed these events with her psychotherapists she is very comfortable with her mother being involved in her mental health care.

Consider the types of situations that might be behind the care team's position.

Questions relating to all six case vignettes:

1. What are the main issues to consider here with regard to effective information sharing?

2. How can this situation be 'resolved'?

3. What would be good information sharing practice between professionals and carers in this situation?

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Addendum

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Addendum:

This report was amended on 13th February 2012 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.