



**NATIONAL MENTAL HEALTH
CONSUMER & CARER FORUM**

**Privacy and Confidentiality
Issues Paper**

2009

Acknowledgements

The NMHCCF Privacy and Confidentiality Working Group commissioned the development of this issues paper to outline key stakeholders' views about privacy and confidentiality

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1. Executive Summary

The National Mental Health Consumer and Carer Forum (NMHCCF) has identified privacy and confidentiality as a matter of great concern for mental health consumers and carers. Following the results of their survey entitled “Confidentiality and Information Sharing with Families and Carers in Mental Health”, the NMHCCF commissioned an issues paper to examine the difficulties surrounding this topic in the Australian mental health system and identify examples of best practice and some potential solutions and ways forward. The NMHCCF funded the Psychosocial Research Centre, the Victorian Mental Illness Awareness Council, and the Victorian Mental Health Carers Network to produce this issues paper. Responses to this paper will be used to establish a NMHCCF position statement to support the sector in improving its approach to the issues.

Privacy and confidentiality have an extensive impact on the relationships between consumers, carers and clinicians. Difficulties arise between these groups when they have different opinions and understandings regarding the information about a consumer’s wellbeing that can, or should, be shared with carers. There is the need for a balance between the consumer’s rights to privacy, and the carer’s need for information in order to provide sufficient support which can be crucial to the ongoing wellbeing of both consumer and carer. Further, in a situation where a consumer has not consented to information sharing with their carer, or does not have the capacity to decide, clinicians must make a complex and difficult judgment about what information needs to be shared. The resulting confusion may lead to a failure to appropriately share information.

This paper will offer insight into the perspectives of consumers, carers and clinicians with regard to privacy and confidentiality in the Australian mental health system, and will also offer examples of best practice from around the world for addressing related issues. In preparation for the paper, scholarly literature was reviewed alongside a survey of the existing 'grey literature'¹. In addition, documentation on policy and legislation, practical guidelines and strategies for best practice were collated, and interviews with selected key stakeholders were conducted. Overall, 17 organisations and 16 individuals were consulted (via direct contact, websites, newsletters, position papers) for information on the topic, including professional, consumer and carer representatives, community and legal organisations, as well as other national and international contacts of the researchers.

A review of confidentiality and information-sharing in policy and law indicated that mental health law and policy around confidentiality and information sharing is extremely complex which can lead to Misunderstanding amongst consumers, carers and professionals about the way the law works. In addition, it is enormously difficult to legislate for the confidentiality and information needs of each person, given the unique nature of each care context. It is also important to note that the way details of legislation are disseminated and implemented is of far greater importance, than the differences between legislations. Moreover, legislation is limited in the extent to which it can remedy the difficulties faced by consumers, carers and professionals. It may be more practical to concentrate on ethics training and practical guidance for health professionals to ensure

¹ Grey literature refers to information that has not been commercially published, such as reports, research papers, working papers, and guidelines produced by a broad range of organisations

reasonable decision-making, than to expect the law to direct behaviour in relation to the disclosure of confidential information.

The literature and interviews on consumer perspective highlight the importance of recognising that the privacy of consumers is a basic human right. In addition, consumers are not necessarily unwilling to share information. However, they believe that private information should only be shared with their consent. Information-sharing that occurs without consent can lead to the deterioration of important therapeutic and other relationships. Moreover, consumers should be allowed greater ownership of their information and participation in their own care and treatment.

When considering the literature and interviews on the family / carer perspective, it is clear that many mental health service providers often see family as being of little importance (or worse, an impediment) in consumer recovery and consequently exclude carers from service planning and provision. It is important that carers are 'kept in the loop' given that they are such a vital part of support structures for consumers and contribute valuable knowledge and experience to assist in the consumer's treatment. Indeed, acknowledging and having an in-depth knowledge of the care context creates a positive therapeutic relationship.

The professional perspective, as indicated by the literature and interviews, reveals that professional ethics guidelines provide little advice to clinicians about information-sharing with carers. Identified barriers to good information-sharing include the consumer withholding consent, concerns about losing the consumer's trust, and fears of legal consequences. It was further suggested by clinician stakeholders that more training on these issues is needed.

In order to promote best practice in information-sharing, there is an identified need for a cultural shift toward the tripartite approach. Several changes can occur at the service level which may help to foster the desired culture (e.g., staff education and support, increased communication about information-sharing between consumers, carers, and clinicians, written agreements about information management). Although legislative change is not essential to achieve good information-sharing practice, consideration of international legislatures may be worthwhile.

2. Introduction

2.1 Preamble

The National Mental Health Consumer and Carer Forum (NMHCCF) has identified privacy and confidentiality as a matter of great concern for mental health consumers and carers. Following the results of their survey entitled “Confidentiality and Information Sharing with Families and Carers in Mental Health”, the NMHCCF commissioned an issues paper to examine the difficulties surrounding this topic in the Australian mental health system and identify examples of best practice and some potential solutions and ways forward. Responses to this paper will be used to establish a NMHCCF position statement to support the sector in improving its approach to the issues.

2.2 The National Mental Health Consumer & Carer Forum

The NMHCCF is an independent national body representing the interests of both mental health consumers and carers in Australia. Through its membership, the NMHCCF gives consumers and carers the opportunity to meet, form partnerships and be involved in the development of mental health policy and the implementation of sector reform. While auspiced by the Mental Health Council of Australia, the NMHCCF was set up in 2002 by the Australian Health Ministers Advisory Council Mental Health Standing Committee and is funded by contributions from each state and territory and the Australian Government.

2.3 Research Partners

A consortium was chosen to develop this issues paper, including researchers, consumers, and carers. The NMHCCF considered the collaborative approach a key strength in appointing these research partners.

Psychosocial Research Centre

This is an established research centre operating within the north west of Melbourne and is a collaboration between the Department of Psychiatry, University of Melbourne and NorthWestern Mental Health. The Centre focuses on psychosocial approaches to prevention, treatment of illness and recovery, which involve consumers and their families, increase community participation and improve economic outcomes for people affected by mental illness. Consistent with the Centre’s Mission, staff aim to engage the perspectives of consumers, carers and advocates in the development of psychosocial policy, practice and research.

Victorian Mental Illness Awareness Council

The Victorian Mental Illness Awareness Council (VMIAC) is Victoria’s peak body in representing consumers of mental health services. The VMIAC is a not-for-profit organisation that aims to provide support, information, education, referrals and advocacy for people who have experienced emotional or mental distress. The Consumer Research and Evaluation Unit of the VMIAC is a consumer-led research team that is committed to

promoting consumer participation in mental health service improvement, and believes that the processes involved in research and evaluation are just as important as the outcomes.

Victorian Mental Health Carers Network

The Victorian Mental Health Carers Network (VMHCN) is Victoria's peak body representing carers, families and friends of people with mental health and related issues. Its Mission is to ensure recognition of the contribution, experiences and needs of carers and families. The VMHCN vision is that carers of people with mental health and related problems will be partners in treatment and service delivery and the lived experience of carers will be a key driver of policy and program formation. Their research arm, the Carers Research and Evaluation Unit, contributes to building the knowledge of mental health with a carer-centred approach. It aims to empower carers to contribute meaningfully to service and policy development and to support their active participation in carer research.

2.4 Background to Privacy & Confidentiality

Privacy and confidentiality are longstanding issues within the mental health sector, and have an extensive impact on the relationships between consumers, carers and clinicians. After deinstitutionalisation these issues have been noted in a growing body of modern literature that describes the difficulty in contemporary mental health systems of balancing consumers' rights to confidentiality and the families' needs to remain informed and involved in a service environment that relies, to a great extent, on individuals and families to maintain their own support structures.

Although privacy and confidentiality are similar terms, and are commonly used interchangeably, the New South Wales Department of Health² offers the following comprehensive definitions for distinction between the terms:

Confidentiality: "an obligation which restricts an agency from using or disclosing any information in a way which is contrary to the interests of the person or organisation which provided it in the first place. It is a mode of managing private information, by the restriction of access to information to authorised persons, entities and processes at authorised times, in an authorised manner."

Privacy: "applies only to personal information and applies irrespective of who provided it to the agency. Privacy is a broader concept than confidentiality and relates to an individual's ability to control the extent to which their personal information, enabling identification, is available to others."

Privacy and confidentiality are enforced by legislation and underpinned by professional codes of conduct to protect health information from unauthorised disclosure. However,

² New South Wales Department of Health (2005). *Privacy management plan – NSW Health* [Policy directive circular]. Sydney, NSW: Legal and legislative services, Department of Health, NSW.

the legislation and codes also provide exceptions which allow the disclosure of mental health information under certain circumstances. These exceptions are a source of much underlying tension and confusion between consumers, carers and clinicians. For the purposes of this paper, these stakeholders are referred to in the following manner:

- Consumers:* People who use, have used, or are eligible to use, mental health services.³
- Carers:* People who provide practical and emotional support to a consumer including relatives, friends or partners. They provide care and support in a non-professional capacity, are mostly unpaid (though not necessarily), and they may or may not live with the person they support.
- Clinicians:* People who work in the field of mental health, including psychiatrists, psychologists, social workers, psychiatric nurses, occupational therapists, case managers, and GPs. Also referred to as professionals.

Difficulties arise between these groups when they have different opinions and understandings regarding the information about a consumer's wellbeing that can, or should, be shared with carers. There is the need for a balance between the consumer's rights to privacy, and the carer's need for information in order to provide sufficient support which can be crucial to the ongoing wellbeing of both consumer and carer. In a situation where a consumer has not consented to information sharing with their carer, or does not have the capacity to decide, clinicians ultimately make the decision about whether information should be shared or should remain private. This can be a complex and difficult judgment, and confusion often arises around the limits and exceptions of the confidentiality and privacy obligations. As a result, "confidentiality" is often inaccurately cited by clinicians as a reason for failing to share information with carers, and has many carers asking for a broadening of the circumstances in which information can legally be disclosed.

2.5 Rationale

Privacy and confidentiality are contentious issues for consumers, carers, and clinicians within the Australian mental health system. It would be beneficial to elucidate these three primary perspectives on privacy and confidentiality, in order to stimulate informed discussion on the topic and to generate some helpful solutions.

2.6 Aims

To examine the issues surrounding privacy and confidentiality in the Australian mental health system from the perspectives of consumers, carers and clinicians. Ultimately, the paper will be used to elicit comment from consumers, carers, clinicians, Mental Health

³ Beresford, P. (2007). User involvement, research and health inequalities: Developing new directions. *Health and Social Care in the Community*, 15, 306-312.

Departments and other interested parties across Australia, leading toward the development of an NMHCCF position paper on privacy and confidentiality.

2.7 Outline of the Paper

This paper will offer insight into the perspectives of consumers, carers and clinicians with regard to privacy and confidentiality in the Australian mental health system, and will also offer examples of best practice from around the world for addressing related issues. Each section of the paper begins with a summary of key points.

In preparation for the paper, scholarly literature was reviewed alongside a survey of the existing 'grey literature'. Documentation on policy and legislation, practical guidelines and strategies for best practice were collated, and interviews with selected key stakeholders were conducted to gain as thorough an understanding of the issues surrounding privacy and confidentiality as possible within the scope of the project (for a list of interview questions that the key stakeholders were asked, see Appendix B. For a summary of key issues identified through stakeholder interviews, see Appendix C). Overall, 17 organisations and 16 individuals were consulted (via direct contact, websites, newsletters, position papers) for information on the topic, including professional, consumer and carer representatives, community and legal organisations, as well as other national and international contacts of the researchers.

2.8 Guiding Principles

Below we describe the core principles that have guided the development of this paper.

Consumers' Right to Privacy – The privacy of consumers is a human right and must be upheld to the fullest extent possible, for the purposes of their treatment and wellbeing.

Carers Must be Treated with Dignity and Respect – It is essential that the views and needs of carers be taken into account when decisions are made that impact on them and in their role as care-providers.

Respect for Autonomy - It is necessary to acknowledge that the Australian mental health system is based in a Western society which values individual rights to autonomy and privacy (in contrast with other cultures in which the family is the unit of society, and individual needs and desires are secondary to those of the family).

Tripartite Relationship – In our view, the ideal culture of a mental health system involves consumers, carers and clinicians working in partnership toward positive outcomes for consumers.

Scope of the Paper – It should be noted that this paper is not intended to provide a comprehensive review of legislation across jurisdictions. Rather, the purpose is to elucidate the issues surrounding privacy and confidentiality in mental health.

3. Confidentiality and Information Sharing in Policy and Law

Key Points:

- It is enormously difficult to legislate for the confidentiality and information needs of each person, given the unique nature of each care context. As the New Zealand Mental Health Commissioner commented, "...it is difficult to legislate for good judgment".⁴
- Mental health law and policy around confidentiality and information sharing is extremely complex. There is great misunderstanding amongst consumers, carers and professionals about the way the law works.
- It seems unlikely that differences between state and territory mental health legislation greatly impact on how confidentiality and information-sharing are *practised* across each state and territory. How the details of legislation are disseminated and implemented is of far greater importance.
- Legislation is limited in the extent to which it can remedy the difficulties faced by consumers, carers and professionals.
- It may be more practical to concentrate on ethics training and practical guidance for health professionals to ensure reasonable decision-making, than to expect the law to direct behaviour in relation to the disclosure of confidential information.⁵

3.1. Introduction

Issues of confidentiality and information-sharing in mental health services are governed by a complex combination of law, policy and professional codes. These rules must account for the balance between ensuring consumers' right to privacy and confidentiality, while taking seriously the needs of carers to be informed and involved – and overall, for both parties to be treated with dignity and respect. Not surprisingly there is a clear tension between consumers' right to privacy and the provision of information to family / carers. The great challenge in developing policy is to create a framework that accommodates the enormous variation in each person's circumstances and the particular context of their own family and community dynamic and yet provides clear

⁴ Mental Health Commission (2002). *Review of the implementation of the Privacy Act 1993 and the Health Information Privacy Code 1994 by district health boards' mental health services* [report]. Wellington, New Zealand: The Mental Health Commission (p. 49).

⁵ McSherry, B. (2008). Health professional-patient confidentiality: Does the law really matter? *Journal of Law and Medicine*, 15, 489-493.

guidance to all parties about how to best manage confidentiality and information sharing day-to-day.

This section will begin by outlining the major issues drawn from the national and international literature. It will then look at how international legal instruments inform Australian legislation (in particular the UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care 1991 [Mental Illness Principles]) and the more recent UN Convention on the Rights of Persons with Disability 2007 (UN CRPD), before looking to other international policies that address the issue. The third subsection will turn to Australian policy and legislation, with a brief look at confidentiality laws in two national jurisdictions, Victoria and the Northern Territory as examples of differing approaches. The final part of the section will consider the limited impact of legislation on day-to-day clinical practice, questioning just how effective the law is in promoting good practice in confidentiality and information sharing.

3.2. Literature Review

There are a number of particularly influential articles in modern literature that have expanded on decades of scholarly research.⁶ For the purposes of this report we are relying almost entirely on literature from the last two decades. The literature and policy review focuses particularly on Australia but also covers the UK, Europe, the USA, and New Zealand.

It is important to note that legal rights to confidentiality are not absolute,⁷ with numerous exceptions across Australian jurisdictions allowing disclosure in certain circumstances.⁸ Such exceptions are covered in various legislations (not simply mental health) in laws as diverse as child protection law, tort law and insurance law. A key finding was that the complex legal tapestry poses great difficulties for all parties (consumer, carer, clinician), which in turn leads to great misunderstanding in both identifying relevant laws and interpreting them.

The efficacy of the law in ensuring good *practice* in confidentiality and information sharing appears to be limited. There is an emerging international consensus in both scholarly and grey literature identifying that legislation largely fails to deal with the practical dilemmas of consumer confidentiality.⁹

⁶ See Leggatt, M., & Furlong, M. (1996). Reconciling the patient's right to confidentiality and the family's need to know. *Australian New Zealand Journal of Psychiatry*, 30(5), 614-22; Szmukler, G. I., & Bloch, S. (1997). Family involvement in the care of people with psychoses: An ethical argument. *British Journal of Psychiatry*, 171, 401-405.

⁷ McSherry, B. 2008, op. cit; McSherry, B., Kämpf, A., Thomas, S., & Abrahams, H. (2008). Psychologists' perceptions of legal and ethical requirements for breaching confidentiality. *Australian Psychologist*, 43(3), 194-204; Slade, M., Pinfold, V., Rapaport, J., Bellringer, S., Banerjee, S., Kuipers, E., & Huxley, P. (2007). Best practice when service users do not consent to sharing information with carers. *British Journal of Psychiatry*, 190, 148-155.

⁸ Clark, K., & North, A. (2007). Legality of disclosure by Victorian psychiatrists of patient information to carers. *Psychiatry, Psychology and Law*, 14, 147-167.

⁹ Gray, B., Robinson, C., Seddon, D., & Roberts, A. (2008). 'Confidentiality smokescreens' and carers for people with mental health problems: The perspectives of professionals. *Health and Social Care in the Community*, 16(4), 378-387.

Australian legislation differs between states and territories and between the private and public sector. However, in general, it was found that for professionals, ethical frameworks are of far greater significance in decision-making than legal requirements, which are of secondary or little importance.¹⁰ This is partly explained by the extremely complex nature of privacy and confidentiality laws relevant to mental health service provision as well as (largely unfounded) fear of litigation if confidentiality is breached. Further, it was found that families / carers are almost entirely excluded from mental health legislation; a central issue given the increasing legal and policy mandate for family participation in supporting mental health consumers.¹¹

3.3. International Framework

3.3.1. Mental Illness Principles and the UN Convention on the Rights of Persons with Disabilities

An important international instrument used to protect the rights of persons with mental health issues is the UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991), known as the Mental Illness Principles. Certainly in Australia, the Mental Illness Principles were used to inform the privacy section of Australia's *National Standards for Mental Health Services (1997)*.¹² Principle 6 of the Mental Illness Principles expressly states that '[t]he right of confidentiality of information concerning all persons to whom these principles apply shall be respected.'

More recently, the United Nations have created a Convention on the Rights of Persons with Disabilities (UN CRPD), signed by Australia in 2007 and put in force in 2008. The Convention explicitly states that "State Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others" (UN CRPD, Article 22, Section 2). Many cite the CRPD as having been developed more fully in partnership with mental health service user-groups and other people with disabilities, marking a paradigm shift away from a social welfare response to disability, to a rights-based approach.¹³ Importantly, this shift is also seen as a move away from substituted decision-making to a supported decision-making framework¹⁴. The UN CRPD now supersedes the Mental Illness Principles to the extent that there is conflict between the two instruments¹⁵. The CRPD arguably require the Australian state and federal governments to implement legally enforceable directives.

¹⁰ McSherry, B. (2008), op. cit.

¹¹ Leggatt, M., Parker, R., & Crowe, J. (In press). Public interest and private concern: The role of family carers for people suffering mental illness in the twenty first century, 1-7.; Lesser, J. (2004). All care and whose responsibility. *Psychiatry, Psychology and Law*, 11(2), 236-243. (p. 238)

¹² Department of Health and Ageing (1997). Australia's *National Standards for Mental Health Services*. Commonwealth of Australia.

¹³ Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, 8(1), 1-34.

¹⁴ Lawson, A. (2007). The United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn? *Syracuse Journal of International Law and Commerce*, 34 (2), 563-597.

¹⁵ Kayess & French 2008, op. cit.

3.3.2. New Zealand

Unlike in Australia, The Mental Health Act in New Zealand requires mandatory consultation with the 'family, *whānau*'¹⁶ of a person detained under the Act¹⁷ unless it can be shown that such consultation is not in the person's best interest. New Zealand legislation starts from the premise that family/ *whānau* are naturally involved in the responses to and treatment planning with consumers in crisis. This legislative change was initiated in part by a statement by the country's Privacy Commissioner who expressed frustration at the refusal of some hospitals to adopt sensible policies on sharing information about consumers with their carers.¹⁸ The New Zealand Mental Ministry of Health responded with detailed guidance which supports close co-operation with families and sharing information, planning, decision-making, and providing support and education when necessary¹⁹. The policies uphold consumer consent; however the New Zealand Privacy Act 1993 and Health Information Privacy Code 1994 do not prevent most aspects of working with families. There are strict provisions to protect consumer confidentiality where the involvement of family could pose a serious health risk to the consumer.

3.3.3. UK Carers' Legislation

The UK has a legislation and policy framework specifically for carers: the UK Carers [Recognition and Services] Act of 1995, the Carers [Equal Opportunities] Act 2004. The legislation is designed to acknowledge carer needs and entitle them to assessment and services in their own right. Nevertheless, the legislation prioritises service user autonomy and the right to be consulted about information sharing with carers.²⁰ This has led to a suggestion to differentiate between personal-sensitive information and general information around potential issues of patient privacy and information to be shared with carers (for more on this point, see Section 5). This is a key recommendation made by a number of authors as a means to solving the dilemmas caused by poor information sharing.

The UK Carers Act 2004 requires local authorities to notify carers of their right to a carer's assessment. The efficacy of the legislation is questionable, however, with one study showing that only one in five carers are offered the assessment in practice.²¹

¹⁶ The term 'whānau' is defined by the National Mental Health Standard as follows: 'The term "family, whānau" includes the extended family, partner, friends or others nominated by the person who receives the service. This term also includes "carers" as identified by the person receiving the service.' NZS 8143:2001, p. 9.

¹⁷ Spencer, G. & Skipworth, J. (2007) Forcing family involvement in patient care: Legislation and clinical issues. *Australasian Psychiatry*, 15(5), 397-401.

¹⁸ Private Mental Health Consumer Carer Network (2008). *Identifying the carer project: Final report and recommendations for the Commonwealth Department of Health and Ageing*, Department of Health and Ageing. Retrieved September 16, 2009 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-i-carer>

¹⁹ Ibid, section 4.5.

²⁰ Rapaport, J., Bellringer, S., Pinfold, V., & Huxley, P. (2006). Carers and confidentiality in mental health care: Considering the role of the carer's assessment: A study of service users', carers' and practitioners' views. *Health and Social Care in the Community*, 14(4), 357-365.

²¹ Ibid.

There are a number of reasons for this, including resource constraints, poor publicity by service providers, conceptual ambiguities about the carer role, and difficulties assessing positive outcomes for carers²². This raises the important point of the need to ensure compliance with legislation. Nevertheless, the carers policy framework in the UK reflects a concerted legislative effort to more fully support the needs of carers to maintain their own health, social inclusion, citizenship participation, and their ability to support the service user. A similar policy framework has been established in the Northern Territory (see Section 3.4.3).

3.3.4. Scottish Mental Health Act

Scotland's Mental Health (Care & Treatment) (Scotland) Act 2003 has rights to involvement and information for carers. The legislation includes directions on the use of Advance Statements (known in Australia as Advance Directives) as well as 'Named Person', which is defined as "someone who will look after the person's interests if he or she has to be treated under the Act".²³ It is compulsory under Scottish law to define a Named Person when a consumer first contacts mental health services. For further information see Section 7 or for a Pro-forma see <http://www.scotland.gov.uk/Publications/2004/10/20016/44075>.

3.4. Australian Policy and Legislation

The basis for national policy on privacy and confidentiality in mental health services is covered by standard 5: Privacy and Confidentiality within the *National Standards for Mental Health Services 1997*. Section 5.1 ensures that "staff of the Mental Health Services comply with relevant legislation, regulations and instruments in relation to the privacy and confidentiality of consumers and carers"²⁴. This standard was informed by The UN Principles on the Protection of People with a Mental Illness (1991), as well as a wide range of Australian documents protecting the rights of consumers. These include: the Australian Health Ministers Mental Health Statement on Rights and Responsibilities 1991/2000, Freedom of Information Act 1982, privacy legislation, departmental guidelines, professional codes of conduct, Registration Acts, and Australian Standards for Medical Records.²⁵

While the above laws and regulations constitute a general framework, different laws will apply to different consumers depending on the setting in which they are seen. State and Territory Mental Health Acts apply to inpatient and outpatient services as well as to community mental health services and registered community support services. They also apply when a person is in any hospital which is licensed for the use of electro convulsive therapy (ECT), that is, most private psychiatric hospitals.²⁶ The wider range

²² Ibid.

²³ The Scottish Government, <http://www.scotland.gov.uk/Publications/2004/10/20017/44081> (2004), retrieved 16 September 2009.

²⁴ Department of Health and Ageing. (1997). *National Standards for Mental Health Services 1997*. Commonwealth of Australia.

²⁵ McSherry, B. (2006). Confidentiality in therapeutic relationships: the need to develop comprehensive guidelines for mental health professionals. *Psychiatry, Psychology and Law*, 13(1), 124-131.

²⁶ Ibid.

of exemptions to confidentiality in the doctor-patient relationship, or clinician-consumer relationship, are covered across a variety of laws, including contract law, tort law, equitable obligations of confidence, ownership, criminal law, human rights, statutory obligations, and professional disciplinary procedures.²⁷

Australia has no *national* legislation addressing the needs of carers specifically. Nonetheless, the National Mental Health Policy 2008 contains clear goals for greater carer involvement in service provision and development. It states:

Carers require acknowledgement and respect for the role they play. To perform their role effectively, *carers must be able to access relevant information and services, whenever necessary*. Carers also need to be able to access information regarding the treatment, on-going care and rehabilitation of the person for whom they are caring²⁸ (authors' emphasis).

3.4.1. Exceptions to Confidentiality

In certain circumstances, practitioners and clinicians may be legally or ethically required to breach confidentiality on the basis of broader societal interest.²⁹ The most commonly cited example when a professional can lawfully breach confidentiality is if they have reason to believe the consumer is at risk of harming others. This exemption is described in the National Privacy Principles (NPP), which permits disclosure if the clinician 'reasonably believes that the use or disclosure is necessary to lessen or prevent ... a serious or imminent threat to an individual's life, health or safety.'³⁰ However, it is notable that there is no common law precedent or legislative *obligation* to disclose information if a consumer is considered to be dangerous to others' safety, there is only *permission* to do so.³¹ The distinction between permission and obligation is important, as presently no laws impose a legal *duty* to disclose confidential information when a patient is perceived to be "dangerous"³². However, it is notable that the 'danger' exemption is quite limited given its provision is for such an extreme scenario. Focusing too specifically on this type of situation, especially when drafting policy and law, can potentially obfuscate the great majority of day-to-day problems caused by poor confidentiality and information sharing practices.

There are specific guidelines for the private sector in the Commonwealth Privacy Act 1988 and its amended NPP.³³ The NPP is different from the Information Privacy Principles (IPP) – used for the public system – in that it does not provide an obligation to

²⁷ Clark & North (2007), op. cit.

²⁸ Department of Health and Ageing (2009). *National Mental Health Policy 2008*. Commonwealth of Australia.

²⁹ Clark & North, 2007, op. cit.; McSherry, B. 2008, op. cit.

³⁰ Australian Government, Office of the Privacy Commissioner. (2006). "Private Sector Information Sheet 1A – *National Privacy Principles*: the ten National Privacy Principles from Schedule 3 of the *Privacy Act 1988* (Cth) as amended to 14 September 2006.

³¹ McSherry, B. (2008), op. cit.

³² Ibid.

³³ Australian Government, Office of the Privacy Commissioner (2006), op. cit.

share information, simply a non-binding compulsion to disclose information when there is a legal obligation to disclose it.³⁴

3.4.2. The Victorian Mental Health Act 1986 (MHA 1986)

The present Act is the oldest of the state and territory mental health legislation. It is currently under review and recent consultations regarding the Act are relevant to the development of mental health legislation nationwide. Victoria's Department of Human Services (DHS) has recently published a report on community consultations about the review and the government response to the findings.³⁵

The Victorian MHA 1986 covers all approved mental health services, which include most public and private mental health services. Private practitioners, such as private psychiatrists and general practitioners, are not covered by the provision but are covered by the Health Records Act and the Commonwealth Privacy Act 1988. Presently, the Victorian MHA allows service providers to share information about a consumer "if the information is reasonably required for the on-going care of the person" and the "guardian, family or primary carer or family member will be involved in the care"³⁶. This applies regardless of whether the consumer is on an involuntary treatment order, or if they are receiving services on a voluntary basis. It is our observation that there is a widespread misunderstanding of this law amongst clinicians – if they are aware of s120A then they assume it does not apply to 'voluntary' patients. Importantly, the Act *allows* but does not *require* disclosure of the information to family and other carers.

Some advocates have voiced concern about the confidentiality exception of the Act outlined in Section 120A (3)(ca) which permits the giving of information concerning the condition of a person who is receiving psychiatric services if communicated in 'general terms'. This distinction is potentially discriminatory as it does not exist in relation to the parallel section governing confidentiality in general health provision under the Health Services Act 1988.³⁷

It has been argued by family carer representative groups that there is a lack of formal recognition in the Victorian MHA of the important role of carers as vital partners in supporting consumers. In fact, the term 'carer' is not even defined in the Act – a key recommendation by a number of key stakeholders in the 2008 consultations. Lesser claims that as well as disenfranchising people in caring roles "this lack of (formal) recognition also discourages staff at mental health services from bringing carers into the treatment loop".³⁸

³⁴ McSherry, B. (2006), op. cit.

³⁵ Department of Human Services VIC. (2009). *Review of the Mental Health Act 1986 Government response to the Community consultation report*. Melbourne, Vic: Author.

³⁶ Victorian Mental Health Act 1986, Section 120A S: i, ii.

³⁷ Mental Health Legal Centre. (2009). *Review of the Mental Health Act 1986 [submission]*. Melbourne, Vic: Mental Health Legal Centre Inc. (p. 90)

³⁸ Lesser, J. (2004), op. cit.

The Victorian Act does not provide an obligation to inform carers, who are reported to lack information about psychiatric diagnosis, the impact and side-effects of psychopharmaceuticals, treatment options (and alternatives), involuntary status and community treatment orders. The often damaging impact of failure to provide even the most generic information is further discussed in Section 5.3.

3.4.3. Northern Territory Mental Health and Related Services Act

The Northern Territory Mental Health and Related Services Act (2004) was based on “Model Mental Health” principles and emphasises the need for information for carers of the person affected by the Act unless there are particular reasons for the exception of this. Importantly, the Northern Territory has also instituted carer-specific legislation (the Northern Territory of Australia Carers Recognition Act 2006) and an associated Carers Charter. The Charter promotes the acknowledgement of carers in the initial assessment of a consumer as well as in the planning and delivery of services. Furthermore carers’ perspectives must be considered when decisions are made that impact on their caring role. The legislation has led to further government directives to ensure departmental compliance with the Charter.³⁹ The NT Mental Health and Related Services Act also contains specific provision for service provision to persons of Aboriginal or Torres Strait Islander background, which has the potential to accommodate information sharing needs that are culturally specific.

3.5. The Limitations of Law

It appears as if differences in the content between state and territory mental health legislation do not greatly impact on how confidentiality and information sharing is *practised* across each state and territory. A greater barrier to ensuring consistent good practice relates to professionals’ misunderstanding, misuse or disregard of privacy and confidentiality laws.⁴⁰ Research indicates that mental health professionals place more weight on ethical responsibilities to confidentiality than the law requires.⁴¹ (For discussion regarding professional ethics and guidelines, see Section 6.)

The misunderstanding of laws leads to a restrictive interpretation of confidentiality policies among the majority of professionals. That is, the withholding of even the most general information about mental health service provision, let alone information relating to discharge and other information directly relevant to the care-giving role. This trend has been noted internationally, in the US⁴² and in the UK⁴³.

³⁹ Leggatt et al. (in press), op. cit.

⁴⁰ Clark & North (2007), op. cit.; McSherry, B. (2008), op. cit.; Pinfold, V., Rapaport, J., & Bellringer, S. (2007). Developing partnerships with carers through good practice in information-sharing. *The Mental Health Review*, 12(2), 7-14 et al.,

⁴¹ McSherry, B. (2008), op. cit.

⁴² Marshall, B. & Solomon, P. (2000). Releasing information to families of persons with severe mental illness: a survey of NAMI members. *Psychiatric Services*, 51,1006-1011.

⁴³ Pinfold et al. (2007), op. cit.

Relevant legislation is extremely difficult to comprehend, making it difficult for clinicians to be aware of exceptions where information can be shared with carers and others. Bernadette McSherry has found that there are “extraordinary complexities” in understanding the various laws that cover confidentiality in mental health therapeutic relationships.⁴⁴ Professionals are expected to trawl through complex legal tapestries and are given little by way of practical guidelines to ensure good implementation of laws.⁴⁵ One legal professional stakeholder summarised it this way:

Mental health laws are incredibly confusing, and it is difficult to know where to find the information you are looking for (even for a lawyer). As a result, many professionals think they are not allowed to involve carers. [Mental health law professional]

Perhaps because of this, ‘confidentiality’ is sometimes used to avoid the complex ethical, clinical and legal issues facing service providers when handling information about mental health consumers, leading to failure to appropriately involve others. This especially might be the case where professionals are constrained by limited resources – a point highlighted by clinicians in our stakeholder interviews.

The ambiguity and confusion about laws may also contribute to a (largely unfounded) fear of litigation, which forces professionals to, in many cases, simply say nothing.⁴⁶ As one legal professional stakeholder pointed out:

Mental health professionals tend to think that (a famous US case where a clinician was sued for breach of confidentiality) constitutes law in Australia. However Australian laws are not absolute - they enable disclosure at the discretion of professionals, although there is no legal duty. For example, 64% of mental health professionals believe they have a legal duty to disclose if someone is at risk of harm, but they had a lack of confidence in their response to this question. [Mental health law professional]

There is considerable confusion among service providers, carers and consumers about how privacy and confidentiality legislation applies in practice. This also leads to confusion amongst consumer and carer advocates. One stakeholder emphasised the hugely “inadequate understanding of the laws”, stating that:

Legislation is very fragmented, for example there are state and Commonwealth legislations as well as the Health Records Act – each with different policies. Although many carers call for the law to change, it needs to be understood that the (Victorian) Mental Health Act for example, actually has very reasonable exceptions, which allow the clinician discretion. [Mental health lawyer]

Resolving the raft of tricky legal matters is made more difficult as there is no statute (legislative) or common law (judicial) body specifically covering medical confidentiality.⁴⁷ McSherry again has argued, “it may be of more practical relevance to concentrate on

⁴⁴ McSherry, B. (2006), op. cit.

⁴⁵ Pinfold et al. (2007), op. cit.

⁴⁶ Ibid

⁴⁷ Leggatt et al (in press), op. cit.

ethics training for health professionals to ensure justifiable decision-making, than to expect the law to direct behaviour in relation to the disclosure of confidential information”.⁴⁸

3.6. Conclusion

While it is difficult to legislate for good judgment, legislation can be effective where it is clear in listing exceptions to confidentiality and adequately protecting consumers’ basic rights to confidentiality. Just as important, it seems, legislation and policy documents must be widely disseminated with systems in place to ensure they are properly enacted. For a selected number of proposed policy and legislative changes, see Section 7.

⁴⁸ McSherry, B. (2008), *op. cit.* (p.493).

4. Consumer Perspectives

Key Points:

- The privacy of consumers is a basic human right.
- Consumers are not necessarily unwilling to share information. However, they believe that private information should only be shared with their consent.
- Information-sharing that occurs without consent can lead to the deterioration of important therapeutic relationships.
- Consumers should be allowed greater ownership of their information and participation in their own care and treatment.

4.1 Privacy is a Human Right

In attempting to understand consumers' views on the issue of information-sharing, the importance of an individual's privacy must first be acknowledged. The United Nations Charter of Human Rights clarifies in Article 12 that "no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks".⁴⁹ Therefore, disclosing personal information without consumer consent may be considered contravening consumers' rightful access to the information protection that is legitimately theirs.⁵⁰ As stated by a mental health lawyer interviewee, "*You can't get around the fact that privacy is a human right*", and similarly, a private sector consumer noted the importance of maintaining this right: "*The rights of the consumer are paramount, it must be respected that they may not wish to share information*". The widespread failure to acknowledge this right to privacy is of utmost concern to consumers.⁵¹

4.2 The Need for Better Legal Protection

An additional issue for consumers is that the conditions of privacy and confidentiality legislations may fail to protect their rights. As discussed in the previous section, there are many forms of legislation to be considered in the mental health sector, each with different implications, and there is concern that confusion over legislation may impact upon the protection of consumers' privacy and good information-sharing practice. A

⁴⁹ United Nations General Assembly (1948). *Universal declaration of human rights*. Retrieved September 15, 2009 from <http://www.un.org/en/documents/udhr/>.

⁵⁰ Privacy NSW (2004a). *Best practice guide: Privacy and people with decision-making disabilities*. Sydney, New South Wales: Office of the NSW Privacy Commissioner.

⁵¹ New South Wales Consumer Advisory Group (2004). *Issues paper: Privacy and confidentiality*. Sydney, NSW: New South Wales Consumer Advisory Group Mental Health Incorporated.

particular concern is the calls to increase the amount of information available to carers, as explicated in a comment from one consumer:

According to Commonwealth and state health ministers, consumers have a right to participate in their own care and with consumer consent the carer can be involved too. All policies already allow carer involvement.

In their review of the Victorian Mental Health Act 1986, the Mental Health Legal Centre⁵², states that while consumers are understanding of carers' situations, they believe that the law allows carers more than enough information as it stands, and therefore do not support any further exception to confidentiality legislation. Rather, the consumer viewpoint is supportive of greater restriction in legislation, which should read that information may only be shared without consent if it is necessary for the person's day-to-day care.⁵³

4.3 Building a Therapeutic Working Relationship Between Consumers, Carers, and Clinicians

In addition to the desire for basic human rights, there are many further reasons for consumers' frustration at information-sharing that occurs without consent. Information about an individual's mental health is extremely sensitive, and it is well known that in some circumstances it can lead to the experience of discrimination and stigmatisation.⁵⁴ A mental health lawyer interviewee elaborated on this point by explaining that "*Even in great relationships there is a limit to what consumers want to be disclosed...*". For example, a consumer may not want their carer to know about their self-harm attempts, or an employer to know their offending history due to their mental illness. The potential effects of sharing information without consent were summarised by a private sector consumer interviewee:

Sharing the wrong information, or too much information, can be damaging to relationships. These relationships can be either therapeutic, or between consumers and carers.

Where information-sharing does occur, some consumer advocates are concerned that carers do not respect the sensitivity of information about their friend or relative. As one consumer stakeholder interviewee stated:

With information comes responsibility. Consumers will be less inclined to share information if their carer openly discusses it with others. Although the majority of carers are respectful, there are some that are ruining opportunities for others.

When consumers are not assured of the confidentiality of the information they provide, they are likely to be less open in their disclosures, which can pose significant problems

⁵² Mental Health Legal Centre (2009), op. cit.

⁵³ Ibid

⁵⁴ Mental Health Commission. (1998). *Blueprint for mental health services in New Zealand: How things need to be* [report]. Wellington, New Zealand: The Mental Health Commission.; Mental Health Commission, 2002, op. cit; Privacy NSW (2004a). op. cit.

within their therapeutic relationships.⁵⁵ Furthermore, consumers report that information-sharing that occurs without their consent leaves them feeling disempowered, ignored and undermined.⁵⁶ A consumer consultant added that:

It must be remembered that any short term 'advantage' that can come from acts of coercion or deception can create long term barriers between that patient and service providers for a long time to come.

Clearly, failure to maintain a consumer's confidentiality can have drastic ramifications within their life, adding more difficulties to an already challenging situation.

4.4 Information-Sharing Should Only Occur with the Consent of the Consumer

Given the potential consequences of poor practises for information-sharing, consumers report that they would like to have control over their own information. It is important to note that consumers are not necessarily *unwilling* to share information, however there is considerable discomfort at the idea of a carer finding out information without consumer consent.⁵⁷ Alternatively, control over their own information may be beneficial to consumer well-being. Many articles have noted that such control can lead to empowerment through feelings of autonomy and increased self-esteem, which is subsequently conducive to a stronger recovery.⁵⁸ It is therefore the opinion of many consumers that information should only be shared when the consumer gives permission for the disclosure.⁵⁹

A private sector consumer affirmed the importance of consumer control over information:

Good information-sharing occurs when the consumer is given the opportunity to determine to whom, and to what extent, information can be shared, if at all.

While a consumer consultant further explained the benefits of consumer control over information:

Keeping the consumer's participation in treatment decisions as full and autonomous as possible – and to be able to more fully 'own' the process – tends to increase their commitment to the various stages and challenges in the recovery process and, further, this is often claimed by consumer advocates to enhance the person's progress.

⁵⁵ Kampf, A. & McSherry, B. (2006). Confidentiality in therapeutic relationships: The need to develop comprehensive guidelines for mental health professionals. *Psychiatry, Psychology and the Law*, 13(1), 124-131.; Ormrod, J., & Ambrose, L. (1999). Public perceptions about confidentiality in mental health services. *Journal of Mental Health*, 8(4), 413-421.; Pinfold et al, (2007), op. cit.; Privacy NSW (2004a), op. cit.

⁵⁶ Pinfold et al. (2007) op. cit.

⁵⁷ Mental Health Commission (2002), op. cit.; Rapaport et al. (2006), op. cit.

⁵⁸ For example, Mental Health Commission, 2002, op. cit; Slade et al. (2007), op. cit.

⁵⁹ Mental Health Commission (2002), op. cit.

Although consumers would like more control over their information, they do understand that there may be times when they lack the capacity to make important decisions about their care. In such cases, it is important for the service provider to assess the type of decision to be made, and the kind of support that is available for the consumer, rather than declaring on the basis of their illness that the consumer lacks the capacity to make the decision.⁶⁰ In times of a true incapacity, consumers are quite supportive of the use of advance directives, with approximately 64% believing them to be good practice.⁶¹ The support for written decisions about care and information-sharing was further substantiated in stakeholder interviews:

One of the quickest ways to find out a consumer's thoughts about information-sharing is to ask them to complete a form on admission that covers who their carer is, and the extent to which they want them involved. If the consumer is too unwell at the time of admission, the form is revisited two days later, and continually reviewed over time and with further admissions. [Private sector consumer]

It should be a legal requirement that consumers are given the opportunity to create an advance directive. These would help everyone to understand their roles and improve communication. [Mental health lawyer]

4.5 Conclusion

In conducting the literature review for this section, it became obvious that there is a remarkable lack of information addressing the consumer perspective on the issue of privacy and confidentiality. This review relies on only a handful of available references, however interviews with consumer stakeholders served well in further elucidating concerns of mental health consumers. The primary concerns of consumers include the lack of respect for their basic human rights, and the legal protection of their privacy. Consumers also asserted that they would like greater control over who has access to their information, and would like the opportunity to develop advance directives to ensure that their wishes are upheld during times of distress. It was indicated that enhanced consumer participation in developing best practice guidelines and mental health legislation is essential.

⁶⁰ New South Wales Consumer Advisory Group (2004), op. cit.

⁶¹ Rapaport et al., (2006), op. cit.; Slade et al. (2007), op. cit.

5. Family / Carer Perspectives

Key points:

- Many mental health service providers often see family as being of little importance (or worse, an impediment) in consumer recovery and consequently exclude carers from service planning and provision.
- Acknowledging and having an in-depth knowledge of the care context creates a positive therapeutic relationship and is conducive to better recovery for consumers.
- Poor information provision to carers adds to what is already a distressing experience, leading to feelings of anger, frustration and disempowerment.
- It is important that carers are 'kept in the loop' given that they are such a vital part of support structures for consumers and contribute valuable knowledge and experience to assist in the consumer's treatment.

5.1 Background: Current Situation and the Need for Change

Literature shows that increasing the involvement of family / carers in the mental health system is one of the greatest areas requiring development.⁶² Despite the emphasis that Australian mental health policy documents place on collaboration with carers, they are generally expected to undertake the caring role with little education or support.⁶³ Meeting the information needs of carers is an issue that is particularly urgent.⁶⁴ This is confirmed by a NMHCCF survey on confidentiality and information sharing, which found

⁶² Lesser (2004), op. cit.

⁶³ McAuliffe, D., Andriske, L., Moller, E., O'Brien, M., Breslin, P., & Hickey, P. (2009) 'Who cares?' An exploratory study of carer needs in adult mental health. *Australian e-Journal for the Advancement of Mental Health*, 8(1), 1-12.

⁶⁴ Leggatt & Furlong (1996), op. cit; Wynaden, D., & Orb, A. (2005). Impact of patient confidentiality on carers of people who have a mental disorder. *International Journal of Mental Health Nursing*, 14, 166-171.

54% of carer interviewees felt they were not given the information and support they need.⁶⁵

This section will examine some of the major issues facing carers in their experience of confidentiality and information-sharing in mental health services. It considers three areas of concern: (1) barriers to positive information-sharing with carers, (2) the impact of poor confidentiality and information-sharing practices, and (3) the rationale for positive information sharing practice.

5.2 Barriers to Positive Information-Sharing

5.2.1 Systemic Culture of Excluding Families

Literature reveals a systemic culture that excludes family / carers, with professionals often perceiving them as an impediment to service provision rather than allies in the recovery process⁶⁶. This creates a dissonance between the Australian policy concept of family-as-partner (where families are viewed as partners in care) and the professional response to carers, which results in a continued lack of involvement of carers in mental health service planning and delivery. The culture of exclusion and the use of 'confidentiality smokescreens' is elaborated upon in the next section. One carer interviewee even identified a systemic practice of "pathologising families so clinicians do not even think that families deserve any help."

Another interviewee recounted the following to highlight this point:

A mother rang the psychiatric inpatient unit to ask about her daughter's health. The response was: 'she is an adult now' (the daughter was just 18). 'We don't have to tell you anything'. (It was not even clear whether the daughter had been asked or whether or not she wanted her mother informed). The mother was extremely upset and disturbed by this, and by the continuing failure to give her any information at all during months of her daughter's treatment... Eventually, this mother needed psychiatric treatment for her own anxiety. [Carer advocate]

5.2.2 Failure to Identify Carers

It has been reported that the conceptual ambiguities about the 'carer' can make it difficult for professionals to involve the consumer's significant relatives and friends in service provision (for example, do carers include young people, partners, neighbours, siblings etc.?).⁶⁷ Poor information-sharing from the outset can mean that carers are not identified and supported in their role. One carer stakeholder recounted a story about carers who were ignored at the beginning of a consumer's service use:

⁶⁵ NMHCCF. (Unpublished). *Confidentiality and Information Sharing with Families and Carers in Mental Health [survey results]*. Canberra, ACT: NMHCCF.

⁶⁶ Lesser (2004), op. cit; Wynaden & Orb (2005), op. cit.

⁶⁷ Rapaport et al. (2006), op. cit.

The consumer was threatening suicide. He asked his carer and girlfriend to take him to a psychiatrist where the consumer was seen alone. Carer and girlfriend were totally ignored and they were left without any knowledge of what to do to help.

Carers' legislation has been mentioned as a means of defining carers and for better protecting the social and citizenship participation of families and other carers more generally (see Section 7).

5.2.3 Carer Confidentiality

A number of carer stakeholders expressed concern that consumer confidentiality is respected while the confidentiality of carers is (often) disregarded. One stakeholder interviewee shared a story to express this concern:

A mother rang the psychiatrist to inform him that her daughter was becoming aggressive, explosive and angry with her parents and her siblings. The mother was becoming frightened and wanted the psychiatrist to consider admitting her daughter to hospital. The psychiatrist then told the girl that her mother had rung and repeated everything the mother had said. The girl was furious with her mother and endlessly berated her, to the point where the mother almost had a breakdown herself. This example shows complete insensitivity to what was happening in the family home; such insensitivity escalated an already tenuous situation and resulted in the police having to be called and the girl taken involuntarily to hospital. [Carer advocate]

This story demonstrates the issue of confusion around what carers can expect from clinicians regarding their own confidentiality. It also relates to the clinician's lack of understanding of the home and family context.

5.2.4 When Consumers Do Not Consent to Disclose Information to Carers

While carers are an extremely diverse group, carer advocacy groups generally accept the consumer's basic right to withhold consent to disclose personal information. They do, however, emphasise that withholding consent may have a significant impact on the level of support that carers can provide.

Sometimes it is clearly not appropriate to share information with carers. As one of the consumer stakeholder interviewees stated, "if the person is a consumer as a result of carer abuse then that carer should have no right to participate in their care (if the consumer refuses consent)". There are also instances where no abuse has occurred and still a consumer refuses consent to share certain information with carers (i.e. due to increased independence). When such a situation arises, carers are arguably disadvantaged by service providers being ill-equipped to deal with families where a consumer does not agree to disclosure of information. (For best practice and recommendations for professional response to consumers not consenting to disclose information, see Section 7 as well as Appendix D.)

5.2.5 Alternative Cultural Values

It is an Anglo-Celtic cultural and philosophical tradition that excludes family from decision-making around the health (physical or mental) of an individual family member. As Szmukler and Bloch have written, “(a) central difficulty is that medical ethics in a traditional Western sense is concerned with the individual”.⁶⁸ The impact of this tradition is clear when we compare Australia’s service provision and policy framework with New Zealand’s, whose model of carer involvement at strategic and care planning levels was largely influenced by the strong family traditions of the Maori community.⁶⁹ The cultures around the world that do not share Anglo-Celtic cultural heritage are well represented within the Australian community.⁷⁰ This potentially poses difficulties for Indigenous and many culturally and linguistically diverse (CALD) families, although literature in this area is scant.

5.3 Impact of Excluding Families and Other Carers

5.3.1. Reducing Carer Wellbeing

It has been found that carers often experience a lack of confidence, skills and organisational backing when they engage mental health professionals.⁷¹ The general experience of families entering the mental health system is one of despair, shame, hopelessness, helplessness, alienation, isolation and discrimination.⁷² Wynaden and Orb’s Australian study surveyed 27 people identifying as primary carers, all of whom reported a lack of engagement by staff, leading to distress and frustration.⁷³ Poor information provision was found to ‘induce feelings of isolation, anxiety, depression, resentment at the service user, anger and fear’⁷⁴. This adds to what is already a difficult time in the lives of many families who report experiencing “significant feelings of loss, grief, isolation, failure and chronic sorrow which lower self esteem and make it even more difficult to ask for help and information”⁷⁵.

5.3.2 Compromising the Carer-Consumer Relationship

Some studies even suggest that the frustration caused by poor information sharing conflates into a ‘culture of blame’ between the carer and consumer.⁷⁶ One carer

⁶⁸ Szmukler & Bloch (1997), op. cit. (p. 405)

⁶⁹ Private Mental Health Consumer Carer Network (2008), op. cit.

⁷⁰ Lesser (2004), op. cit.

⁷¹ Slade et al. (2007), op. cit.

⁷² Baker, K. (2007). Families: A help or hindrance in recovery? *Alternatives Beyond Psychiatry*, P. Sastny & P. Lehmann (Eds.), Peter Lehmann Publishing.

⁷³ Wynaden & Orb (2005), op. cit.

⁷⁴ Ibid. p.379

⁷⁵ Ibid. p.383

⁷⁶ Gray et al. (2008), op. cit.

stakeholder expressed frustration about the conflict arising from poor information sharing:

Clinicians work in such a way that they turn consumers and family members against each other because they often see families as the problem. The barriers to be overcome then become huge.

The controversy around issues of privacy, confidentiality and information-sharing cause clear tension between consumer and carer advocates. Some mental health consumers / psychiatric survivors have been sceptical of family involvement in the recovery movement. Indeed, a number of consumers report feeling the controlling and paternalistic experiences of their own families, as well as broader family advocacy organisations⁷⁷. Quite often it is the *lack* of information and strategies for supporting the consumer that causes families to potentially hinder their relative's recovery. However as Baker identifies, "most people who are in extreme distress want the love and support of their families and most families want to be helpful in a caring way"⁷⁸. The NSW Consumer Advisory Group (CAG) highlights the importance of providing support for families in its issues paper on privacy and confidentiality. The third guiding principle for the report identifies that "support for families and carers is vital"⁷⁹.

5.4 Outcomes of Good Information Sharing with Families

A large evidence-base suggests that the support needs of consumers and carers are interdependent and that providing support and education to families / carers correlates directly with health benefits to consumers.⁸⁰ For example, there are educational approaches to inform families of people diagnosed with schizophrenia that are associated with a reduced relapse rate and potentially better family coping and resiliency.⁸¹ In addition, greater carer involvement in, and understanding of, consumers' situations has been shown to facilitate better recovery for consumers.⁸² There are numerous other examples where family-sensitive service provision is associated with better outcomes for consumers and greater satisfaction for clinicians.⁸³

5.4.1 Open and Effective Dialogue

One carer interviewee recounted the following story about an effective information-sharing scenario where the clinician initiated open dialogue:

⁷⁷ Baker (2007), op. cit.

⁷⁸ Ibid. p.256

⁷⁹ New South Wales Consumer Advisory Group (2004), op. cit. (p.9).

⁸⁰ For example, see Private Mental Health Consumer Carer Network (2008), op. cit. (Sec. 3.2.2.)

⁸¹ Cited in Szmukler & Bloch (1997), op. cit (p 401)

⁸² Wynaden & Orb (2005), op cit.

⁸³ McFarlane, W.R., Dixon, L., Lukens, E., et al. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy*, 29, 223-245.

The clinician called in the consumer and his mother. The clinician told the consumer that his mother needed help in understanding his illness so that she could be helpful, and not do things that might hinder his recovery. The clinician also told the consumer that certain information that the consumer wanted to be kept private would be, and that his mother understood his need for privacy with his clinician.

It is also important to note that providing carers with recognition and respect requires not simply the opportunity for them to seek advice but also, importantly, to convey information to services. Where possible, carers require an information flow, where their perspective is duly considered. Indeed, the experience of having services provided 'to' carers rather than 'with' them, means that carers experience services as disempowering and paternalistic.⁸⁴ On the other hand, a dialogue ensures carers are involved in information-sharing in an inclusive manner.

One carer stakeholder recounted an example where a case manager, consumer and his father, along with a carer consultant, met to work out how to manage money demands on the father. The father's needs, wishes and frustrations were all aired within a 'safe' environment and a compromise position was reached successfully.

5.5 Conclusion

Families, friends and partners can play a vital support role in a consumer's recovery and should be naturally incorporated within service provision. Yet traditionally, carers have not been given adequate information or strategies to assist them in their role. Needless to say carers need certain information so they can access services and attain their entitlements; make significant decisions about their own lives and that of their families; and most importantly, contribute positively to consumer recovery.

⁸⁴ Gray et al. (2008), op. cit.

6. Professional Ethics, Guidelines and Issues

Key points:

- Professional ethics guidelines provide little advice to clinicians about information-sharing with carers.
- From clinicians' perspectives, key barriers to information-sharing include the consumer withholding consent, concerns about losing the consumer's trust, and fears of legal consequences.
- Clinician stakeholders agreed that more training is needed.

6.1 Professional Bodies' Guidelines

Within the public mental health system, clinicians usually work in multidisciplinary teams. Each profession is governed by separate guidelines or codes of ethics as mandated by its College, Association or other professional organisation. It should be noted that many members of these professional associations, particularly psychiatrists and psychologists, work privately rather than in the public mental health system. Perhaps as a consequence, the guidelines tend to focus on working one-on-one with individual clients in a private setting rather than on working with consumers and their carers within a negotiated framework. The following professional codes are examined here:

- The Royal Australian & New Zealand College of Psychiatrists (RANZCP) Code of Ethics (2004)⁸⁵
- The Australian Psychological Society (APS) Code of Ethics (2007) and Ethical Guidelines (6th ed.) (2004)⁸⁶
- Australian Association of Social Workers (AASW) Code of Ethics (2nd ed.) (1999)⁸⁷
- Australian Nursing and Midwifery Council (ANMC) Code of Ethics for Nurses in Australia (2008) and Code of Conduct for Nurses in Australia (2008)⁸⁸

⁸⁵ Royal Australian and New Zealand College of Psychiatrists (2004). *The RANZCP Code of Ethics*. Melbourne: The RANZCP.

⁸⁶ Australian Psychological Society Ltd. (2007). *Code of ethics*. Melbourne, Vic: Australian Psychological Society.; The Australian Psychological Society Ltd. (2004). *APS Ethical Guidelines (6th ed.)*. Melbourne: The Australian Psychological Society Ltd.

⁸⁷ Australian Association of Social Workers (1999). *AASW Code of Ethics (2nd ed.)* Canberra: Australian Association of Social Workers.

⁸⁸ Australian Nursing and Midwifery Council (2008a). *Code of Ethics for Nurses in Australia*. Dickson, ACT: Australian Nursing and Midwifery Council.; Australian Nursing and Midwifery Council (2008b). *Code of Conduct for Nurses in Australia*. Dickson, ACT: Australian Nursing and Midwifery Council.

- Australian Association of Occupational Therapists (OT Australia) Code of Ethics (2001)⁸⁹

6.1.1 Commonalities

Generally the guidelines emphasise the protection of consumers' information and the circumstances, particularly legal obligations, under which clinicians may breach confidentiality. Each set of guidelines contains standards or principles regarding privacy and confidentiality, which all share some basic features: they each instruct professionals to maintain consumers' confidentiality, and each qualify this with a statement to the effect that confidentiality is not absolute, listing three circumstances in which confidentiality may be breached:

- 1) For the purpose of preventing harm (to the consumer or others);
- 2) In compliance with legal obligations, such as a court subpoena; and
- 3) With the consent of the consumer.

Further guidance given by the various organisations includes:

- Information obtained from sources other than the consumer is subject to the same principle of confidentiality as that obtained from the consumer (RANZCP).
- Consumers should be informed about confidentiality and its limits as part of the process of obtaining informed consent at the start of a therapeutic relationship, and again as necessary (APS; RANZCP).
- Provision of a professional service to consumers may require that information be shared among relevant others including professionals and family members (APS; ANMC).
- Clinicians will ascertain to whom consumers wish their information be given or not be given, and in what detail (AASW). Written consent from the consumer should be obtained indicating to whom information can be disclosed, under what circumstances and which information can be released (APS).

6.1.2 Limitations

- Virtually no guidance is given in any of these professional guidelines about sharing appropriate information with consumers' families or carers.
- It is unclear whether consumers and carers were consulted during the development of the guidelines.

6.1.3 Inconsistencies

Little conflicting guidance could be discerned between the various professional codes. Their main inconsistency was the extent to which they addressed the issues, rather than the provision of conflicting advice.

⁸⁹ Australian Association of Occupational Therapists (OT Australia) (2001) *Code of Ethics*. Retrieved June 30, 2009 from [http://www.ausot.com.au/documents/OT%20AUSTRALIA%20Code%20of%20Ethics\(1\).pdf](http://www.ausot.com.au/documents/OT%20AUSTRALIA%20Code%20of%20Ethics(1).pdf)

6.1.4 Comparison Between Professional Guidelines and Policy and Law

An in-depth analysis of the similarities and differences between the professional guidelines described above and the various laws and legislation that govern mental health services is beyond the scope of this paper. Instead, an example of a broad area of agreement and an example from one jurisdiction of a key inconsistency are described here.

An obvious area of agreement between the professional guidelines and the laws and legislation described in the Policy and Law section of this paper (see Section 3) is the three circumstances in which confidentiality may be breached: to prevent harm, in compliance with legal obligations, and with the consent of the consumer.

The most striking point of difference between the various professional guidelines and Section 120A of the Victorian Mental Health Act is that the Act allows information to be disclosed to carers “if the information is reasonably required for the ongoing care of the consumer”, even if the consumer does not give consent.⁹⁰ Disclosure of information under these circumstances would constitute a breach of the Social Workers’ (AASW), Psychologists’ (APS) and Occupational Therapists’ (OT Australia) Codes of Ethics, since these Codes all stipulate that consumers’ consent must be obtained in order to share private information (with the exceptions of the duty to warn and as required in legal proceedings). The Psychiatrists’ (RANZCP) Code of Ethics neither explicitly permits nor prohibits this type of information-sharing since it does not refer to consumers’ consent (except to say that it should be obtained in order to share clinical information with colleagues). The Nurses’ (ANMC) Code of Ethics does not specifically prohibit this type of information-sharing, and directs nurses to “conform to relevant privacy and other legislation”.

In this latter example, it could be argued that, although service providers have legal grounds to share necessary information with carers (with or without consumers’ consent), they cannot be expected to do so as long as it is not articulated within and supported by their professional ethical codes.

6.2 Clinicians’ Perspectives on Privacy and Confidentiality in Practice

The basis for the development of professional guidelines concerning confidentiality discussed in Section 6.1.1 is that confidentiality is crucial for the clinician-consumer therapeutic relationship. Threats to confidentiality jeopardise the quality of the information exchanged between clinician and consumer and the mutual trust necessary for effective therapy. Indeed, clinicians have long regarded confidentiality as the cornerstone of the helping relationship.⁹¹

⁹⁰ Victorian Mental Health Act 1986, s120A.

⁹¹ Koocher, G. P., & Keith-Spiegel, P. (1998). *Ethics in psychology* (2nd ed.). New York: Oxford University Press.

Few researchers have examined clinicians' perspectives on sharing information with families.⁹² Even fewer have examined clinicians' understanding and implementation of professional codes of ethics, policy and legislation. Key issues from clinicians' perspectives identified from the literature mostly arise from difficulties in implementing the ethical guidelines, and are described in the following sections. Key issues that arose from the key stakeholder interviews with clinicians are also described below.

6.2.1 Balancing Consumers' Right to Privacy with Carers' Need for Information: Comments on Professional Guidelines

Balancing the consumer's right to confidentiality with the carer's need for information forms perhaps the biggest issue within the literature on clinicians' perspectives on privacy and confidentiality. Unfortunately, clinicians are given little or no guidance in these matters from their professional Codes of Ethics. One stakeholder noted that the biggest challenge for clinicians in implementing professional ethical guidelines is:

The balance between the rights of the consumer to ensure that their private information is kept confidential and the need to involve others in their care in order to work toward recovery. Ethical guidelines need to address this balance but they don't! [Ex-Chief Psychiatrist]

Another noted the limitations of guidelines:

Although there is a role for guidelines, etc., I don't think they have an enormous impact on individual [clinicians]. It's individual [clinicians] taking into account the particular circumstances of the [consumer] that makes a difference. [Medical advisor with RANZCP]

The same stakeholder went on to comment that ethical guidelines do not reflect the shift in mental health practice toward recognition of carers:

Psychiatrists are very Mindful of the fact that the work they do depends on privacy and confidentiality; this is the cornerstone of psychiatry, and underlies all clinical practice. So, privacy and confidentiality is our starting point; our focus is much more on protecting patients' privacy than focusing on their families' needs. This is not in the ethical guidelines because our focus is on the person who we are treating. However, there is a shift happening, and focusing on carers' needs is becoming much more prevalent. [Medical advisor with RANZCP]

An alternative approach to professional Codes of Ethics is to develop workplace policies. Two studies in the UK asked professionals about policies and guidelines in their workplace. Almost half of professionals surveyed reported that their service had a policy about sharing information with carers. Among those with policies, the majority found them very helpful or quite helpful (82-86%).⁹³ We could find no equivalent survey of Australian mental health workers, so it is not known if the situation is similar here.

⁹² Dixon, L., Lucksted, A., Stewart, B., & Delahanty, J. (2000). Therapists' contacts with family members of persons with serious mental illness in community treatment programs. *Psychiatric Services*, 51(11), 1449-1451.

⁹³ Pinfold et al. (2007), op. cit.; Slade et al. (2007), op. cit.

6.2.2 When Consumers do not Consent to Disclosure of Information

Even more challenging, though somewhat less frequent an issue, is managing information-sharing with families when consumers do not consent to the disclosure of their information.⁹⁴ Clinicians sometimes face the dilemma of respecting the consumer's wish that information not be shared and trying to reconcile this with their own professional judgement that family involvement would be beneficial.⁹⁵ One UK study found that consumers withholding consent was the clinician's primary reason for not sharing information with carers.⁹⁶ It was also listed as the biggest barrier to effective information-sharing by one stakeholder (a medical advisor with RANZCP).

6.2.3 Concerns about Losing Consumers' Trust

As a consequence of their desire for good therapeutic relationships with their clients, clinicians may worry that disclosing information to carers will compromise the consumer's trust, especially when this has been difficult to achieve.⁹⁷ As one stakeholder noted:

If the therapeutic relationship between consumer and clinician is tenuous, the worker needs to work hard to maintain the client's engagement. Any innocuous contact with the family may be seen as a threat by the client. This is a real problem, especially for clients who have paranoia or delusions about people around them including their family. Workers are focused on the client's potential reaction. This needs to be recognised [by carers] as a worrying dilemma. [Manager of a family mental health service]

6.2.4 Fear of Legal and Professional Consequences

An issue that arose from both the literature and stakeholder interviews was clinicians' concerns about the legal and professional consequences of sharing information with carers. Fear of litigation has been cited within the literature as a major reason given by clinicians for withholding information from carers.⁹⁸ A UK study found that concerns about being sued – together with concerns about losing the consumer's trust, as discussed earlier – lead to clinicians finding it easier and safer to say nothing to carers.⁹⁹ It has been acknowledged that litigation following inappropriate disclosure of consumer information is actually rare.¹⁰⁰

⁹⁴ Szmukler & Bloch (1997), op. cit.

⁹⁵ Chen, F. (2008). A fine line to walk: case managers' perspectives on sharing information with families. *Qualitative Health Research*, 18, 1556.

⁹⁶ Slade et al (2007), op. cit.

⁹⁷ Chen (2008), op. cit.

⁹⁸ Leggatt & Furlong (1996), op. cit.

⁹⁹ Gray et al (2008), op. cit.

¹⁰⁰ McMahan, J., Hardy, J. & Carson, R. (2007) *Identifying the carer project. Final report and recommendations for the Commonwealth Department of Health and Ageing*. Retrieved June 30 2009 from: <http://www.drinkingnightmare.gov.au/internet/main/publishing.nsf/Content/mental-pubs-i-carer-toc>

Fear of litigation was cited within stakeholder interviews as a significant barrier to information-sharing, and as a common and unwarranted problem. One professional stakeholder summed up the issue:

In my experience...litigation doesn't happen! Those cases where practitioners are being sued are about not sharing information; other cases have been about sharing information with inappropriate people such as lawyers and police. So, practitioners' fears do not reflect reality. Litigation doesn't happen when information is shared with primary carers, or with other health/community services. Fear of being sued is what causes paralysis among clinicians. Part of what underlies the fear of litigation is that there are a multiplicity of policies and legislation – this causes the thinking, "I'm not going to disclose because I'm going to get sued." [Ex-Chief Psychiatrist]

6.2.5 Need for Training

Training of mental health clinicians is oriented towards maintaining consumer confidentiality rather than information-sharing. In a UK study by Gray and colleagues,¹⁰¹ clinicians reported that shortcomings in their training and lack of awareness of carer rights created uncertainties when managing information-sharing with carers; that some clinicians were uncertain how far they could involve carers, even in scenarios of risk; and that clinicians have expressed the need for training in confidentiality and carer rights.¹⁰²

All professional stakeholders interviewed agreed that further training is needed for clinicians. One noted, "There should be ongoing education – supervision, peer review groups, and involvement of consumers and carers in training programs." Another commented:

Training for clinicians is necessary but not sufficient. Stand-alone training in confidentiality, like many other topics, will not shift clinicians' practice. Clinicians also need support and organisational endorsement [of good information-sharing]. Training should be offered as part of a package; by offering 'privacy and confidentiality training' there's a danger in privileging it and making it into more of a negative issue than it really is. For example, it could be incorporated into a training package about working with families. Undergraduate training could incorporate the value of good information-sharing and provide examples of different ways of managing confidential information. [Manager of a family mental health service]

6.2.6 Barriers to Information-Sharing

Stakeholder interviewees listed several significant barriers to effective information-sharing with carers:

- A culture of treating the individual

¹⁰¹ Gray et al (2008), op. cit

¹⁰² Ibid.

Two stakeholders mentioned that the mental health system's culture of working with consumers as individuals to the exclusion of others involved in their care was a major issue and a barrier to good information-sharing. "The default position is individual-focused, as though the person is in a bubble – this is not suited to working with serious mental illness, especially where there's decreased ability to function; this notion is ineffective. It's a cultural issue. Cross-culturally it's much less of an issue than in Australia."

- Clinicians' lack of confidence

One stakeholder considered the biggest barrier was clinicians' lack of confidence: "An issue underlying clinicians' lack of information-sharing is their discomfort or anxiety in working in a situation other than one-on-one, individual sessions. Many clinicians lack confidence working with a group of people at a time, and a key flag that this may be the case is when they cite reasons of confidentiality as a reason to not do this."

- Time pressure

Insufficient time, large workloads and under-staffing were mentioned by two stakeholders as key barriers to good information-sharing. As one noted:

Many case managers with workloads of 30 or more are under pressure by their organisation to keep things simple, and be reactive in their work with clients. These clinicians may think, "Why would I open a can of worms? I've got enough on my plate with this client's problems, I don't need their parents' problems too." [Manager of a family mental health service]

- Misunderstanding of relevant laws

As one stakeholder noted, "Section 120A [of the Victorian Mental Health Act (1986)] is widely misunderstood – this prevents [consumers] from getting proper care." Another noted that there are "daily issues in interpreting legislation" for clinicians.

- Fear of litigation

See *Fear of legal and professional consequences* (section 6.2.4).

- Consumers not consenting to information-sharing

See *When consumers do not consent to disclosure of information* (section 6.2.2).

- Service-level problems

Stakeholders identified service-level barriers to information-sharing. A common theme was the lack of organisational endorsement for individual clinicians to share information with carers. Another was the practical difficulties faced by clinicians who do practice good information-sharing. For example, "you may have clearly documented a privacy and confidentiality agreement in a client's file – you may have even put a huge note on the front cover warning staff not to disclose any information to a certain person – but how's the receptionist at the busy front desk supposed to know about that when someone calls?" (Chair of an ethics and complaints panel for a professional body).

6.3 Conclusions

Clinicians are provided with little guidance about how to share information with carers from their professional ethical guidelines. It was widely acknowledged that the training given clinicians neglects the topic of information-sharing, focusing as it does on an individual treatment culture which emphasises maintaining consumer confidentiality. Clinicians cited several barriers, at service-level and the individual level, both unfounded fears and genuine dilemmas, each of which appears to contribute to clinicians' hesitancy to disclose information to carers.

7. Best practice: Possible Ways Forward

Key points:

- There is a need for a cultural shift towards the tripartite approach to treatment.
- Several changes can occur at the service level which may help to foster the desired culture (e.g., staff education and support, increased communication about information-sharing between consumers, carers, and clinicians, written agreements about information management).
- Although legislative change is not essential to achieve good information-sharing practice, consideration of international legislatures may be worthwhile.

7.1 Cultural Change

The overarching conclusion in relation to best practice concerning privacy and confidentiality is the need for a cultural change in the mental health system. In particular, rather than a culture predicated on professional judgments and exclusions, the culture should reflect the importance of information-sharing by working toward a tripartite model of treatment collaboration. More specifically, professionals should aim to work with both consumers and the individuals who are of significant support to the consumer.¹⁰³ The remainder of this section will discuss best practice options and recommendations at service level and legislative level that may lead toward the desired cultural change.

7.2 Staff Education & Training about Information-Sharing Policies

A prominent theme throughout the literature and interviews with consumer, carer, and clinician stakeholders was the need for greater understanding of current legislation by clinicians. As explained throughout this issues paper, the laws are quite accommodating and permit discretion to clinicians, however the common withholding of important information suggests that clinicians may not understand this.¹⁰⁴ Numerous papers and

¹⁰³ Avon & Wiltshire (2006). *Confidentiality and information sharing with families and carers: Best practice guidelines*. Chippenham, UK: Avon and Wiltshire Mental Health Partnership NHS Trust. Gray et al, (2008); op. cit.; Pinfold et al, (2007), op. cit; Privacy NSW (2004a), op. cit.

¹⁰⁴ Privacy NSW (2004a), op. cit.; Slane, B. (2001). *Privacy law in New Zealand: Eight years on. Notes for an address by the Privacy Commissioner, Bruce Slane, to Privacy: Making it your business conference*. Auckland, New Zealand: The Privacy Commissioner's Office.

guidelines advise that clinicians require comprehensive training on privacy policies¹⁰⁵, which was echoed by the following stakeholder:

Better staff training in information provision would help, including intensive work on how to use the privacy and confidentiality provisions in a flexible and consumer-empowering way. [Consumer Consultant]

This training should equip professionals with an understanding of their obligations regarding information-sharing, and the ability to give clear reasons for their decisions (e.g., whether it is for therapeutic or legal reasons).¹⁰⁶ The training should also provide real life examples, and ongoing sessions to discuss difficult issues that have arisen.¹⁰⁷ One stakeholder elaborated on this point:

Further education and training could involve, for example, giving scenarios for clinicians to work through. There needs to be more written material available; it needs to be added into postgraduate curriculums for all disciplines; and the RANZCP guidelines could be added to. [Ex-Chief Psychiatrist]

7.3 Organisational Support for Workers

While training on privacy and confidentiality policies is viewed as potentially beneficial, clinicians also require further support in effecting change toward improved information-sharing practice. As explicated by a manager of a family mental health service:

Training for clinicians is necessary but not sufficient. Stand-alone training in privacy and confidentiality, like many other topics, will not shift clinicians' practice. Clinicians also need support and organisational endorsement of good information-sharing. [Manager of a family mental health service]

Such support firstly involves normalising the concept of information-sharing, for which interviewees provided the following suggestions:

Normalising the notion of family involvement in care. For example, having posters about this in the waiting area, having a standard spiel for initial sessions to explain this concept ('Part of the way we work here is to have family involvement'). [Manager of a family mental health service]

Good information-sharing is when implemented strategies to achieve active and meaningful family involvement occur as part of everyday routine treatment, and is not considered 'something extra'. [Carer Consultant]

¹⁰⁵ For example, Carers Australia (2007). *Carers guide to information sharing with mental health clinicians* [Leaflet]; Mental Health Commission (2002), op. cit.; Mental Health Commission (2004). *Review of the information sharing policies and practices of district health board mental health services* [report]. Wellington, New Zealand: The Mental Health Commission.; Pinfold et al., 2007, op. cit.

¹⁰⁶ Mental Health Commission (2002), op. cit.; Mental Health Commission (2004), op. cit.; Privacy NSW, (2004a), op. cit.; Slane (2001), op. cit.

¹⁰⁷ Mental Health Commission (2002), op. cit.; Pinfold et al. (2007), op. cit.

The literature provides further ideas on how clinicians can be assisted in good information-sharing practices. For example, in New Zealand, clinicians are supported by a free privacy helpline run by the New Zealand Privacy Commissioner that delivers guidance tailored to the situation, and many services have an in-house privacy expert who can offer staff a second opinion.¹⁰⁸

7.4 Discussion about Privacy, Confidentiality & Information-Sharing at Initial Engagement

Once clinicians are understanding of policies and receive support in information-sharing practices, it is necessary to consider the most effective ways to foster a tripartite relationship between consumers, carers, and clinicians. The literature consistently recommends that clinicians have an in-depth discussion with consumers regarding confidentiality and consent to disclose information at the earliest possible opportunity, when the consumer is not acutely ill. This discussion should cover the circumstances under which consent is required and the benefits of including carers, such as additional support and help in identifying early warning signs.¹⁰⁹ Interviewees gave further insight into the type of discussion that should be conducted at the beginning of treatment:

Addressing information-sharing at the beginning of treatment; discuss why information would be shared, with whom information can and cannot be shared, what information can and cannot be shared, whether family members can be invited into sessions or contacted via phone. [Manager of a family mental health service]

It is well established that active involvement of family/carer in the provision of psychiatric treatment substantially improves prognostic outcomes in the disorder. A rationale for this must be provided so all parties understand why information-sharing is so important. [Carer Consultant]

A mental health lawyer emphasised the advantage of this approach:

Giving consumers clear, upfront information about the limits of confidentiality can increase confidence and trust in the service provider, and can also ease the consumer's anxiety around how information will be used, potentially leading to a less aversive experience of the mental health service. [Mental health lawyer]

If consumer consent is not attainable, the clinician may negotiate for restricted conditions of disclosure.¹¹⁰ This routine collection of consent should ideally occur as part of the initial assessment on admission, with regular revisitations to see if the consumer has changed their Mind.¹¹¹

¹⁰⁸ Mental Health Commission (2002), op. cit.; Slane (2001), op. cit.

¹⁰⁹ Avon & Wiltshire (2006), op. cit.; Mental Health Commission (2004), op. cit.; Pinfold et al. (2007), op. cit., Slade et al. (2007), op. cit.; Szmukler & Bloch (1997), op. cit.

¹¹⁰ Mental Health Commission (2004), op. cit.

¹¹¹ The Office of the Chief Psychiatrist. (2005). *Working together with families and carers: Chief Psychiatrist's Guideline*. Melbourne, Vic: Mental Health Branch, Metropolitan Health and Aged Care Services Division, Victorian Department of Human Services.; Pinfold et al. (2007), op. cit.; Wynaden & Orb (2005), op. cit.

When a consumer refuses to consent to their family being involved, staff are required to keep on asking them in order to find out why consent is not being given. [Carer Consultant]

7.5 Building a Working Tripartite Relationship

Gaining consent to involve carers in the consumer's care and treatment is the first step in developing the tripartite relationship, however this relationship requires maintenance. The literature suggests that good information-sharing practice requires that consumers, carers, and clinicians work together towards the best interests of the consumer with suggestions that clinicians may benefit from training on how to work in effective partnership with consumers and carers.¹¹² Additionally, some interviewees suggested that consumers and carers may benefit from being educated on each other's experiences:

Good information-sharing involves open and frank discussion in the community, and two-way education for consumers and carers. Carers need to understand the impact that their comments can have on consumers, and consumers should understand the strain that carers can go through in having to do something against someone's will. [Public sector consumer]

Good information-sharing requires an understanding of each other's perspectives. Carers need to understand consumers' concerns about privacy, however carers also need support for when they do not receive information. [Mental health lawyer]

Having the client tell the family in session what it's like to experience certain symptoms, like how they feel when they hear voices. That's more informative to families than just giving them a brochure. [Manager of a family mental health service]

Other interviewees emphasised the need for greater communication and collaboration in general:

Clinicians routinely elucidate and support clients and their family/carer in effective communication and problem analysis techniques to increase their capacity to manage environmental stresses and achieve better health outcomes. [Carer Consultant]

The three parties should come to an agreement on the principle of why information is communicated, how it is to be done, and what sorts of information do and do not need to be shared. [Ex-Chief Psychiatrist]

Put them into a room and make them talk to each other! These are complex issues, we can't just say, "Do these three things and it will all work out". It all depends on the particular circumstances. [Medical advisor with RANZCP]

¹¹² For example, Avon & Wiltshire (2006), op. cit.; Gray et al. (2008), op. cit.; Pinfold et al. (2007), op. cit.; Privacy NSW (2004a), op. cit.

These recommendations align well with the practice of Behavioural Family Therapy which is a type of psychoeducational program for consumers and their families currently being trialled in Victoria under the title of Building Family Skills Together. Similarly, another program entitled Multiple Family Groups (MFG) involves several families, including the consumers, meeting regularly to learn good communication and problem-solving skills. These groups have been conducted in various services in Australia. In their 2006 study, Bradley and colleagues¹¹³ found that multiple family groups had significantly lower relapse rates, lower ratings on the Brief Psychiatric Rating Scale and improved vocational outcomes.

7.6 Best Practice When Consumers Refuse Consent

As the primary challenge of working effectively with carers occurs when consent to share information is not attained, the majority of best practice literature focuses on this scenario. In order to achieve good practice, clinicians must first understand that carers have rights even when there is not consumer consent to share. According to legislation and the literature, regardless of consent status carers are entitled to receive general information about the consumer (which is discussed in greater detail in Section 7.7). Slade et al.¹¹⁴ have developed a best clinical practice framework for when consumers refuse consent to share information (see Appendix D). This includes the clinician exploring the decision with the consumer, liaising with the carer, and discussing potential consequences with the consumer. The clinician then exercises clinical judgment, considering the known consumer views, before deciding to share some or all information.

When consent is refused, carers should have access to appropriate supports, including: assistance and guidance from staff; an annual assessment and care plan based on their own caring, physical and mental health needs; carer information packs; and carer education (e.g., managing difficult behaviour, access to local resources and peer-support networks).¹¹⁵ These supports are considered necessary because, as explicated by a carer consultant:

It takes more than one session and a few brochures, for families to really grasp the manifestations of mental illness. [Carer consultant]

To ensure that carers are consistently provided with sufficient knowledge and support to provide care, it has been suggested that clinicians may benefit from “carer training”, which may be best led by consumers and carers themselves.¹¹⁶

¹¹³ Bradley, G. M., Couchman, G. M., Perlasz, A., Nguyen, A. T., Singh, B., & Riess, C. (2006). Multiple-Family Group Treatment for English- and Vietnamese-speaking families living with schizophrenia. *Psychiatric Services, 57*, 521-530.

¹¹⁴ Slade et al. (2007), op. cit.

¹¹⁵ Avon & Wiltshire (2006), op. cit.; Gray et al. (2008), op. cit.; Partners in Care (2004). *Carers and confidentiality in mental health: Issues involved in information-sharing* [leaflet]. London, UK: Partners in Care.; Pinfold et al. (2007), op. cit.; Rapaport et al. (2006), op. cit.; Slade et al. (2007), op. cit.

¹¹⁶ Carers Australia (2007), op. cit.; Fadden, G. (2006). Training and disseminating family interventions for schizophrenia: developing family intervention skills with multi-disciplinary groups. *Journal of Family Therapy 28*, 23-38.; Gray et al. (2008), op. cit.; Office of Chief Psychiatrist (2005), op. cit.; Slade et al. (2007), op. cit.

7.7 Disclosure of Essential Information

In order to explain to consumers and carers the conditions under which consent is required to disclose information, there is a need for clear understanding of the distinction between general and personal-specific information by all parties. The literature defines general information as “information that supports carers in their role, without providing new details specific to the service user”, while personal information is understood to be “new and specific to the service user”¹¹⁷ Importantly, it is also noted that whether information is general or personal is case-specific.¹¹⁸ These definitions of the types of information emphasise that support and some information can be provided to carers without patient confidentiality being broken, with some common examples in the literature listed as the type of mental illness, medication and side-effects, likely course and outcomes, expected behaviours, and an understanding of the care plan.¹¹⁹ Interviewees also stressed the importance of understanding these distinctions:

The idea of what is confidential information, and what is general information that can be shared, needs to be much better understood and practised. [Carer Consultant]

Good information-sharing should include the disclosure of essential information such as the symptoms of early warning signs of relapse, specific risks in the individual care plan, information about the client’s treatment plan. It does not have to include any private information about the client that does not have direct impact on the treatment plan... Even when a patient does not consent to communicating with their carer, good information-sharing means that you tell them that we still need to disclose the essential information to the carer. [Ex-Chief Psychiatrist]

7.8 Written Agreements about Information Management

An additional practice that is integral to good information-sharing involves planning for potential fluctuation in the mental state of consumers.¹²⁰ One stakeholder identified the type of agreement that ought to be made:

In advance of a crisis, form an agreement with all parties about the circumstances in which confidentiality can be breached – much like forming an advance directive – in the event of a crisis. [Medical advisor with RANZCP]

Another identified a method of recording such an agreement:

(An example of good information-sharing involves) filling out a form on admission that covers 1) who is your carer?, 2) do you want them involved?, 3) to what extent do you want them involved (tick box options)?. If the consumer is too

¹¹⁷ Slade et al. (2007), op. cit. (p.152)

¹¹⁸ Slade et al. (2007), op. cit.

¹¹⁹ Avon & Wiltshire (2006), op. cit.; Rapaport et al. (2006), op. cit.

¹²⁰ Slade et al. (2007), op. cit.

unwell at the time of admission, the form is revisited two days later, and continually reviewed over time and with further admissions. This form is currently being used in some private hospitals. This clarifies permissible information-sharing for all parties involved, and is a very simple way to overcome barriers to good information-sharing. The consumer's wishes are written in black and white for everyone to see, and refer to. [Private sector consumer]

Similarly, the literature advocates that all consumers should routinely be required to develop an advance directive with their clinician and carers (if agreed), to be subject to continuous review and development.¹²¹ An advance directive enables the consumer to indicate how they wish to be treated for their illness if their decision-making ability becomes impaired.¹²² Advanced directives serve the important function of ensuring that a consumer's wishes are being upheld to the fullest extent possible, and that their information is being treated in a respectful manner, even when the consumer lacks the capacity to make decisions regarding their own care.

Advance directives do not presently have legal recognition in Australia. If this were to occur, there would be great need to inform consumers, carers and service providers about their legal status. Undoubtedly the many issues around advance directives are beyond the scope of this paper. Certain questions will no doubt need to be resolved, such as whether or not there is an allowance for clinical discretion in extremis, since not all circumstances can be anticipated in advance. A pro-forma of what an advance directive might look like has been developed by the Victorian Mental Health Legal Centre.¹²³

7.9 Possible Ways Forward in Legislation

Although it is widely acknowledged in the literature that legislative change is not necessarily required in order to achieve good practice,¹²⁴ there is some scope to potentially improve current legislative provisions. Scotland's 2003 Mental Health Act established a (Named Person) policy whereby a consumer of 16 years and over can nominate someone to receive all papers, medical and sensitive information about them and represent their interests. If the consumer does not nominate a Named Person, the responsibility defaults firstly to the primary carer, and then to the nearest relative.¹²⁵ Under this policy, the Named Person must have access to all information, which thereby eliminates some of the aforementioned challenges associated with information-sharing, particularly during times of incapacity. However, in cases where alternative decision-making occurs it is important that the consumer is involved in the decision-making process as much as possible, by being given appropriate information and support and

¹²¹ Avon & Wiltshire (2006), op. cit.; Mental Health Commission (2002), op. cit.; Slade et al. (2007), op. cit.

¹²² Mental Health Act Review Group (2008). *Mental health act review*. Scotland: Mental Health Act Review Group.

¹²³ See: http://www.communitylaw.org.au/mentalhealth/cb_pages/images/mhlcadvancedirective.pdf, retrieved 16 September 2009.

¹²⁴ Mental Health Commission (1998), op. cit.; Mental Health Commission (2002), op. cit.; Privacy NSW. (2004b). *Submission: Review of the Mental Health Act 1990: Discussion Paper 1: Carers and Information Sharing*. Sydney, NSW: Office of the NSW Privacy Commissioner.

¹²⁵ Mental Health Act Review Group (2008), op. cit.

having their previously expressed wishes acknowledged.¹²⁶ In line with this, Scotland's 2003 Mental Health Act also has a principle stating that clinicians must consider the consumer's past and present wishes and advance statements.¹²⁷

7.10 Carers' Legislation

The essential role of family, friends, and partners in the lives of the vast majority of consumers is being recognised and supported worldwide by innovative policy and legislation¹²⁸ (see also Section 5). This can be seen in the evolution of international legal frameworks covering mental health consumers and their supporters. For example, where the UN Mental Illness Principles (1991) do not specifically mention family carers and their role in support and care¹²⁹ the UN CRPD explicitly addresses the role of family in its Preamble, declaring that:

...the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.¹³⁰

It should be noted that the Preamble does not contain binding legal obligations but it does play an important role in how the Convention is interpreted.

It is hard to say how Australia's ratification of the UN CRPD will affect laws relating to privacy and confidentiality in mental health (and mental health legislation generally). It seems likely that it will add weight to the argument to strengthen the right to privacy and confidentiality of the consumer. Nevertheless, there is definitely scope for the Convention to transform the way family and 'carers' are conceptualised in legislation and how the law might support their needs.

Carers Australia has campaigned for a definition of 'carer' to be established in national legislation in order to firmly establish a policy framework to support carers consistently throughout the states and territories.¹³¹ Carer legislation is now in place in the NT, SA, Victoria and WA. A number of states now have a carer charter, a carer policy or carer action plan (ACT, NSW, Queensland, SA, Victoria and WA), which buttress carer programs within their jurisdiction. They also set a legislative standard for the treatment of carers by government services.¹³² The Western Australian Act in 2004 was the first to define 'carer' in Australia and to incorporate a Carers Charter in the legislation. It

¹²⁶ Mental Health Commission (2002), op. cit.

¹²⁷ Mental Health Act Review Group (2008), op. cit.

¹²⁸ Leggatt, Parker & Crowe (in press), op. cit.

¹²⁹ United Nations General Assembly (1991). Principles for the protection of persons with mental illness and the improvement of mental health care. Adopted by General Assembly resolution 46/119 of 17.

¹³⁰ United Nations General Assembly (2006). Convention on the Rights of Persons with Disabilities. Adopted by the General Assembly resolution 61/611 of 15. Retrieved September 15, 2009 from <http://www.un.org/disabilities/convention/conventionfull.shtml>.

¹³¹ Carers Australia (May 2008). *Federal Budget Analysis, 2008-09*, Canberra.

¹³² Carers Australia (2008), op. cit.

requires that the views and needs of carers are taken into account by medical professionals, public hospitals and those involved in delivering home and community care and disability services, alongside the views and needs of people receiving care when decisions are made that impact on the caring role¹³³. The extent to which carer legislation has affected the use of confidentiality and information-sharing in these jurisdictions is unknown.

7.11 Dissemination of Policy Documents

It has been noted by Privacy NSW, that “once equipped with some factual information about how the principles in privacy legislation are intended to apply, problems that may appear intractable can be worked through by service providers, carers and consumers in an open, sensitive and privacy-respectful manner”.¹³⁴ It is therefore vital that policy documents on confidentiality and information-sharing for consumers, carers and professionals be widely available and easy to access.¹³⁵ Codes of practice then need to be developed in accordance with what the Acts proclaim, as is being proposed in Victoria.¹³⁶ Widely disseminated practical guidance will help to facilitate compliance with the intentions of the Act.

The Victorian Department of Human Services document *Confidentiality under the Mental Health Act 1986* is a good example of a policy document that addresses practical issues facing consumers, clinicians and carers. It clearly explains the limitations under the Act and provides a clear table of the “Summary of legal grounds for disclosing mental health consumer information”. This table not only provides an overview of the specific grounds for information disclosure, it also categorises these exceptions according to the requester (i.e. advocate, carers, police, child protection) and directs them to the relevant legislation and guideline reference.¹³⁷

7.12 Establishing a National Mental Health Commission to implement national standards

In Ireland, Canada, New Zealand, and the USA, Mental Health Commissions have been established which regularly review policy and planning in national or state mental health systems. The Mental Health Commission in the Isle of Man Government for example, ensures the operation of their own Mental Health Act Code of Practice, reviewing and monitoring compliance with the Act.¹³⁸ Similarly, New Zealand’s Mental Health Commission has published a number of national reviews of privacy and confidentiality practices in the mental health system.¹³⁹ Whether a National Mental Health Commission would be of benefit in Australia is currently undetermined, however it is worthy of consideration.

¹³³ Ibid.

¹³⁴ Privacy NSW (2004a), op. cit.

¹³⁵ Pinfold et al. (2007), op. cit.

¹³⁶ Department of Human Services (2009), op. cit.

¹³⁷ Department of Human Services VIC (2008), *Confidentiality under the Mental Health Act 1986 - November 2008*, Melbourne, Vic. See <http://www.health.vic.gov.au/mentalhealth/pmc/confidentiality.htm>

¹³⁸ Dept of Human and Social Services, Isle of Man, <http://www.gov.im/dhss/services/health/practice.xml>

¹³⁹ Mental Health Commission (1998), op. cit.; Mental Health Commission (2002), op. cit.

7.13 Conclusions

Privacy and confidentiality in mental health is a worldwide issue, and for this reason it is beneficial to gain an understanding of how other countries are addressing the topic, as well as consulting with local stakeholders. The primary theme throughout the literature and stakeholder interviews was the need for a cultural change that is supportive of the tripartite approach to achieving optimal treatment and recovery for the consumer. In order to potentially foster the desired culture, there are many changes that can be considered at both the service level (e.g. training and support for staff, increased communication between all parties), and the legislative level (e.g. advance directives, carer legislation).

NMHCCF Advocacy Brief

Issue: Privacy and Confidentiality

Background

Current practices around privacy, confidentiality and information-sharing are a significant concern for mental health consumers, their families and their carers.

There is a lack of knowledge about the laws governing privacy and confidentiality, which vary between states and territories. This inconsistency has the potential to compromise both the privacy of consumers' information and their ability to access and provide information to family/carers which is required for their caring role.

The NMHCCF is calling for clarification of all privacy and confidentiality legislation – or the lack of it – across Australia

Key Points for Consumers and Carers

In 2007-08, the NMHCCF conducted a consumer and carer survey on privacy and confidentiality issues and concerns. The data was collated and analysed in a preliminary way to form the basis of an Issues Paper, which is currently being written by research consultants and is due for completion by August 2009.

The key points from the preliminary survey include:

- **Consumers and carers** reported privacy and confidentiality is sometimes used as a way to exclude them from gaining information;
- **Consumers and carers** were not satisfied when mental health services did not acknowledge the importance of talking with them about how they would like their health information to be shared;
- **Consumers and carers** said that there were some issues regarding privacy and confidentiality and information sharing on which they could agree and others where they could not;
- **Consumers and carers** liked the concept of an agreed approach to exchange of information;
- **Consumers and carers** believed that additional assistance and support from clinicians would allow better management of information-sharing between them;
- **Consumers** denied access to their health information saw this refusal as potentially harmful to the relationship between clinician and consumer;
- **Consumers** would like the opportunity to decide what information is shared with their carers;
- **Consumers** would like to be advised and consulted about who has the right to access their personal health information; and
- **Carers** are not always provided with the information they need to assist them in their caring role.

Key Issues for the Future

The Issues Paper

An Issues Paper has been written by consultants using a collaborative approach with consumer, carer and clinician project teams, to ensure that the views and perspectives of the three major stakeholders are fully explored. The paper examines the impact of privacy and confidentiality on the experience of consumers and carers in our national mental health system and will help generate a comprehensive range of solutions and recommendations for the final report following input from key stakeholders across Australia.

The NMHCCF will use the Issues Paper to develop a position statement on Privacy and Confidentiality, which will be finalised and published in 2010.

The findings and recommendations listed in this Advocacy Brief will be reviewed and possibly modified after this work is complete.

Recommendations for change from the preliminary survey analysis

- Consumers, carers and clinicians should engage in open discussion about what information can be shared with whom, and when, and how.

The NMHCCF endorses the promotion of three-way dialogue between treating clinicians/mental health services, consumers and carers about what information can be shared, and how and when it should be shared. Open communication has the potential to reduce misunderstandings and antagonism around information-sharing.

Name of Nominated NMHCCF contact on this issue

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(Revised December 2009)

List of key stakeholder interview questions

1. Could you describe your current (or past) role(s) in the mental health system?
2. What are the key (2 or 3) issues that you think should be addressed in our paper?
3. What are some specific examples you can give of good and bad practice in information-sharing?
4. What does good information-sharing look like?
5. How can we maximise the collaborative relationship between consumers, carers and clinicians for the benefit of consumers and carers without compromising consumers' confidentiality?
6. What barriers do you think hinder the development of good information-sharing?
7. How can we overcome those barriers?
8. What are some specific instances of what has worked in terms of implementation of good practice?

Summary of key issues from stakeholder interviews

Consumer stakeholders:

- Consumers: the rights of consumers are paramount; consumers have a right to protect their own privacy and to participate in their own care, and any information-sharing must be conducted *with their consent*
- Carers: with the consent of the consumer, the carer should have the opportunity to be involved in consumers' care and treatment and to be provided with relevant information about the consumer's circumstances; "with information comes responsibility" – carers should respect this information.
- Professionals and practice: staff hiding behind privacy & confidentiality as an excuse; the "crisis culture" of the Australian mental health system that works against developing a holistic care plan with the consumer and carer.

Carer stakeholders:

- Information-sharing: lack of it; barriers to information-sharing, including the different legislations and misinterpretation of these; best practice - and policies that support it; addressing the rationale for importance of information-sharing, rather than an emphasis on privacy and confidentiality, including that failure to share information hinders the consumer and the carer from achieving what they should be achieving in their lives. Improvements in information-sharing would 'redress the imbalance' and recognise the confidentiality needs of carers.
- Carers are given enormous responsibility but few rights: carers need certain information so they can attain their entitlements and access services, and to make significant decisions about their own lives and that of their families.

Professional stakeholders:

- Theoretical issues: attaining an appropriate balance between the needs and rights of all people involved, with the aim being to promote person-centred care; treatment of mental illness and recovery cannot be achieved without the ability to communicate with others involved in the consumer's care (done in the best interests of the consumer, and with respect to their privacy; there also needs to be enough information given to carers); start using the same principles as used within other systems of health care that include communication between the people involved in the consumer's care.
- Practice issues: the skill involved in applying the concepts in policies and guidelines to the practicalities of working with consumers and families; advice to practitioners about how to apply these concepts on a day-to-day basis; obligations of individual practitioners, to both professional bodies and their employers, regarding confidentiality; less about legal provisions and more about managing two sets of relationships.
- Service issues: the potential risk of harm that comes from inappropriate disclosure of information is given too much emphasis - the converse needs

more consideration – potential harm arising from *not* providing information to families when they need it; privacy and confidentiality are not sufficiently addressed by services – we need systems whereby staff can readily access advice and consult with one another about issues that arise.

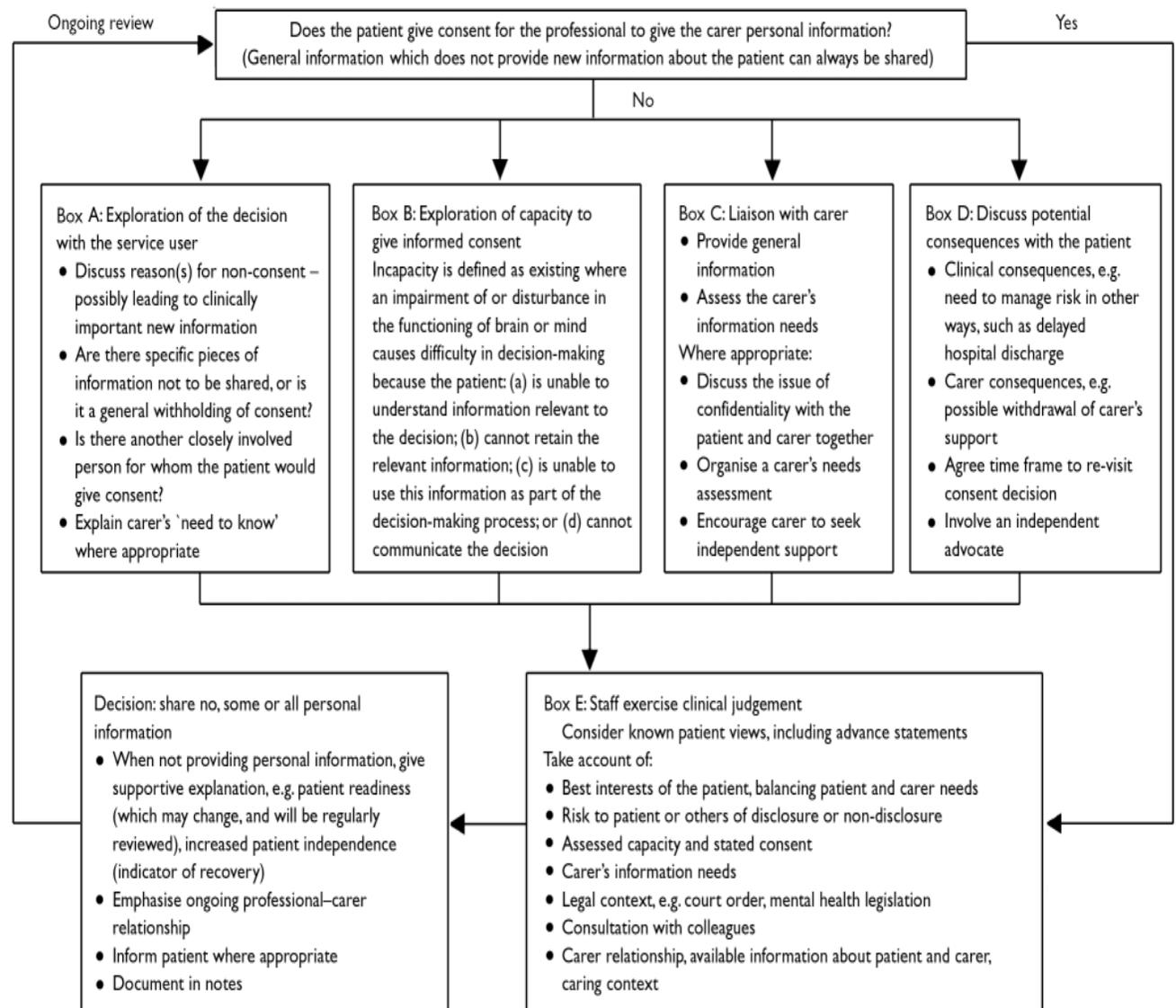


Figure 1. Framework for best clinical practice when consent is not given to share information with carers. From: Slade et al., (2007). Best practice when service users do not consent to sharing information with carers. *British Journal of Psychiatry*, 190, 148-155. Reproduced with permission from the first author.