

Recommendations for information sharing that supports family involvement and upholds the rights of service users

Recent reported instances of people experiencing significant mental health difficulties being released from hospital without family being notified has raised calls for revisions or appeal of PHIA (Personal Health and Information Act), particularly as it applies to mental health patients.

Challenges and barriers to information sharing, along with a general lack of collaboration among mental health professionals, service users and families, is an unfortunately common experience – not only in Manitoba’s mental health care system, but in mental health care systems world-wide.

Best practices and inclusive approaches to mental health recovery that include, incorporate and acknowledge family’s important role in supporting relatives with mental illness or mental health disturbances exist and should be incorporated into Manitoba’s mental health system.

Families as key supports in a mental health system

Family caregiving has a history of being discouraged, particularly with psychiatric and psychological models of care that blamed families for mental illness or distressⁱ. Yet families provide significant, often long-term, caregiving and support to family members with mental illness or mental health issues. The importance of families in providing care and supports has risen since the deinstitutionalization of mental health facilities and the restructuring of the health care system in Canadaⁱⁱ.

Professional attitudes have generally evolved to either recognize the care that families provide, or in any case, to acknowledge the care that families are obligated to provide. The latter is particularly the case in states that do not provide a full range of treatment options or do not adequately provide important social determinates of health (eg. housing, social supports)ⁱⁱⁱ.

Despite an increasing acknowledgement of the caregiving performed by families, international research suggests that many families experience barriers to being effective caregivers, especially in interactions with the formal mental health system and primary care. This brief focuses on barriers related to information sharing by medical and/or mental health professionals and are specific to cases where the service user has an acute mental health disturbance, and more often, a serious mental illness (SMI).

Barriers to information sharing

Health privacy laws and regulations can be complex and are often contradictory^{iv}. Policies tend to emphasise professional codes of conduct and most professionals face large fines and censure if or when they break or contravene regulation. The result is that health care professionals are given strong incentive to not share information, even in incidences where risk to the service user is high. In short, “professionals can find it easier and safer to say nothing”.^v Grey et al (2003) call this a “confidentiality smokescreen”. In CMHA’s perspective, confidentiality smokescreens are institutional in nature rather than deliberate attempts to abdicate responsibility on the part of health care professionals. It is for this reason we advocate that the practical barriers to information

sharing should to be assessed and that this can be accomplished while maintaining the rights of people experiencing mental health challenges to their health privacy.

Practical factors create barriers to information sharing. For example, mental health care professionals are often not trained or supported to interpret privacy protocol. Further, illustrating the skill to do so is not viewed as a key workplace competency. Training and guidance on interpreting confidentiality laws and practices is uneven, ambiguous and infrequent^{vi}. Professionals need to understand the key difference between general and personal information; they need clinical skills to access what family caregivers already know; and be able to create a context for dialogue between service users and family – even during times of acute crisis^{vii}.

Mental health professionals can also experience barriers to information sharing in their interaction with families. Barriers include a lack of time to engage family and/or engage family^{viii} and service users in dialogue. From mental health professional's perspective, families can contribute to barriers to collaboration (upon which information sharing rests) because they can be in a state of “emotional burnout”^{ix} or lack basic mental health and illness knowledge. The result is that families are commonly positioned within mental health systems to “keep on caring” without adequate or up-to-date information^x. Notably, this can hinder a family's ability to provide care or support to their loved one^{xi}.

Best practice frameworks have been developed and can be adopted to a Manitoba content (see Appendix for one such example). To avoid such frameworks being adopted only at the whim of individual professionals^{xii}, the adoption of such frameworks need to be incorporated into Manitoba's shift to a recovery-oriented mental health system which supports families and offers substantive involvement as well as family-focused supports and programs.

Upholding the rights of service users

Service user's place a high level of concern on information sharing with family, even where family is acknowledged as “supportive”^{xiii}. Non-consent to share information can be clinically viewed as a (case-specific) instance of independence and self-determination, which are important indicators of recovery and well-being^{xiv}. Given that a large percentage of people with serious mental illness rely socially and economically on family^{xv}, calls to change or abandon regulations that uphold the rights of people with mental health issues and illnesses miss the mark.

The Canadian Mental Health Association, Manitoba and Winnipeg, suggest the problem lies not with PHIA but with its interpretation and, in particular, with the training of health care staff to confidently interpret it. We also argue that support for families within the mental health care system needs to be institutionally supported, with services developed to work directly with families. CMHA also recognizes that mental health services are underfunded – the volume of need for services exceeds the available resources. This is a major barrier for mental health professionals to have the time to engage family and/or service users in dialogue about care and treatment.

Recommendations

- 1. Information sharing with family, and the inclusion of family as key supports in a recovery plan, need to be supported at an institutional level**

- Create professional roles and robust services that serve and support families within the mental health system.
- Encourage collaboration between staff and families, especially in the service of creating dialogue between health care staff, families and service users.
- Involve service users and families in the creation of information / educational material on mental illness, confidentiality issues and information sharing.
- Promote the role of advance statements (i.e. health directives) as a part of mental health education for both service users and families.

2. Professionals need the skills to resolve information-sharing dilemmas

Mental health care professionals – and all those who work in health care – must be trained to interpret privacy laws and regulations in an ethically robust way. It needs to be recognized that laws, regulations, and policies are often complex (rather than straightforward), sometimes contradictory, requiring active interpretation and an ability to parse complex ethical quandaries. This is especially the case when service users do not grant consent to share information with family but where it may be in the best interest of the service user's health or safety to do so. Professionals need training time dedicated to explore the complex ethical, legal and practical dilemmas around confidentiality and information sharing. As part of their ongoing workplace training, professionals should study conflicts in confidentiality and how barriers to information sharing can be resolved in practice.

3. Systematically review Manitoba legislation and RHA guidelines

Review Manitoba legislation and regulations, as well as Regional Health Authority guidelines and policies, with the purpose of identifying confusing and contradictory policy and practice. How do Manitoba's current laws and policies help or hinder health care professionals? Have high penalties for breaking confidentiality encouraged an institutional smokescreen approach to confidentiality and created barriers to information sharing? How can barriers to family involvement (broadly construed) be encouraged while maintaining service user consent and rights to privacy?

4. Incorporate family involvement in the making of a recovery-oriented mental health system

Emerging evidence suggests that structured and meaningful family involvement can strengthen the recovery pathways of service users. But mental health professionals are strongly disincentivized from engaging family, or engaging service users' to include family in their recovery planning or crisis intervention. Engaging family and service users require mental health providers to have time to identify and engage with families.

Define a professional role for mental health professionals that facilitates the engagement of family in service user's recovery planning and across various contexts of care (i.e. type of illness, stage of recovery, past history, social or economic circumstances). This should include, but not be limited to, a specific role for providers to explain the instances where a person is clinically determined to have the capacity to reasonably prohibit sharing of all or some of their health information.

Create professional accountability measures in clinical practice that include family involvement. This can include, for example, early identification of family members, but should also include the incorporation of the expert knowledge families have about the service user's history or current crisis.

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APPENDIX

One example of best practice frameworks is Slade et al's 2007 "Framework for best clinical practice when consent is not given to share information with carers":

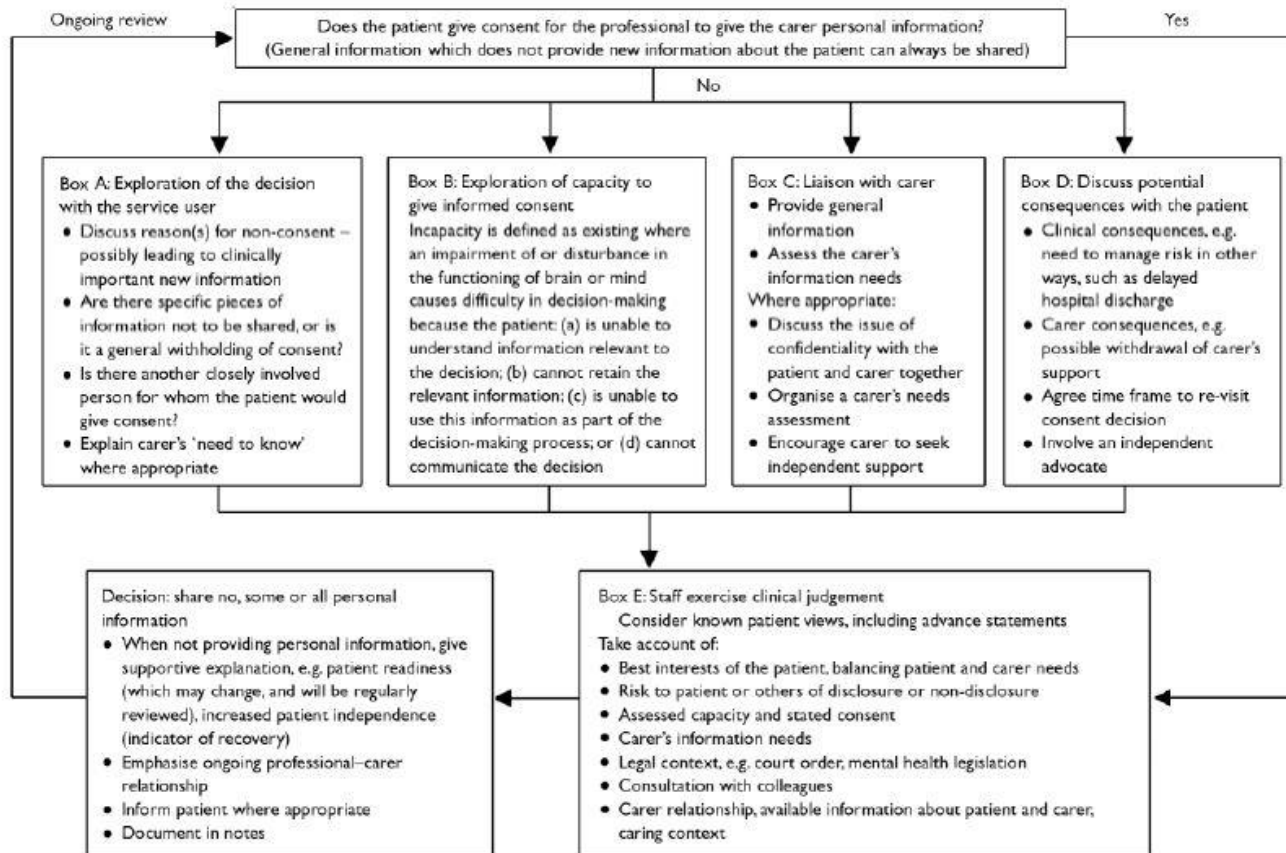


Fig. 1 Framework for best clinical practice when consent is not given to share information with carers

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- ⁱ J. Rowe (2012) "Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals", *Journal of Psychiatric and Mental Health Nursing* 19: 70-82.
- ⁱⁱ C. Ward-Griffin, R. Schofield, S. Vol et al (2005) "Canadian families caring for members with mental illness: A vicious cycle", *Journal of Family Nursing* 17: 140-161.
- ⁱⁱⁱ Ibid.
- ^{iv} The contradictory and ambiguous nature of confidentiality and privacy laws is noted in all the papers cited in this brief. M. Slade et al's 2007 paper included a review of policy in the UK. They found, for example, that in 56 policies and 35 supporting documents, only 5 policies "provided practical guidance on how to appropriately share information" (p. 149).
- ^v B. Gray, C. Robinson, D. Seddon, and A. Roberts (2008) "'Confidentiality smokescreens' and carers for people with mental health problems: The perspectives of professionals", *Health and Social Care in the Community* 16: 378-387 at 382.
- ^{vi} B. Gray et al.
- ^{vii} M. Slade et al (2007) "Best practice when service users do not consent to sharing information with carers: National multimethod study", *British Journal of Psychiatry* 190: 148-155.
- ^{viii} M.J. Kaas, S. Lee and C. Peitzman (2003) "Barriers to collaboration between mental health professionals and families in the care of persons with serious mental illness", *Issues in Mental Health Nursing* 24: 741-756. Kaas et al also found that disagreements over treatment and lack of success in working with families were also cited by mental health professionals as explanations for why families experienced barriers.
- ^{ix} Kaas 2003.
- ^x B. Gray, C. Robinson, D. Seddon, and A. Roberts (2008) "'Confidentiality smokescreens' and carers for people with mental health problems: The perspectives of professionals", *Health and Social Care in the Community* 16: 378-387 at 379.
- ^{xi} C. Wilkinson and S. McAndrew (2008) "'I'm not an outsider, I'm his mother!': A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings", *International Journal of Mental Health Nursing* 17: 392-401.
- ^{xii} R. Lakeman (2003) "Practice standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation", *International Journal of Mental Health Nursing* 17: 44-56.
- ^{xiii} M. Slade et al.
- ^{xiv} M. Slade et al at p. 153.
- ^{xv} T. Marshall and P. Solomon (2003) note that a high percentage of service users live with care givers (~50%) and 77% have frequent contact. Families are thus key players of a social support network, as well as economically relied upon. (T. Marshall and P. Solomon [2003] "Professionals' responsibilities in releasing information to families of adults with mental illness", *Psychiatric Services* 54: 1622-1628.)