Establishing a Circle of Care: The Development and Evaluation of a new Consent Form

by

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This informed consent form is meant to be used by agency and ministry staff as part of the broader services they provide, or under supervision of agency staff, to enhance communication and optimize service provision.
DEDICATION
This thesis is dedicated to those people who have left traces in my heart: Oma, Oma and Opa, Ana, Mama and Papa, and my husband.
ABSTRACT
The purpose of this project was to investigate current practices and processes of sharing clients’ personal health care information among agencies and, based on that information, design a comprehensive consent to share personal health information form. An interdisciplinary network of practitioners, often referred to as Circle of Care, works collaboratively with the goal of providing quality treatment care. As this was a quality assurance project, the main objective was to design a new consent form to improve service provision among the members of the circle of care. It was hypothesized that the new consent to share private health care information document would be rated by users as more positive than the currently used consent form. This project consisted of a thorough literature review, gathering and analyzing of local agencies’ consent documents and examining current legal, ethical, and social requirements for the overall consent process. Staff from the placement agency served as participants, who provided feedback on a questionnaire, which was specifically designed to assess, compare, and contrast the standard with the new consent form, using six constructs: legibility, comprehensiveness, comprehensibility, practicality, simplicity, and time-effectiveness. Results indicated perceived improvements across the six constructs, and statistically significant increases were documented for 4 of the 6 constructs: legibility, comprehensiveness, practicality, and simplicity. It was concluded that the positive data trend was evidence of significant improvements on the new consent to share personal health care information document.
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CHAPTER I: INTRODUCTION

Overview
Canadians take immense pride in their efforts to provide quality patient care. Over the past decade, a revolutionary model of patient care has entered the Canadian health care system and gained popularity among different service providers. The circle of care is a multidisciplinary team approach to patient care. A team of practitioners from different areas of expertise consult and collaborate in order to provide optimized services to their clients. As part of this process, agencies disclose and exchange their patients’ private health information with each other. However, ethical and legal requirements are in place so that a client must provide informed consent before any information can be shared with another service provider. A 2006 study by Schachter and Kleinman investigated the documentation of informed consent among 1600 psychiatrists in Ontario. The study yielded shocking results because more than 37% of the participants did not gather their clients’ informed consent prior to sharing information, and only 11% felt that it was a necessary protocol. Certainly this begs the question whether or not practitioners are sufficiently familiar with the legal requirements of obtaining clients’ consent. As a result, it seems prudent to review the current guidelines regarding the manner and compliance for obtaining clients’ informed consent.

Rationale
The Canadian government has put forth a multitude of ministries and agencies serving Canadians and their health issues. Service providers range from family practitioners to mental health care practitioners, social services, disability services, children aid services, and many others; these service providers form the clients’ circle of care. As part of the circle of care, practitioners often require access to various types of health care information to aid them in understanding their patients’ needs in order to conceptualize treatment options and provide optimized services. However, collaboration among agencies is often stalled by a time-consuming process of obtaining the clients’ consent for sharing their health care information, resulting in increased wait and referral times. Given the importance of a multidisciplinary approach to client care, it would seem more efficient to design a new consent to share information form in order to improve interagency communication and enhance the exchange of clients’ personal health care information.

Hypothesis
It was hypothesized that the target agency’s staff would rate the newly designed consent to share health information form more positively when compared with the current consent form. Further, the expected outcome was that the new consent form would be implemented across agencies and ministries in South Eastern Ontario. Ultimately, it was hoped that the new document would facilitate interagency communication and decrease wait times for the exchange of information and service provision.

Chapter Overview
Chapter II: literature review.
In this section, the author explored the ethical, legal, and social requirements involved in obtaining clients’ informed consent to disclose private health information. Key concepts such as confidentiality, privacy, and consent were defined. Special attention was given to the Canadian
Code of Ethics and current laws and regulations set out by the Canadian Psychological
Association and the Privacy Commissioner of Canada – Personal Health Information Protection
Act (PHIPPA), and Personal Information Protection and Electronic Documents Act (PIPEDA).
This section also identified controversial topics and gaps in the current literature on informed
consent, which enriched the complexity of the topic. A comprehensive summary amalgamated
the main points of the research findings.

**Chapter III: method.**
The method section provided a detailed, step-by-step process of the procedures that
resulted in the development of the new ‘consent to share information’ document. Input from the
participants, staff from a psychology clinic, guided the author in designing the new document by
completing a pre-post questionnaire evaluating the strengths and shortcomings of the agency’s
current consent to share information document. The questionnaire examined the following six
constructs: legibility, comprehensibility, comprehensiveness, practicality, simplicity, and time
effectiveness.

**Chapter IV: results.**
This chapter will consist of three components: a description and interpretation of the
statistical analysis of the pre-post questionnaire; a visual presentation of the raw scores in
tabulated and graphical format; and the final product: the new ‘consent to share information’
document - *Establishing a Circle of Care*.

**Chapter V: discussion.**
This chapter will provide a synopsis of the study’s main findings in conjunction with an
interpretation of the study’s results. The author will link back the results to the initial hypothesis
and determine whether the study yielded significant results and produced the expected
outcomes. Further, the author will analyze the strengths and limitations of the study by
evaluating multi-level challenges and the study’s contributions to the field of behavioural
psychology.
CHAPTER II: LITERATURE REVIEW

Overview
The purpose of this literature review was to identify common ethical, legal, and social components, which require consideration in the informed consent process. Designing a new consent to share health care information document appears to be a straightforward process, yet it entails thorough research and understanding of the competing requirements for compliance. This project will begin by defining the circle of care, followed by an exploration of ethical conduct and the investigation of current laws and contemporary social issues relevant to consent. It will conclude by summarizing the main findings and proposing key elements considered critical for a new consent document based on the findings from the literature review.

Circle of Care
A circle of care refers to the network of agencies and people who provide quality patient care. Understanding who is involved in a circle of care is important because it can promote the effective exchange of health care information and enhance consultation among the involved health care providers. The goal of a circle of care is to provide time-effective treatment by combining the expertise and resources of different professions by integrating patients’ health care information (Reid & Wagner, 2008). As part of the circle of care, practitioners often require access to various types of health care information to aid them in understanding their patients’ needs in order to conceptualize treatment options and provide optimized services. This process can be stalled by the process of gathering a client’s consent to share certain or all pertinent information with other professionals (Reid & Wagner, 2008). In order to facilitate this process, the Information and Privacy Commissioner of Ontario (IPC, 2009) developed a document detailing circumstances in which a practitioner can assume implied consent and situations that require informed consent. A health practitioner can only assume implied consent if all of the following six criteria are met:

I. The health information custodian must fall within a category of health information custodians that are entitled to rely on assumed implied consent.
II. The personal health information to be collected, used, or disclosed by the health information custodian must have been received from the individual, his or her substitute decision-maker or another health information custodian.
III. The health information custodian must have received the personal health information that is being collected, used or disclosed for the purpose of providing or assisting in the provision of health care to the individual.
IV. The purpose of the collection, use or disclosure of personal health information by the health information custodian must be for the provision of health care or assisting in the provision of health care to the individual.
V. In the context of disclosure, the disclosure of personal health information by the health information custodian must be to another health information custodian.
VI. The health information custodian that receives the personal health information must not be aware that the individual has expressly withheld or withdrawn his or her consent to the collection, use or disclosure. (Information and Privacy Commissioner of Ontario [IPC], 2009, pp. 7-22)
However, in cases that implied consent cannot be assumed, health care practitioners require a written documentation of the client’s informed consent for the disclosure of personal health information. Reid and Wagner (2008), however, pointed out a caveat with regards to this traditional model of the circle of care, which is that while health records would be more compatible and accessible, there is no guarantee that health care will be more standardized let alone coordinated. Therefore, the authors proposed an even more advanced clinical information system – ‘care across the continuum’ – in which the care should be coordinated by the primary physician. This would have the advantage that the care would be patient-centred, for all medical information would be discussed not only among professionals but also directly with the patient, so that decisions are made collaboratively. Ultimately, this could lead to improved patient self-management (Reid & Wagner), which is the best possible outcome a practitioner can hope for. However, this would also mean that the physician would have to be available and willing to spend time sharing this necessary information with the patient, which can be a time-consuming process. Nevertheless, different ideologies set aside, in order to be able to implement the circle of care, it is essential for health care providers to be familiar with the ethical, legal, and social requirements of consent.

### Ethical Requirements

Introduced by the Hippocratic Oath in 5 BCE, codes of ethics have evolved over time, reflecting contemporary changes in social and political contexts. The development of ethics is an ongoing, dynamic process, which requires time and thorough deliberation since the finished product consists of ethical standards that lay the foundation for professions and their professional conduct. The most influential code to date for the helping professions is the Canadian Code of Ethics.

**Canadian Code of Ethics.**

Over the past quarter century, extensive research has been conducted to identify, design, and implement best practice ethical approaches for dealing with clients and their personal health care information. In the late 70s, the Canadian psychological community decided to design their own code of ethics because it would reinforce Canadian identity, serve as a guidance for psychologists, and provide an ethical framework to assist with moral dilemmas (Pettifor, Sinclair, & Strong, 2005). After an eight-year developmental process, the introduction of the Canadian Code of Ethics in 1986 was the onset of providing an ethical and moral framework for psychologists and clinicians not only in Canada but across the world. That year marked a hallmark in the development of ethics with the institution of the four core ethical principles: Respect for the Dignity of a Person, Responsible Caring, Integrity in Relationships, and Responsibility to Society (Canadian Psychological Association [CPA], 2000). The primary purpose of the code is to provide a reflection of basic moral and ethical values not a set of prescribed rules; in fact, this co-dependence between values and ethical behaviour is meant to dictate the grounds of the ethical decision making process. Pettifor, Sinclair, and Strong put this well: “codes of ethics are carefully deliberated documents since they crystallize a profession’s wisdom and values” (2005, p.184).

Since its initial establishment, the Canadian Code of Ethics has undergone revisions in 1991 and 2000 to address and incorporate feedback from the psychological community and changes in the social environment. These revisions focused mainly on improving the ethical
decision making process and shifting the code’s emphasis from individualism to collectivism (Sinclair, 2011). The latter pertained to a global criticism that the code reflected Western beliefs while being insensitive towards indigenous and Eastern cultures. Therefore, one of the main goals of the revision was to create awareness among psychologist about their responsibility to be cognizant of the effects of cultural diversity. A third revision is proposed for 2012 in order to address arising concerns regarding the misuse of technology, primarily concerning the disclosure and exchange of patients’ electronic health care information. As a result of the new technology, it will be important to establish new guidelines.

While the code has undergone significant revisions, its pillars and core have remained the same: the four core ethical principles and the ethical decision making model. For this reason, the Canadian Code of Ethics has been used as a guideline in designing other ethical codes for developing and developed nations alike across the world; examples include Norway, New Zealand, Mexico, and South Africa (Pettifor et al., 2011). These nations were inspired by the conceptual clarity and practicality of the code, yet each nation adapted the code based on its cultural, social, and political needs. For example, the development of the South African code of ethics incorporated a human rights component, which paved the way for democratization in South Africa (Pettifor et al., 2011). As a result, the Canadian Code of Ethics is both nationally and internationally acclaimed because of its lengthy developmental process, introduction of moral framework, utility as an educational tool, conceptualization, and higher order thinking (Bryceland & Stam, 2005; Pettifor et al., 2011).

**Principle I – Respect for the Dignity of the Person.**

Principle I of the Canadian Code of Ethics was highlighted because it emphasizes on a person’s moral rights, and it has been given more weight and therefore supersedes the remaining three principles (Canadian Psychological Association, 2000). In order for health practitioners to promote best practice, there are three key elements to be followed, all of which are relevant to the present discussion: informed consent, privacy, and confidentiality.

**Informed consent.**

Obtaining clients’ informed consent for treatment and/or the disclosure of their private health information is paramount since this process is a direct reflection of the practitioner’s respect for the client’s self-determination and beneficence (Schachter & Kleinman, 2006), which in turn results in an improved client-practitioner relationship. For the most part, informed consent is usually acquired via the patient’s signature on a consent form, which includes the details of the treatment, benefits and risks, associated costs, and patient’s right to termination (CPA, 2000). However, a person’s signature on a document does not equal informed consent. In fact, informed consent is an ongoing process involving dialogue between the patient and the practitioner, during which the practitioner provides as much detail to the client as is required to further understanding. Mohr and Nunno (2011) identified the following six key elements of informed consent: “competence, disclosure, understanding, voluntariness, consent (or refusal of consent) and authorization” (p.42); the literature, however, suggests that disclosure, competence, and voluntariness encompass the above six elements (Adcock, 2009; Cahana & Hurst, 2008; Schachter & Kleinman, 2006; Vitiello, 2009). Disclosure of all pertinent information refers to the practitioner educating the patients on the information they need to know to make an informed decision. Disclosure alone is insufficient as participants need to fully comprehend the
information presented to them (Cahana & Hurst, 2008). Voluntariness pertains to clients’ commitment to therapy or agreement to disclose their personal health information without coercion or penalty for declining (Fisher, 2004). Overall, it is important that a practitioner follow the guidelines of obtaining informed consent as a means of safeguarding the patient and the therapeutic alliance. One question remains unanswered: In the end, do health care practitioners actually know with certainty that their clients provided informed consent, or do practitioners assume informed consent because they have no means of measuring disclosure, comprehension, and voluntariness (Cahana and Hurst, 2008)? This is to be kept in mind whenever practitioners acquire their clients’ verbal or written consent.

**Privacy.**

The concepts of privacy and confidentiality are essential elements for the client-practitioner relationship. Privacy refers to a person’s identity, which makes it a person’s constitutional right to be protected from unsanctioned intrusions. Once a person enters a therapeutic relationship with a health practitioner, the client puts his/her trust in the practitioner to safeguard this private information. This is of particular importance in a relationship between therapist and client because a client becomes vulnerable in the process of exploring his/her own identity, values, and beliefs. In fact, “self-disclosure accompanied by self-scrutiny, can usually only take place within a sphere of privacy” (Gutheil, 2001, p. 348). The same concept applies to private health information, which is not supposed to be shared with any third parties unless authorized by the patient. In order to ensure a person’s privacy, practitioners are cautioned to record minimal amount of information necessary and to store that securely (CPA, 2000).

**Confidentiality.**

Confidentiality falls within the same category as privacy. A practitioner cannot relay any information disclosing his/her client’s identity to any third party unless authorized by the client or required by law (CPA, 2000). There are three types of violations: The practitioner did not know; there was reasonable cause; and it was due to wilful neglect (Letzring & Snow, 2011). Regardless of the reason, in all cases the practitioner is supposed to inform the client of the breach.

Confidentiality does, however, have its limits. For example, when a physician becomes aware of or suspects that a child is harmed or neglected, confidentiality can be breached if the client discloses information that needs to be reported under the Child Abuse Reporting Law; further, if the client identifies harm to self, the practitioner has the legal obligation to disclose the client’s information (CPA, 2000). Another exception to confidentiality pertains to a practitioner’s duty to take the stand in the court of law and share pertinent information about a client with the judge. Confidentiality can also be breached to third parties in cases of serious harm to self or others. The duty to break confidentiality in cases of threats of harm to others is also known as the Tarasoff Warning, named after a female student who was stabbed to death by a former acquaintance, who, prior to the incident, disclosed to his counsellor his intent to kill Tarasoff. Even though the counsellor involved the police, he failed to warn the victim herself. As a result, the Tarasoff Warning was implemented in 1976; at first, the courts decided that a practitioner had a duty to warn potential victims (Tarasoff I), but it was soon changed to a duty to protect (Tarasoff II). The rationale behind this was that warning a victim about a potential threat is beneficial to both victim and patient as it saves lives and spares the perpetrator the legal
consequences (Gutheil, 2001). While this appears reasonable at first glance, potential dilemmas quickly unfold. Clinicians are no longer confident whether they can work within the parameters of confidentiality since breaching confidentiality is a moral dilemma in itself. Therapy might no longer be a viable option as clients may be afraid to share their violent fantasies due to the erosion of the trusting relationship. Simone and Fulero (2005) go so far to proclaim that practitioners can never make the right decision since it is impossible to comply with both ethical and legal obligations, and in the end, the onus will always be on the practitioner. In contrast, Walcott, Cerundolo, and Beck (2001) suggest that while the Tarasoff Warning had great implications in the 70s, 80s, and 90s, a shift has happened that requires practitioners to go through a comprehensive risk assessment process before making any decisions. In a nutshell, it appears that the Tarasoff debate led to a shift in the way practitioners make decisions.

Legal Requirements

Compliance with legal guidelines is important because it defers legal actions and safeguards the provision of services.

**Personal Information Protection and Electronic Documents Act (PIPEDA).**

In January 2004, the College of Psychologists of Ontario published a new privacy legislation in order to improve practice surrounding the collection, use, and disclosure of patients’ private health care information (PHI). The Personal Information Protection and Electronic Documents Act (PIPEDA) is a federal act that applies to any psychological body that provides goods and services to clients (The College of Psychologists of Ontario, 2003b). In order for each organization to comply with the regulations set out by PIPEDA, an Information Officer must be appointed, whose role is to develop a privacy policy for the organization. This privacy policy must address the current practices of collecting, using, and disclosing PHI and modify these practices if necessary (The College of Psychologists of Ontario, 2003a). A fundamental principle of this act is the patients’ right to access any of their health care information; additionally, a practitioner has the legal obligations to inform individuals about the disclosure of their health information. Because of these changes, the process of obtaining a client’s informed consent has become an essential element of adhering to the new privacy act. Moreover, the Privacy Commissioner of Ontario made a clear distinction between obtaining a client’s informed consent for treatment and obtaining a client’s informed consent for the purpose of disclosing PHI to members of an interdisciplinary team approach (The College of Psychologists of Ontario, 2003a). Violations of the act are dealt with by either the College itself or the Federal Court of Canada.

**Personal Health Information Protection Act (PHIPA)**

Shortly after the enactment of PIPEDA, the provincial government of Ontario released the Personal Health Information Protection Act (PHIPA) in order to provide practitioners with clearer guidelines in terms of handling individuals’ personal health information (Service Ontario, 2010). The distinction between PHIPA and PIPEDA is minimal but important. PHIPA pertains to personal health information only while PIPEDA also refers to commercial information. More importantly though, PHIPA provides a clear definition of personal health information:

It must relate to an identifiable individual, including information that can be combined with other data to then identify the individual; it can be in oral or recorded format (thus
simply asking a question even if the answer is not recorded can constitute collecting personal health information); and it relates to the individual’s physical or mental condition, health care, provider of health care services, payment for the health service including health card number, substitute decision maker, and non-health care information (e.g. home contact information) mixed in with other personal health information. (The College of Psychologists of Ontario, 2004, p. 7)

Another difference between PHIPA and PIPEDA is that PHIPA defines what constitutes valid consent and describes instances in which consent can be implied, written, or verbal (Service Ontario, 2010). Consent is implied when a client seeks out a practitioner for the provision of care; written or verbal consent is mandatory if the practitioner discloses personal health information to other custodians or for the purpose of research (The College of Psychologists of Ontario, 2004). This can be overruled in case of a subpoena or in case of emergency (Privacy Commissioner of Ontario, 2008). Also, indirect collection of pertinent information from third parties is permitted without obtaining the client’s consent. The discrepancies between the two documents present potential for problems, particularly for practitioners in Ontario. While all practitioners are encouraged to adhere by both PHIPA and PIPEDA if possible, there is a lack of clear instructions concerning the right path of action in case of a dilemma. Due to the fact that there is an abundance of legal constitutes, it is important to highlight the most applicable guidelines in a comprehensive document to facilitate patient care. These guidelines become even more malleable with the advances of modern technology.

**Electronic evolution.**

With the latest technological development, today’s society has become subject to a virtual world of information. The Internet has become the number one medium through which people exchange information. While this new line of communication has definitely led to accelerated and time-effective communication, many health practitioners disregard the disadvantages of advanced technology. Once information has been entered into a device that is connected to the Internet, any skilled computer specialist can access said data. Many instances have been reported of personal data theft; consequently, the Privacy Commissioner of Ontario established guidelines for the safe handling of PHI: No identifiable information ought to be stored on a portable device, and all PHI needs to be encrypted or coded (as cited in Nicholson, 2011). Along with that, personal information should not be transmitted through regular e-mail (The College of Psychologists of Ontario, 2003). Additionally, Nicholson proposed that the Canadian Code of Ethics is a good guideline for practitioners as the same principles still apply; therefore, it can aid practitioners in evaluating the risks and benefits associated with issues resulting from technology (2011). While it would be impossible for practitioners to keep up with the evolution of technology, it is their responsibility to the patient and society to become informed consumers of the latest technology because the shift away from traditional practice will impact service provisions. While using the Internet for communication purposes among members of the circle of care could be a time-effective practice, practitioners have to be cautious not to compromise their clients’ privacy and confidentiality. That is the reason why practitioners will need to review the process of sharing information with new electronic capability and identify safety measures as technology is moving really fast.
Social Requirements

It has become evident that ethical and legal requirements are complex, complicated, and sometimes even contradictory; however, there is another factor that needs to be considered in designing a consent document: influences from the social environment.

Impact of Culture.

Since Canada is a multicultural country, there are social influences that affect the client-practitioner relationship. As noted earlier, the demographic changes in Canada following the waves of immigration led to a revision of the Canadian Code of Ethics to reflect the multi-facet nature of the nation. One example that reflects these changes is that among many cultures the process of signing a document has negative associations, which is why patients can no longer be pressured into giving written consent if that process interferes with their cultural belief system; hence, voluntary oral consent suffices in which case the practitioner has to note this in his/her notes. Another common issue pertains to role diffusion; there are cultures in which parents are authoritarian and make decisions on behalf of their children, and these parents do not tolerate interference from third parties (Fisher, 2008). An example that would illustrate this is the Shafia case that was trialed in Kingston, Ontario. A Middle Eastern patriarch killed his three daughters and wife because he felt that the influences from the Western culture had interfered with his teachings and belief systems and therefore negatively affected the mentality of his family members. Shafia’s daughters had reached out for help to school counsellors and family aid services, yet when these people tried to liaise between father and children, their help was dismissed and regarded as intrusion. As a result of that, Shafia felt obliged to end the ‘suffering’ of his family and punished them for disobeying his orders. While this is an extreme example of cultural influences, it brings across the message that many cultures do not even permit the advice from third parties. It is therefore the practitioner’s responsibility to be familiar with the common cultural practices and beliefs of his/her patients (Canadian Psychological Association, 2000).

Assent versus Proxy Consent.

One topic that has stirred controversy among Canadians is whether children/adolescents should be given the right and autonomy to provide informed consent, and if so at what age. The alternative would be parental (proxy) consent, in which case the minor’s parents or legal guardians give consent on behalf of their children. An instant of assent occurs when a minor gives consent to medical treatment (Alkhatib et al., 2008). In 2010, the Ontario Ministry of Children and Youth Services (MCYS) performed a review of the Child and Family Services Act. One of the main findings was that there was no particular section that addressed the issue of youth assent, yet consensus among youth was that they wanted to be able to provide consent in the process of sharing their information with agencies and service providers. In conjunction with the present discussion, it was also found that in order to improve service provision for children and youth, a partnership had to be formed among agencies in order to provide “timely, effective services to young people and helped providers to develop better plans for young people” (MCYS, 2010, para 25). Due to the absence of a legislated framework, the MCYS suggested that new policies needed to be drafted and incorporated into the current acts. Hence, from the ministry perspective, no definite answer can be given for the current debate.

The Canadian law varies across provinces and territories reflecting the tension between acknowledging adolescents’ increased cognitive maturity and society’s duty to protect adolescents from making unwise decisions (Schachter, Kleinman, & Harvey, 2005). In some
provinces, legal age equals mental capacity (i.e., 18), yet in other provinces physicians are
strongly recommended to include minor children in the informed consent process. While
opponents argue that adolescents should not be granted the right to take their own medical
decisions seeing that they are often inclined to take risks in order to obtain immediate
gratification, proponents counter argue that by allowing children the right to assent, will improve
the patient-practitioner relationship and enhance cooperation with treatment. Similarly,
advocates debate that children and adolescents should be given opportunities to exercise decision
making in response to authority figures (Fisher, 2004). There is however consensus among
Canadian clinicians that adolescents should be included in the informed consent process if
possible; more importantly, at the age of 14, most adolescents will have met the necessary
cognitive milestones to comprehend the complexity of medical situations warranting informed
decisions (Schachter et al., 2005).

The Canadian Paediatric Society (CPS) has put forth guidelines for practitioners to aid
them with any arising ethical or legal conflicts. According to the CPS (2004), the goal of any
practitioner is to make decisions that reflect the best interest of the patient; therefore, it is the
practitioner’s responsibility to act as an advocate for the minor and mediate a collaborative
decision making process between the health care team, parents, and child. As previously
discussed, there are three hallmarks for any person to make an informed choice: decision-making
capacity, voluntary consent, and adequate disclosure of relevant information (Canadian
Paediatric Society [CPS], 2004; Schachter et al., 2005). If an adolescent meets these criteria,
his/her consent has weight. In case of a disparity between the parents’ and the child’s wishes, the
practitioner has to evaluate the competing interests in order to maximize benefits and minimize
harm. This also applies to situations in which the legal guardians are suspected of abuse or
incapability of making informed decisions for their children. In such cases, the CPS recommends
that if a conflict cannot be resolved, the practitioner is required to involve the assistance of an
institutional ethics committee or legal counsel (2004). Overall, the Canadian debate suggests that
an adolescent’s capacity to consent requires assessment on a case-by-case basis; also, more
empirical research is warranted regarding outcome measures of adolescents making medically
informed decisions.

To further explore this controversy, it is worthwhile to consider countries other than
Canada, such as the United States and the United Kingdom. In the U.S., similar procedures to
those used in Canada have been adopted in most states. The mature minor doctrine assumes that
adolescents aged 14 and older have reached the maturity required to make important medical
decisions (Alkhatib, Regan, & Jackson, 2008; Fisher, 2004). However, the following factors
need to be taken into consideration while determining a minor’s capacity: intelligence, cognitive
development, experience with illnesses, age, and family background (Alkhatib et al., 2008). This
might change given the latest research findings suggesting that children do not understand the
scope of research procedures until late adolescents/early adulthood (Fisher, 2004). In order to put
an end to the American debate, Vitiello proposed the development of standardized instruments
that assess both children’s and parents’ comprehension of the informed consent process (2008).
Nevertheless, such instruments need to be handled with caution as the practitioner’s input still
needs to be taken into consideration.
In Britain, on the other hand, practitioners refrain from using the term assent because children have the legal right to provide consent, participation involves partial decision making, and the term assent may be misused when children refuse to participate (Coyne, 2010). The U.K. has a fixed minimum age for giving informed consent, which is 16 years and older following an assessment of mental capability (Adcock, 2009). An instance of refusal can be overruled if the practitioner deems it to be in the best interest of the child. In addition to that, children seven years and older have the legal right to refuse, and it is the law to seek their assent (Nicholson as cited in Coyne, 2010). The U.K. differs from the Canadian approach in that once the parents have been appointed as the primary decision maker, the responsibility is entirely removed from the children, and their opinion has no more weight (Adcock, 2009).

In summary, it appears that at present this topic remains subject to dispute. However, strict ethical and legal guidelines are in place to protect children from potential harm. Since the literature cannot determine a distinct correlation between a child’s chronological age and competence, it remains the practitioner’s responsibility to assess cognitive ability on a case-by-case basis. Additionally, society’s understanding of children’s maturation is an ever-evolving process, which entails continuous re-evaluation. Lastly, before any policies concerning age limits are put in place, policy makers need to investigate the issue further by conducting structured research on parental role in the informed decision making process (Roberson, 2007). Overall, given the current literature, adolescents should be given an opportunity to provide assent if deemed capable during the informed consent process. Therefore, for the purpose of this project, adolescents’ legal and ethical rights need to be incorporated into the overall consent process, consent form, and the sharing of private health care information.

The social debate proposes no clear conclusions for service providers. Ultimately, the practitioner has to act in his/her clients’ best interests, sometimes even if that means to overrule a client’s wish or disregard a client’s culture.

Informed Consent Requirements

Besides compliance with ethical, legal, and social requirements, other factors play a role in designing a ‘consent to share information’ document. A 2010 study by Albala, Doyle, and Applebaum investigated the evolution of consent forms over the past quarter century. The results demonstrated two trends: Over time, consent forms have become consistently longer, and with increased length, comprehension was proportionally compromised (Albala, Doyle, & Applebaum). Consent forms increased in length because ethical conduct required that certain components be included in a consent form; however, research found that patients’ are less likely inclined to fully read a lengthy document, and their comprehension was found to be poorer in comparison to shorter documents (Mann as cited in Vitiello, 2008). Stunkel et al. (2010), on the other hand, found that research of patients’ overall comprehension and satisfaction was inconclusive and not affected by the document’s length or complexity. Yet another view was presented by Cahana and Hurst (2008), who stated that rather than improving the actual consent form, it was warranted to improve the consent process, which in turn will produce enhanced understanding. If a practitioner devotes the time to explain the scope of the study as well as associated risks and benefits to the patient, this interpersonal component can achieve a higher level of comprehension (Vitiello, 2008). Creating a trusting relationship is the first step in having a successful informed consent process. In fact, the signed consent form is just an indication of
the client’s comprehension, yet the form should never be the sole component in the informed
consent process, let alone replace a dialogue between practitioner and patient (Schachter &
Kleinman, 2006). However, this process needs to take place in a timely manner; hence, a form’s
practicality and time-effectiveness are essential components of a solid consent form (Stunkel et
al. 2010). On a last note, consent always needs to be documented whether it was obtained orally
or in written form because it protects the patient and the health practitioner’s reputation. In terms
of format, in order for a consent form to meet the criteria of legibility, it has to be no smaller than
size 12 font and include headings, diagrams, and figures to highlight key points (Vitiello, 2008).
Also, the information should be written at a grade 5/6 reading level in order to meet the needs of
both adults and children (Schachter, Kleinman, & Harvey, 2005).

Summary

The above analysis demonstrated that designing a new consent form is a complex process
that entails many ethical, legal, and social requirements. The review of the literature showed that
while some guidelines are ambivalent and up to interpretation, others require more prescribed
adherence. Consequently, it is important that every practitioner becomes familiar with possible
ethical, legal, and social requirements and discrepancies, and develop protocols to deal with such
situations. Designing a consent form that will facilitate inter-agency communication for the
disclosure of an individual’s personal health information can be the first step in overcoming such
conflicts by incorporating all necessary aspects of the informed consent process in one
document. In the end, it is hoped that the new consent form will be a first step towards
establishing a circle of care and improved and time-effective service provision.
CHAPTER III: METHOD

Participants

For the purpose of this study, the placement agency’s staff served as participants. The 20 participants included the clinic director, secretary, two part time psychologists, and 16 graduate students; this resulted in a diverse sample. Their ages ranged from early 20s to late 50s with the majority of the participants being younger than 30 (i.e., 15 of the 20 participants had an average age of 25). The participants came from various ethnical backgrounds, yet the majority was Caucasian. All participants pursued their post-secondary education in psychology or a related field of social sciences. Their education levels varied from undergraduate degree, to master’s degree, PhD, and fully licensed psychologist. Since each participant assumed a different role in the clinic, each was able to provide distinct input to the study: The clinic director worked in collaboration with various mental health care agencies, and he depended on effective communication and exchange of personal health care information. In his role, he was often the sounding board for his colleagues’ dissatisfaction regarding current practices surrounding the process of interagency communication. The secretary dealt with incoming referrals and requests for clients’ information on a regular basis. The part time psychologists worked onsite only once a week, which is why they relied on time-effective communication with other professionals in the field. Lastly, the graduate students chose cases not only based on client profile but also accessibility of additional information.

This was a sample of convenience for the student researcher, who completed a placement at the agency. Also, the agency, a psychology clinic, was regarded as a relay centre in the process of gathering and transmitting clients’ mental health care information to other agencies, and as such, was considered a representative sample of all participating agencies and ministries of the circle of care.

Informed Consent Procedures

Participants provided informed consent following St. Lawrence College ethical guidelines. Since the participants’ role was limited to providing feedback on a questionnaire, written consent was not required. Instead, each participant was given the questionnaire along with a description of the study and its benefits and procedures. The student researcher verbally informed each participant of his/her right to withdraw from the study without incurring any consequences concerning their employment status with the agency. Further, the student researcher informed each participant that completion of the questionnaire served as implied consent to participate in the study.

Inclusion Criteria

The student researcher established two inclusion criteria to ensure that only those participants be selected for the study who could provide relevant feedback on the informed consent form and process. The first criterion referred to employment status or practicum experience at the psychology clinic for a minimum of three months. The second criterion required that the participants had experience filling out the agency’s current ‘consent to share information’ document. For the purpose of this study, experience was defined as having filled out a minimum of six forms.
Exclusion Criteria
Exclusion criteria only pertained to placement students. Participants were excluded from the study if they were in their first semester of their graduate studies because the clinic director determined that these students did not have the necessary familiarity with clients, case conceptualization, and bureaucracy.

Recruitment Procedures
As mentioned earlier, all participants were selected based on their involvement with the placement agency. Therefore, the recruitment process was simple and only consisted of sending an email to all prospective participants briefly describing the study and arranging 15-minute meetings with individual participants for the pre and post administration of the questionnaire.

Setting and apparatus
The research portion of the study took place at the placement agency and the local library where the student researcher had access to all relevant documents and materials pertaining to the subject matter. The administration of the questionnaire was conducted in a designated office at the placement agency to ensure privacy and quiescence. The office was equipped with minimal office furniture – computer, desk, and chair – to minimize the possibility of distraction.

Measures
The primary measure of this study was a questionnaire *(Questionnaire to Evaluate the Content of Consent to Share Information Forms see Appendix A)*, which was designed by the student researcher to evaluate the participants’ responses to the target agency’s current and new ‘consent to share information’ form. The questionnaire consisted of the following six constructs that were chosen from the current literature to assess and compare the quality of the two forms: legibility, comprehensibility, comprehensiveness, practicality, simplicity, and time effectiveness. The individual constructs were defined as follows:

*Legibility* refers to the font size, organization, and creativity of the document.

*Comprehensibility* entails that the content of the document is understandable.

*Comprehensiveness* is defined as the scope of the document. Does the form cover all pertinent aspect of informed consent? Is it too broad or too narrow?

*Practicality* refers to the document’s utility and applicability in terms of its content

*Simplicity* refers to the straightforwardness of the content. The form does not require many instructions.

*Time effectiveness* refers to minimal use of time on both ends – practitioner and patient.

Using a five-point Likert-type scale, all responses were assigned a score from one to five (Equivocal = 1; strongly disagree = 2; disagree = 3; agree = 4; strongly agree = 5). The rationale behind using this format was that by employing a Likert-type scale, the results could be
presented in numerical data, which allowed for easy interpretation of the results. Additional qualitative data in the form of written, unstructured commentary was collected and analyzed. The questionnaire did not entail any specific scoring; however, the higher the score, the more satisfaction the participant expressed with the particular component. Since this questionnaire was created by the student researcher, there was no psychometric information regarding its reliability and validity.

Procedures
The procedure consisted of the following seven steps:

I. Research
II. Designing of the questionnaire
III. Analysis of agencies’ ‘consent to share information’ documents and policies and procedures manuals
IV. Pre-administration of questionnaire
V. Matching of pre-administration responses with agencies’ documents
VI. Designing new ‘consent to share information’ form
VII. Post-administration of questionnaire
VIII. Analysis of data obtained from questionnaire

Research
The first step involved research of ethical practices surrounding the process of gathering and sharing clients’ personal health care information. Part of this research included analyzing up-to-date government regulations concerning the establishment of a client’s circle of care. Most pertinent information came from the Ontario College of Psychologists and the Ontario College of Physicians.

Designing of the questionnaire
The purpose of the questionnaire was twofold: The primary purpose was to evaluate and compare the participants’ responses on pre and post measures for which the Likert scale was used. The secondary purpose was to obtain the participants’ opinions and ideas based on their experiences in the profession. The questionnaire encompassed six constructs, which were chosen due to their prominence in analytical research. The two most common ones were practicality and comprehensibility since the purpose of any document is to be user-friendly and understandable.

Analysis of agencies’ ‘consent to release information’ documents and policies and procedures manuals (refer to Appendices B)
The student researcher scrutinized each agency’s consent form and identified commonalities and discrepancies among the documents. Key components in each form were highlighted and integrated into the new document.

i. School boards
   a. Algonquin District Catholic School Boards (Appendices C, D, E)
   b. Limestone District School Board (Appendix F)
ii. Child & Family Services
a. Pathways (Appendix G)
b. Open Doors for Lanark (Appendices H, I)

iii. Hospitals
a. Kingston General Hospital (Appendices J)
b. Hotel Dieu (Appendix K)

iv. Mental Health Services
a. Queen’s Psychology Clinic (Appendix L)

v. Policies & Procedures
a. Open Doors for Lanark Children and Youth (Appendix M)

**Pre-administration of questionnaire**

The student researcher followed a similar protocol for each meeting to ensure integrity across participants (refer to Appendix N). The researcher arranged individual meetings with each participant for the pre and post administration of the questionnaire.

During the pre-meeting, the student researcher explained the study and the questionnaire and addressed any arising questions or concerns. The student researcher advised participants of their right to withdraw from the study and about the fact that their consent was implied once they completed the questionnaire. The participants were then handed a pen, the questionnaire, and the agency’s ‘consent to share information’ document (see Appendix L). If the participant did not have any further question, the student researcher left the room and allotted approximately ten minutes for completing the questionnaire. In case the participants required assistance, the student researcher remained in close proximity to the office. Once the participant finished filling out the questionnaire, he/she handed the questionnaire to the student researcher.

**Matching of pre-administration responses with agencies’ documents**
The next step was to compare the content of the existing documents with the comments and suggestions made by the participants. This step was important as it was the precursor to designing the new document. The student researcher was looking for components that came from both sources, which means that if a suggestion was made by one of the participants, it was taken into consideration if a similar idea was present in one of the other consent forms.

**Designing of the new ‘consent to share information’ form**
The goal was to design a new ‘consent to share information’ document that not only encompassed all legal and ethical requirements but also addressed the suggestions made by the participants as well as included components that were present in the other agencies’ documents.

**Post-administration of questionnaire**
A process similar to the pre administration took place. Participants were handed the questionnaire along with the new ‘consent to share’ document (refer to Appendix O). The student researcher led the participants into the same office and allowed the participants up to ten minutes to complete the questionnaire. The student researcher was available to address any questions.
Analysis of data obtained from questionnaire
The last step included a statistical analysis comparing pre and post scores from the questionnaire using a one tail t-test in order to assess whether the results of the new ‘consent to share information’ document yielded statistically significant results compared to the current document. A computation of Cohen’s d determined whether the study produced a small, moderate, or big effect size.
CHAPTER IV: RESULTS

This section provides a description of the data obtained from the statistical analysis of the pre- and post-administration of the questionnaire. Table 1 presents pre-post descriptive statistics arranged by construct; Table 2 exhibits results from the one-directional repeated measures t-test; and Figure 1 is a visual presentation of average pre/post questionnaire scores organized by construct. The participants’ raw scores can be found in the Appendix P.

Increases in mean, median, and mode scores were noted across all six constructs from pre-to-post administration of the questionnaire while standard deviation scores decreased, indicating less variability in the data for the post-questionnaire scores (Table 1). The biggest increases were seen for practicality and simplicity; in terms of practicality, increases of 0.90, 1.00, and 2.00 for mean, median, and mode scores were demonstrated respectively; with regard to simplicity, increases of 1.00, 1.00, and 1.00 for mean, median, and mode were established. Minor differences or decreases were determined for comprehensibility and time effectiveness (0.25, 0.00, -1.00; 0.40, 1.00, 0.00). Modest increases from pre-to-post took place for legibility and comprehensiveness (0.65, 0.00, 0.00; 0.65, 0.50, 1.00). A similar, visual trend can be seen in Figure 1, which depicts an increase between pre-and-post scores via bar graphs.

Table 1

Pre-Post Results – Descriptive Statistics

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Pre</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Post</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>Median</td>
<td>Mode</td>
<td>SD</td>
<td></td>
<td>M</td>
<td>Median</td>
<td>Mode</td>
<td>SD</td>
</tr>
<tr>
<td>Legibility</td>
<td>4.35</td>
<td>5.00</td>
<td>5.00</td>
<td>0.81</td>
<td></td>
<td>5.00</td>
<td>5.00</td>
<td>5.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Comprehensiveness</td>
<td>3.80</td>
<td>4.00</td>
<td>4.00</td>
<td>0.95</td>
<td></td>
<td>4.45</td>
<td>4.50</td>
<td>5.00</td>
<td>0.60</td>
</tr>
<tr>
<td>Comprehensibility</td>
<td>4.00</td>
<td>4.00</td>
<td>5.00</td>
<td>0.95</td>
<td></td>
<td>4.25</td>
<td>4.00</td>
<td>4.00</td>
<td>0.72</td>
</tr>
<tr>
<td>Practicality</td>
<td>3.60</td>
<td>4.00</td>
<td>3.00</td>
<td>1.05</td>
<td></td>
<td>4.50</td>
<td>5.00</td>
<td>5.00</td>
<td>0.76</td>
</tr>
<tr>
<td>Simplicity</td>
<td>3.80</td>
<td>4.00</td>
<td>4.00</td>
<td>0.70</td>
<td></td>
<td>4.80</td>
<td>5.00</td>
<td>5.00</td>
<td>0.41</td>
</tr>
<tr>
<td>Time-Effectiveness</td>
<td>4.10</td>
<td>4.00</td>
<td>5.00</td>
<td>1.07</td>
<td></td>
<td>4.50</td>
<td>5.00</td>
<td>5.00</td>
<td>0.61</td>
</tr>
</tbody>
</table>

*Note. M=Mean; SD= Standard Deviation*
A repeated measures $t$-test was conducted for each of the six constructs to explore absolute differences between pre-and post results. Results were classified as either statistically significant if $p < 0.001$, marginally significant if $0.001 < p < 0.01$, or non significant if the $t$ value was outside the critical area. Significant differences were noted for four of the six constructs (Table 2): legibility, $t(19) = 3.58$, $p < 0.001$, $r^2 = 0.4027$; comprehensiveness, $t(19) = 3.11$, $p < 0.001$, $r^2 = 0.3573$; practicality, $t(19) = 3.60$, $p < 0.001$, $r^2 = 0.4055$; and simplicity, $t(19) = 5.63$, $p < 0.001$, $r^2 = 0.6252$. Marginally significant increases were observed for comprehensibility, $t(19) = 1.56$, $p < 0.07$, $r^2 = 0.1135$ and time-effectiveness, $t(19) = 1.63$, $p < 0.06$, $r^2 = 0.1227$. Further, a calculation of Cohen’s $d$ was used to measure effect size. Large effect sizes were seen for legibility (1.13), comprehensiveness (0.82), practicality (0.98), and simplicity (1.74) while a small and medium effect size was measured for comprehensibility and time-effectiveness, respectively (0.30; 0.50).
Table 2

*Pre/Post Results – One-Directional Repeated Measures T-Test*

<table>
<thead>
<tr>
<th>Construct</th>
<th>Pre</th>
<th>Post</th>
<th>t(19)</th>
<th>p</th>
<th>Cohen’s d</th>
<th>$r^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>$SD$</td>
<td>$M$</td>
<td>$SD$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legibility</td>
<td>4.35</td>
<td>0.81</td>
<td>5.00</td>
<td>0.00</td>
<td>3.58</td>
<td>0.001</td>
</tr>
<tr>
<td>Comprehensiveness</td>
<td>3.80</td>
<td>0.95</td>
<td>4.45</td>
<td>0.60</td>
<td>3.11</td>
<td>0.003</td>
</tr>
<tr>
<td>Comprehensibility</td>
<td>4.00</td>
<td>0.95</td>
<td>4.25</td>
<td>0.72</td>
<td>1.56</td>
<td>0.07</td>
</tr>
<tr>
<td>Practicality</td>
<td>3.60</td>
<td>1.05</td>
<td>4.50</td>
<td>0.76</td>
<td>3.60</td>
<td>0.001</td>
</tr>
<tr>
<td>Simplicity</td>
<td>3.80</td>
<td>0.70</td>
<td>4.80</td>
<td>0.41</td>
<td>5.63</td>
<td>0.001</td>
</tr>
<tr>
<td>Time-Effectiveness</td>
<td>4.10</td>
<td>1.07</td>
<td>4.50</td>
<td>0.61</td>
<td>1.63</td>
<td>0.06</td>
</tr>
</tbody>
</table>

The results from the statistical analysis were reinforced by the qualitative data collected from both questionnaires (refer to Appendix Q). Results from the pre-test indicated that the majority of the participants were satisfied with the length and practicality of the consent form while the consensus was that the layout, clarity, and content required revision. In particular, the participants emphasized on including a list of local service providers so that clients could simply authorize agencies to become part of their care. In terms of the post-test, written feedback was unanimous in that all participants made a positive comment about the document’s layout.
CHAPTER V: DISCUSSION

Summary

The purpose of this project was twofold: The main goal of the project was to provide a comprehensive review of the relevant literature and legislations related to sharing of health care information among agencies. The second goal was to devise a document that would be consistent with current practices of the interdisciplinary circle of care allowing for multi-institutional collaboration among agencies. It was hypothesized that the target agency’s staff would rate the new consent to share information form more positively when comparing to the current agency’s consent form. The research findings were consistent with this hypothesis because it was found that the results from the post-questionnaire were consistently higher in comparison to pre-scores. This trend was seen across the six constructs. However, statistically significant differences were found for four of the six constructs: legibility, comprehensiveness, practicality, and simplicity whereas marginally significant differences were noted for comprehensibility and time-effectiveness. A possible explanation for the latter might be that the new document had not yet been implemented in the psychology clinic, and participants had not had the opportunity to work with the consent form; therefore, the participants had no means of knowing whether the consent form was in fact time-effective. As for comprehensibility, statistically significant differences were expected because the focus of the consent form was to design an all-encompassing document, yet the results indicated that this goal was not met entirely. Nevertheless, standard deviation scores decreased on average 30% to 50%, which was an indication of less variability in the data, suggesting that participants’ scoring became more homogeneous. The same could be said about the qualitative data as participants’ comments about the new consent form were similar as the focus was on the excellent visual presentation and concise content. This in turn demonstrated a greater degree of agreement among participants. A similar trend was seen with regards to the qualitative data gathered from the questionnaire since comments on the post-questionnaire were more positive and suggestions for improvements were limited. Overall, the data indicated improvements from pre-to-post questionnaire, which could be interpreted as a direct reflection of the new, improved consent to share personal health care information document.

Strengths

The results from the questionnaire’s statistical analysis supported the hypothesis, which indicated that improvements were noted across all six constructs from pre- to post-administration of the questionnaire. Moreover, a calculation of Cohen’s $d$ illustrated statistically significant improvements for four of the six constructs: legibility, comprehensiveness, practicality, and simplicity. Another strength was the final product itself as it adhered to contextual, structural, and visual guidelines from the current literature. Establishing a Circle of Care turned out to be a comprehensive, two-page document, incorporating essential elements from legal, social, and ethical contexts. Besides the document’s complex content, its overall structure met legibility requirements by using a size 12 font, diagrams, bold and capital letters, and underlining of pertinent information to highlight key points. The new consent form was written at a Grade 5/6 reading level in order to meet the reading levels of both children and adults. This project would not have produced such significant results if the initial developmental process had not laid a solid foundation. Information for this project was gathered via in-depth
research and from a multitude of sources, including the Canadian Code of Ethics, PHIPA, PIPEDA, and the local agencies’ current consent to share information documents.

Limitations

While this project produced results that were consistent with the hypothesis, the study had a few limitations. First, a non-randomized sample of twenty participants was insufficient to serve as a representative sample of the target population. The sample had an unbalanced ratio of gender: Seventy-five percent of the participants were female. Also, the majority of the participants were students at the agency, and thus, their experience in the field and their understanding concerning the ideology of the circle of care were limited. The sample was taken from a psychology clinic, which was representative of one branch of the circle of care only. It would have been nice to have gotten input from other agencies on the new consent form. Because of these drawbacks, generalizing the findings to the full target population could be difficult. A second limitation pertains to the questionnaire: The 5-point Likert-type scale ranged from 1 equivocal to 2, strongly disagree, 3 disagree, 4 agree, to 5 strongly agree. The order in which the Likert scale was given led to ambiguity and inaccuracy of the overall results as equivocal should not have come before strongly disagree since it pulled down the results. Scoring equivocal with a score of 1 lowered the overall scores. Instead, such responses should not have been factored into the statistical analysis since they might have skewed the accuracy of the results. However, since equivocal was chosen only by participant six for two of the six questions, the overall results were still valid. Another limitation of this study was that the questionnaire had no demonstrated validity or reliability as it had been specifically designed for this study and not applied previously. The last limitation pertains to the researcher’s lack of knowledge about the agencies that are covered under the umbrella of the circle of care; hence, essential information might have been left out.

Multi-Level Challenges to Service Implementation

While there is a plethora of multi-level challenges during service implementation, it is anticipated that the two most challenging factors across the four levels will pertain to the protection of clients’ confidentiality and rights.

Client.

There are a few challenges to consider for clients once data transfer takes place. It is important to have data encrypted and/or password protected to safeguard a client’s privacy from any unauthorized access. Along with security, data should only be forwarded to certain people in the target agency to avoid unnecessary exchange of personal health information. Also, whenever data is exchanged electronically, a single glitch in the system can lead to data loss, which is why a backup plan needs to be in place to address unforeseen problems. Due to any of these challenges, the privacy may be compromised. Another problem pertains to the recipients of the information: Occasionally, when practitioners receive information on a new client, it is a natural process that the information paints a picture not only of the client’s medical history but also of any interpersonal challenges encountered with that client. As a result of these detailed records, the practitioner might develop unconscious bias toward the client, which can diminish the quality of the treatment.
Program.

At the program level, challenges can arise while gathering and exchanging clients’ private health care information. For example, the practitioners may not explain the document in much length, which might lead to a lack of knowledge and understanding on the part of the clients. Also, some practitioners may not follow proper protocol or become complacent with the process since they might not believe in the importance of the circle of care or are unwilling to embrace this new model of client care. Moreover, often times, practitioners believe that their approach is best practice and do not wish to consult with other agencies, which can be detrimental to the client. All of these practices can result in compromised client care and privacy.

Organization.

Challenges encountered at this level are closely linked to the challenges pointed out at the client level. Any inaccurate data exchange will reflect negatively on the organization itself and the circle of care as a whole. Besides, it is a common phenomenon that the more experts that are involved in designing a treatment plan, the more polar the opinions might be, which can then lead to an increased number of disagreements. For example, one agency’s approach to client care might deviate from the remaining agencies since its focus might be client-centred as opposed to family-centred; therefore, treatment can no longer be holistic, and in the end, the client will receive quality-diminished care.

Society.

With regard to the field of mental health services and stigmatization, society has undergone significant changes by shifting from institutionalization to integration, yet society still dictates the parameters of social norms. Society has a tendency to accept one standard deviation above/below the mean while anything that falls beyond one standard deviation requires further efforts to gain social acceptance and avoid stigmatization. The same can be said for expectation bias as society puts forth criteria for standardized treatments including time frame, level of intrusiveness, and available funds. Therefore, if there are more drawbacks than advantages to this innovative system of client care, the Ministry of Health and Long Term Care might remove funding and shift back to traditional client care.

Contributions to the Field of Behavioural Psychology

The importance of obtaining a client’s informed consent has been repeatedly demonstrated in any mental health-related field. It is at the core of any therapeutic relationship because it lays down a set of ground rules and directives, which help both the client and practitioner. Quality assurance is a necessary process that all agencies and organizations are wise to employ. Evolving current issues and contemporary life make reassessment of protocols a necessary objective. Updating and re-examining clarity within a consent form assists with comprehension for both clients and practitioners. All documents must be cohesive and comprehensive to ensure consistency and proper communication across agencies. 

Establishing a Circle of Care reflects on current social, legal, and ethical requirements; hence, this project enhanced the field of behavioural psychology.
**Recommendations**

For future projects, it would be beneficial to extend the questionnaire to other agencies since it would produce a more diverse sample with an increase in the data pool. This in turn could lead to a more thorough analysis of the new consent to share information document by obtaining more detailed feedback. Along with that, it would be useful to re-design the Likert-type scale on the questionnaire to follow a standard format and, hopefully, not affect the accuracy of the results. Therefore, it is recommended to include a not applicable (N/A) category, which would replace equivocal, and no score would be assigned to this category. Lastly, it would be interesting to do a follow-up study and identify how many agencies and/or ministries implemented the new consent to share information document. Outcome studies could investigate whether communication amongst members of the circle of care has indeed become time-effective and whether it led to reduced referral times and improved service provision.
References


Canadian Psychological Association (2000). *Canadian code of ethics for psychologists*. Ottawa: CPA.


Appendix A: Questionnaire to Evaluate the Content of Consent to Share Information Forms

100 Portsmouth Avenue
Kingston, ON
K7L 5A6

Student Researcher: Sarah Obeidi
4th Year Student B.A. Applied Behavioural Psychology

Contact Information: Sobeidi28@student.sl.on.ca
613-483-6865

Re: Completion of Questionnaire


Description of Study:
The main goal of this study is to provide a comprehensive review of the relevant literature and legislation related to sharing of health care information among agencies. The second goal is to devise a document, based on this review, which will facilitate inter-agency communication within the six counties (Frontenac, Hastings, Lanarc, Leeds & Greenville, Lennox & Addington, and Prince Edward). The main focus of this revised form will be on respecting the client’s right to privacy and informed consent while allowing different care providers to exchange information that enhances continuity of care. Thus, the document aims to be consistent with current practices of the interdisciplinary circle of care allowing for multi-institutional collaboration among agencies. As part of this development, the researcher will analyze the applicability and usefulness of the document by seeking feedback from agency staff regarding both the currently used and newly developed forms.

Benefits:
The direct potential benefits to the participants include increased awareness of common practices surrounding the process of gathering private health care information. Indirect benefits might include decreased wait time in between referrals and improved and faster service provision, which in turn can lead to better patient outcomes. Overall, this document could lead to effective, time-saving communication between service providers.

Description of Procedures:
The procedure is very simple. You will be handed a two-page questionnaire, a pen, and the ‘consent to share information’ document. The questionnaire will consist of six constructs assessing the quality of the current and new ‘consent to share information’ form (legibility, comprehensibility, comprehensiveness, practicality, simplicity, and time effectiveness) using a 5-point Likert Scale. You will then be asked to follow the student researcher into a designated
office space where you will have 15 minutes to complete the survey. After providing verbal instruction regarding the completion of the questionnaire, the student researcher will leave the room but remain in close proximity to answer any questions. After you finish filling out the questionnaire, you will hand it over to the student researcher, who then ensures that everything was answered according to the guidelines.

**Right to Withdraw:**
Participating in this study is based on a voluntary basis, which means that you can either agree or refuse to participate in this study. Also, once you agreed to take part, you have the right to withdraw from this project at any time without having to worry about any consequences; i.e. risking your work relationships or your employment status with this agency.

**Consent:**
A completed questionnaire will serve as you giving informed consent to participate in this study.

**Privacy of Your Information:**
Every attempt will be made to keep any identifying information strictly confidential unless required by law. Prior to you completing the questionnaire, any information identifying you will be assigned a code to assist in ensuring confidentiality and in differentiating participants. The one copy that will have your name and information will be stored with the agency supervisor in a locked file cabinet in his office at the placement agency. You will not be identified by name in any reports, presentations, or publications resulting from this project.
QUESTIONNAIRE TO EVALUATE THE CONTENT OF CONSENT TO SHARE INFORMATION FORMS

Please take out the ‘Consent to Share Information’ document while answering the following questions. Make sure you comprehend the statements before attempting to answer them. Most of the questions have a 5-point Likert Scale beside them, allowing you to rank your responses from 1– neither Agree nor Disagree, 2 – Strongly Disagree, 3 – Disagree, 4 – Agree, to 5 – Strongly Agree.

1. Position in Agency

<table>
<thead>
<tr>
<th>Position</th>
<th>Director</th>
<th>Undergraduate Student</th>
<th>Graduate Student</th>
<th>Clerk</th>
<th>PhD Student</th>
</tr>
</thead>
</table>

2. Frequency of Usage of ‘Consent to Share Information’ Form

<table>
<thead>
<tr>
<th>Frequency</th>
<th>1-2 times per month</th>
<th>3-4 times per month</th>
<th>more than 5 times/month</th>
</tr>
</thead>
</table>

3. Questions regarding Content and Utility

<table>
<thead>
<tr>
<th>Category</th>
<th>Equivocal</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**Legibility**
The form is well organized, using an appropriate font size, and emphasizing on sections when necessary (i.e. highlights or underlines).

**Comprehensiveness**
This document covers the most important ethical aspects involved in the informed consent process and the sharing of clients’ private health care information (i.e. option for children’s assent, adolescents’ right to informed consent).

**Comprehensibility**
The content is understandable.

**Practicality**
This document helps me in sharing important information with other agencies and service providers. It allows the client to choose from a list of applicable service providers.
**Simplicity**
This form is user friendly and does not require any instructions.

**Time Effectiveness**
I do not require much time and effort to complete this form.

4. Additional Commentary

4.1. Has this document facilitated the exchange of information between your agency and other agencies?

   Explain:

4.2. Are you aware of comments from other agencies concerning inter-agency communication?

   Explain.

4.3. Suggestions for improvements
Appendix B: Analysis of Commonalities and Discrepancies among Agencies’ Consent Documents

<table>
<thead>
<tr>
<th>COMMONALITIES</th>
<th>DISCREPANCIES</th>
<th>ELEMENTS FROM THE LITERATURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying information</td>
<td>List of service providers</td>
<td>Assent versus proxy consent</td>
</tr>
<tr>
<td>Purpose of document</td>
<td>Time-line (i.e. how long consent is valid)</td>
<td>Grade 5/6 reading level</td>
</tr>
<tr>
<td>Client’s/Guardian’s signature</td>
<td>2-way consent</td>
<td>Size 12 font</td>
</tr>
<tr>
<td></td>
<td>a) consent to share information with other agencies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b) consent to receive client’s information from other agencies</td>
<td></td>
</tr>
<tr>
<td>Release of all or partial information</td>
<td></td>
<td>1-2 pages in length</td>
</tr>
<tr>
<td>Description of information that will be shared</td>
<td>Detailed informed consent process</td>
<td></td>
</tr>
<tr>
<td>Parties information can/cannot be shared with</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C: Consent Form (Consent to the Disclosure, Transmittal or Examination of a Clinical Record from Clinical Records Compiled in the ALCDSB School Board) – Algonquin and Lakeshore Catholic District School Board

ALGONQUIN AND LAKESHORE CATHOLIC DISTRICT SCHOOL BOARD
151 Dairy Avenue, Napanee, Ontario K7K 4B2
Student Services Department
Telephone: 613-354-2255 Fax: 613-354-9850
1-800-581-1116

Consent to the Disclosure, Transmittal or Examination of a Clinical Record

I, __________________________________________________________________________ (Print full name of person)
of __________________________________________________________________________ (Address)
Hereby consent to the disclosure or transmittal to or the examination by ______________________________________________________________________________ (Name of Facility)
Of the clinical record compiled in Algonquin and Lakeshore Catholic District School Board
In respect of ________________________________       ______________________________
(Name of Pupil)                                                  (Date of birth)
_____________________________       __________________________________
(Name of Pupil)                                                  (Date of birth)
___________________________________________
(If other than pupil, state relationship to the patient)
Date: __________________________ (Month, day, year)

Note: This form will expire, unless acted upon, one year from the date of signing

The Algonquin and Lakeshore Catholic District School Board (ALCDSB) complies with Ontario’s Personal Health Information Protection Act (PHIPA). The ALCDSB Personal Health Information Protection Policy details the reasons for the collection and disclosure of personal and health information. Please refer to privacy statement attached.
Appendix D: Consent Form (Consent to the Disclosure, Transmittal or Examination of a Clinical Record to the ALCDSB School Board) – Algonquin and Lakeshore Catholic District School Board

ALGONQUIN AND LAKESHORE CATHOLIC DISTRICT SCHOOL BOARD
151 Dairy Avenue, Napanee, Ontario K7K 4B2
Student Services Department
Telephone: 613-354-2255
Fax: 613-354-9850
1-800-581-1116

Consent to the Disclosure, Transmittal or Examination of a Clinical Record

I, ____________________________________________
(Print full name of person)

of ____________________________________________
(Address)

Hereby consent to the disclosure or transmittal to or the examination by:

The Algonquin and Lakeshore Catholic District School Board

of the clinical record compiled ____________________________________________
(Name of Facility)

In respect of
(Name of Pupil) ____________________________________________
(Date of birth)

(Name of Pupil) ____________________________________________
(Date of birth)

(If other than pupil, state relationship to the patient)

Date: __________________________
(Month, day, year)

Note: This form will expire, unless acted upon, one year from the date of signing

The Algonquin and Lakeshore Catholic District School Board (ALCDSB) complies with Ontario’s Personal Health Information Protection Act (PHIPA). The ALCDSB Personal Health Information Protection Policy details the reasons for the collection and disclosure of personal and health information. Please refer to privacy statement attached.
Parental Consent for Third Party Reports

The information gathered on this form is pursuant to the *Education Act and the Municipal Freedom of Information and Protection of Privacy Act*. Information will be used to prepare assessment records; maintain records for all students. Users: Student, Services Staff, Principal of student, all teachers responsible for the student’s program and designated staff or clerical functions.

To assist in planning the school program for my son/daughter __________________________

D.O.B.: ________________________________
   (Month, day, year)

I, __________________________________________________________________________
   (Print full name of Parent/Guardian)

Hereby give my permission for the _________________________________________________
   (Type of Report)
   ________________________________
   (Date of Report)

to be placed in the Ontario School Record (OSR).

Date: ___________________________          Parent/Guardian ________________________________

TO BE ATTACHED TO OSR COPY OF REPORT

The Algonquin and Lakeshore Catholic District School Board (ALCDSB) complies with Ontario’s Personal Health Information Protection Act (PHIPA). The ALCDSB Personal Health Information Protection Policy details the reasons for the collection and disclosure of personal and health information. Please refer to privacy statement attached.
CONSENT FOR RELEASE OF INFORMATION

Student:________________________________________         Student Number:_____________

Birthdate: ________________         Present School: _________________         Grade:_________

(Y/M/D)

I give consent to  __________________ give or receive information regarding my child’s/ward’s
academic, social, emotional, behavioural, medical, or school attendance concerns to the
following person(s): _____________________________________________________
______________________________________________________________________
______________________________________________________________________
Exceptional Conditions: __________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

This form is valid for the 20__- 20__ school year only.

____________________________________  _________________________
(Signature of Parent/Guardian/Adult Student)         (Date)

____________________________________  _________________________
(Signature of Parent/Guardian/Adult Student)         (Date)

______________
(Witness)
Appendix G: Consent Form – Pathways Children’s Services and Adult Developmental Services

Collaborative Access Process to Services

Common Consent to Share Information

<table>
<thead>
<tr>
<th>Release of Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>I ______________________ of ___________________________</td>
</tr>
<tr>
<td>Surname</td>
</tr>
<tr>
<td>Given Name</td>
</tr>
<tr>
<td>Address</td>
</tr>
<tr>
<td>Hereby consent in the sharing of information to from the following:</td>
</tr>
<tr>
<td>• ______________________ Name of Agency, Facility or Private Practitioner</td>
</tr>
<tr>
<td>• ______________________ Name of Agency, Facility or Private Practitioner</td>
</tr>
<tr>
<td>• ______________________ Name of Agency, Facility or Private Practitioner</td>
</tr>
<tr>
<td>• ______________________ Name of Agency, Facility or Private Practitioner</td>
</tr>
<tr>
<td>in respect of Child/Youth Adult with a Developmental Disability</td>
</tr>
<tr>
<td>Consumer’s Name</td>
</tr>
<tr>
<td>Date of Birth</td>
</tr>
<tr>
<td>for the purpose of ___________________</td>
</tr>
<tr>
<td>Description of the information to be shared is as follows:</td>
</tr>
<tr>
<td>Any pertinent information</td>
</tr>
<tr>
<td>Specifically the following information:</td>
</tr>
<tr>
<td>___________________________________</td>
</tr>
<tr>
<td>___________________________________</td>
</tr>
<tr>
<td>___________________________________</td>
</tr>
<tr>
<td>___________________________________</td>
</tr>
<tr>
<td>___________________________________</td>
</tr>
<tr>
<td>This consent is valid for the following period: One year from signing date</td>
</tr>
<tr>
<td>(specify time frame) from signing date</td>
</tr>
<tr>
<td>I understand that I may revoke this consent in writing at any time.</td>
</tr>
<tr>
<td>Signature</td>
</tr>
<tr>
<td>Date</td>
</tr>
<tr>
<td>Witness</td>
</tr>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>
CONSENT AND AUTHORIZATION

For clients 12 years of age or older for nonresidential services.

Client’s name: _____________________________________________________________

Client #: ___________________ Date of Birth: ________________________________

I, ___________________________ consent to receive services from

OPEN DOORS for LANARK CHILDREN AND YOUTH for the following purposes:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

I understand the nature and purposes of the services to be provided. Any major changes will be discussed with me, and cannot be made without my permission.
I also understand that this consent is valid for one year or until the completion of service, whichever is earlier and I may revoke my consent at any time.

________________________________________________________________________

(signature of client) (date)

________________________________________________________________________

(signature of parent/guardian if applicable) (date)

________________________________________________________________________

(signature of witness) (date)
Appendix I: Consent Form – Open Doors for Lanark Children and Youth

CONSENT to DISCLOSE PERSONAL HEALTH INFORMATION

I, __________________________________, _____________________________________________
Last Name of Client/Parent/Guardian                       First Name

Address
___________________________________________________________________________

Hereby authorise _____________________________________________________________
To disclose the following personal health information:
___________________________________________________________________________
___________________________________________________________________________

To Open Doors for Lanark Children and Youth

From the records of ____________________  ____________________  _________________
Last name of client  First Name          Birth (mm/dd/yr)

I understand that this personal health information is to be used only by the recipient for the purposes of:
___________________________________________________________________________

I hereby waive any and all claims against Open Doors in connection with the disclosure of this personal
health information.

This consent has been fully explained to me and I(we) understand that I(we) can refuse to sign.

<table>
<thead>
<tr>
<th>Authorization Signatures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject of Information</td>
</tr>
<tr>
<td>(print name(s) or, if appropriate, ‘Entire Family’)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

* EXPIRY DATE  (mm/day/year) ____________________________ (maximum is one year)
* Authorizing person(s) may cancel or change the above authorization(s) in writing at any time prior to the expiry date, unless action already has been taken on the basis of the authorization(s).
REQUEST FOR PERSONAL HEALTH INFORMATION

I hereby authorize: ____________________________________________________________
(name of person/facility/agency releasing information)

________________________________________________________________________
(name of person/facility/agency releasing information)

To release information to Hotel Dieu and Kingston General Hospitals from the records of:

(apply pt. addressograph label if available)

Patient Name: ______________________________________________________________

Address: __________________________________________________________________

Date of Birth: _______________________
(yyyy/mm/dd)

The following medical/surgical/psychiatric information is required concerning treatment on/from:

________________________________________________________________________
(Description of personal health information and dates of contact/hospitalizations)
________________________________________________________________________
________________________________________________________________________
for the purposes of ongoing patient care.

Date: __________________________
(yyyy/mm/dd)

Patient Signature: __________________________________________________________

Information collected & requested by:___________________________________________
(print name and telephone or page/no.)

Telephone or page number: ________________________________________________

This authorization must contain the original signatures, photocopies will not be accepted. It is understood that this authorization may be rescinded or amended in writing at any time by the patient. This authorization automatically expires ninety days after the date signed above.
AUTHORIZATION TO RELEASE PERSONAL HEALTH INFORMATION

I hereby authorize: ____________________________________________________________
(name of person/facility/agency releasing information)

__________________________________________________________________________
(name of person/facility/agency releasing information)

To release information to Hotel Dieu and Kingston General Hospitals from the records of:

(apply pt. addressograph label if available)

Patient Name: _____________________________________________________________

Address: __________________________________________________________________

Date of Birth: _______________________
(yyyy/mm/dd)

The following personal health information is to be disclosed concerning treatment on/from:

☐ Hotel Dieu Hospital visits  ☐ Kingston General Hospital visits

Any information that would assist with psychiatric treatment and ongoing medical care.
(Description of personal health information and dates of contact/hospitalizations)

__________________________________________________________________________
__________________________________________________________________________

for the purposes of psychiatric treatment and ongoing care.

Date: ____________________________
(yyyy/mm/dd)

Patient Signature: ___________________________________________

Relationship to patient: ____________________________________________

Information collected & requested by:______________________________________
(print name and telephone or page/no.)

This authorization must contain the original signatures, photocopies will not be accepted. It is understood that this authorization may be rescinded or amended in writing at any time by the patient. This authorization automatically expires ninety days after the date signed above.
Appendix L: Consent Form – Queen’s University Psychology Clinic

Authorization for Release of Information from the Psychology Clinic at Queen’s

I, _________________________ , _________________________
Surname               Given Name

Hereby authorize The Psychology Clinic at Queen’s, Department of Psychology, Queen’s University, to release the information identified below to

________________________________________________________
Name of Agency, Facility, Private Practitioner or Other

From the records of ____________________________  ____________________________
Name of Client               Date of Birth

Description of the information to be shared is as follows: (Please initial beside all pertinent information)

______ Any pertinent information regarding this client.

______ Specifically the following information: __________________________________________

I understand that the information is to be used for the purposes of:

______ Information Sharing               ____  Educational Planning

______ Service Planning               ____  Other:

This consent is valid for the following period:

______ One year from signing date               ____  Specific time frame (please indicate time frame)

I understand that I may revoke this consent in writing at any time.

_________________________       __________________________
Signature               Date

_________________________       __________________________
Signature               Date

_________________________       __________________________
Witness               Date
PURPOSE

- To articulate *Open Doors for Lanark Children and Youth’s* commitment to protection of client confidentiality, verbal and written, in accordance with the Child and Family Services Act and Personal Health Information Protection Act. (PHIPA).

POLICY

- Under PHIPA, *Open Doors for Lanark Children and Youth* is a health information custodian and as such, adheres to the ten privacy principles underlying the Act.

- All employees, volunteers and agents of Open Doors are expected to hold confidential all information acquired in the course of their work. Confidential information includes written materials received about clients, verbal reports disclosed about clients, the contents of interviews with or about clients and their records. This obligation for confidentiality extends to all aspects of record keeping, on computer and audio visually throughout the continuing casework relationship and after the client has ceased to receive service.

Exceptions to this only occur when

- the client has signed a written release authorizing the disclosure of material to a specific outside agency or person maintaining confidentiality might cause serious harm to the client or to a third party a summons to appear has been received a child under the age of 16 who is suspected of being in need of child protection services.

PROCEDURE

- Each staff member, student, volunteer and researcher will be required to sign a Confidentiality Agreement, stating that they have read and understood the Confidentiality of Client Information/Privacy Policy, and agreed to uphold the procedures.
1. Adherence to the 10 privacy principles will be maintained as follows:

<table>
<thead>
<tr>
<th>Privacy Principle</th>
<th>Requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accountability</td>
<td>A contact person is designated to assist clients in meeting privacy dealing with any access requests, privacy related inquiries and complaints, and Commissioner investigations. The contact person identified is Ms. Nicki Collins.</td>
</tr>
<tr>
<td>Identifying Purposes</td>
<td>All clients are given a booklet informing them of the purposes for which their personal health information is collected, used and disclosed. This information is discussed orally.</td>
</tr>
<tr>
<td>Consent</td>
<td>Open Doors for Lanark Children and Youth relies on implied consent when collecting and using personal health information and expressed consent for disclosing, whenever possible.</td>
</tr>
<tr>
<td>Limiting Collection</td>
<td>Collection of personal health information is limited to that which is necessary for the identified purposes.</td>
</tr>
<tr>
<td>Limiting Use and Disclosure</td>
<td>Use and disclosure of personal health information is limited to the identified purposes, unless further consent is obtained or use or disclosure is permitted or required by law.</td>
</tr>
<tr>
<td>Accuracy</td>
<td>Reasonable steps to ensure that clients’ personal health information is as accurate, complete and up-to-date as is necessary for the purposes for which they are uses or disclosed. Whenever information is disclosed, the person to whom we disclose information is informed of limitations on the accuracy, completeness or up-to-date character of the information.</td>
</tr>
<tr>
<td>Safeguards</td>
<td>Technical, administrative and physical safeguards are put in place to protect clients’ privacy and the confidentiality of their personal health information.</td>
</tr>
<tr>
<td>Openness</td>
<td>A written statement on our information practices (e.g., collection, use and disclosure of personal health information) is distributed to all clients receiving treatment.</td>
</tr>
<tr>
<td>Access</td>
<td>Clients are given access to, and the ability to correct, their personal health records if they meet the requirements of the Act in a timely manner.</td>
</tr>
<tr>
<td>Challenging Compliance</td>
<td>Simple complaint procedures are developed to allow individuals to challenge our privacy practice.</td>
</tr>
</tbody>
</table>
2. Clients should be advised of *Open Doors for Lanark Children and Youth* ability to maintain confidentiality and privacy of personal health information.

3. Cases involving discussion of abuse, assault and other criminal acts, as well as, those dealing with custody and access disputes are at particular risk of subpoena. Representatives of *Open Doors for Lanark Children and Youth* should take this into account in their discussions with potentially affected clients and in their record keeping. Whenever practical, the client should be advised if a worker has been called to testify in a case involving the client, or if the client’s file has been subpoenaed.

4. With the exception of the circumstances noted in the policy, and in accordance with the Child and Family Services Act, clients and/or their guardians will sign a Consent to Disclose form before any information is shared with a third party, whether in a verbal or written format.
Appendix N: Questionnaire Administration Protocol

1. Set up 15-minute meeting with participants
2. Meet participants at the clinic
3. Lead participants to the designated office space
4. Hand participants description of the study, the questionnaire, and pen
5. Introduce study and questionnaire to participant
6. Allot five minutes for participants to read the instructions
7. Ensure that participants are informed of their right to refuse to participate or to withdraw at any point in time without incurring adverse consequences
8. Inform participants that they give consent to participate in the study by filling out the questionnaire
9. Ensure to emphasize to ask questions when needed
10. Collect questionnaire upon completion
I. Appendix O: Establishing a Circle of Care

A Circle of Care refers to the network of agencies and people who provide care to you/your child. This line of communication is important because it can lead to the **effective exchange of health care information** and **enhanced consultation** among health care providers. There are 3 steps involved in this process:

1. We want to know who has been part of your/your child’s care.
2. Let us know which of the parties from the *List of Available Service Providers* belong in your circle of care and which of those we have your permission to contact
   a. Check “YES” (Y) if someone has provided care **AND** we have your permission to talk to them, and, if possible, include the name of the contact person
   b. Check “DON’T TALK TO” (DT) if someone has provided care, **BUT** we do not have permission to talk to them
3. We will use this information to create a consent form for you to sign later

### List of Available Service Providers: Agencies & People

<table>
<thead>
<tr>
<th>Mental Health Clinicians</th>
<th>Family Physician</th>
<th>Paediatrician</th>
<th>Psychologist</th>
<th>Psychiatrist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
</tr>
<tr>
<td>DT</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental Health Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providence Care</td>
</tr>
<tr>
<td>Frontenac Community Mental Health</td>
</tr>
<tr>
<td>Other:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>School Boards</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algonquin Catholic District School Board</td>
</tr>
<tr>
<td>Limestone District School Board</td>
</tr>
<tr>
<td>Queen’s University</td>
</tr>
<tr>
<td>St. Lawrence College</td>
</tr>
<tr>
<td>Royal Military College</td>
</tr>
<tr>
<td>Other School:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family &amp; Children Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment/Vocational Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer</td>
</tr>
<tr>
<td>Welfare Services</td>
</tr>
</tbody>
</table>
II. Consent to Share Personal Health Information

*Please read carefully and ask for clarification if necessary*

The following information is gathered in order to obtain your consent to share parts OR all of the information pertaining to you/your (child’s/legal dependent’s) clinical records with other health care and service providers and/or significant people in your (his/her) life. Communication can take place in 2 ways, and it is YOUR CHOICE if you consent to one, both, or neither.

Please check the boxes that apply to you

☐ 1) I give consent to the Queen’s Psychology Clinic to disclose my information to any of the above people/agencies.

☐ 2) I give consent to any of the following agencies to forward my medical, educational, or vocational information to the Queen’s Psychology Clinic

Note:*  

*If you are between the ages of 14 and 18, you have the legal right to say whether you consent to sharing your health information with other parties. HOWEVER, your decision can be overruled by Dr. __________________________ at any time.

☐ I understand that I can revoke my decision and consent in written form at any time. This consent will lose its validity after one year to-date.

I hereby authorize The Queen’s Psychology Clinic to release the information identified above.

*This form was explained to me by:*

________________________  __________________________  __________________
Witness                          Signature                          Date

I understand and agree with the above outlined conditions.

________________________  __________________________  __________________
Participant’s Name              Signature                          Date

________________________  __________________________  __________________
Guardian’s Name                  Signature                          Date
### Appendix P: Participants’ Raw Scores

**Table 1**

*Participants’ Questionnaire Pre/Post Raw Scores*

<table>
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<tr>
<th>Participants</th>
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<th>COP</th>
<th>PRA</th>
<th>SIM</th>
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Note. LE= legibility; COM= Comprehensiveness; COP= Comprehensibility; PRA=Practicality; SIM=Simplicity; TE=Time-Effectiveness.
## Appendix Q: Qualitative Data Gathered from the Questionnaires

<table>
<thead>
<tr>
<th>Current Consent Form</th>
<th>New Consent Form</th>
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<tr>
<td><strong>Positives</strong></td>
<td><strong>Positives</strong></td>
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<tr>
<td>Brief (1 page)</td>
<td>Excellent visuals</td>
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<tr>
<td>Time-friendly</td>
<td>Mentioning of 2-way communication</td>
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<tr>
<td>Easy to handle</td>
<td>Clear instructions to clients</td>
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<tr>
<td>Assent</td>
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</tr>
<tr>
<td></td>
<td>Purpose of document was mentioned, which facilitates comprehension on the part of the client</td>
</tr>
<tr>
<td></td>
<td>Opportunity to choose from a list of service providers – time efficient</td>
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<tr>
<td><strong>Suggestions for Improvement</strong></td>
<td><strong>Suggestions for Improvement</strong></td>
</tr>
<tr>
<td>Include a list of service providers</td>
<td>Less wordy</td>
</tr>
<tr>
<td>Make certain phrases/words more distinct by bolding or underlining them</td>
<td>Extend list of service providers once this form will be introduced to agencies outside of Kingston</td>
</tr>
<tr>
<td>Include section on assent vs. consent</td>
<td></td>
</tr>
<tr>
<td>Only have primary physician fill out consent form</td>
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</tr>
</tbody>
</table>