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Electronic Health Information and Privacy Survey: What Canadians Think — 2007

FINAL REPORT

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Canada Health Infoway, Health Canada,
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por-rop@hc-sc.gc.ca

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EKOS Research Associates
99 Metcalfe Street, Suite 1100
Ottawa ON, K1P 6L7
p. 613.235.7215
f. 613.235.8498
e. pobox@ekos.com

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1. Executive Summary

The Advisory Council on Health Infostructure identified the Electronic Health Record (EHR) – a health record of an individual that is accessible online from many separate, interoperable automated systems within a secure electronic network – to be of pivotal importance to an integrated health care delivery system.

Canada Health Infoway, Health Canada, and the Office of the Privacy Commissioner of Canada have co-sponsored the current research to explore Canadian attitudes towards electronic health information and their privacy. More specifically, the survey sought to examine Canadians' expectations related to the privacy, confidentiality and security of personal health information, balanced with health care considerations (e.g., use, quality, and access).

Each organization has conducted previous research with the general public on these types of issues:

- 2003, Canada Health Infoway *Public Attitudes to Electronic Health Records and its Linkages*
- 2004, Health Canada *Pan-Canadian Health Information Privacy and Confidentiality Framework*
- 2007, The Office of the Privacy Commissioner of Canada *Canadians and the Privacy Landscape*.

EKOS Research Associates was commissioned by the sponsors to build on the previous public opinion research to both assess how certain trends are evolving as well as contribute to the development of new knowledge and understanding on these topics.

The objectives of the current study are to measure the following:

- perceptions of personal privacy and privacy of personal health information;
- awareness of laws / oversight bodies in relation to personal health information;
- perceptions and experiences related to electronic health information;
- secondary use of electronic health information; and
- the public's level of trust, comfort and tolerance for the electronic health record.

The results of this study are based on a 20-minute telephone survey with a random sample of 2,469 Canadians, aged 16 years and older. Surveying on the study was undertaken between June 22nd and July 19th, 2007. Key findings of this research are discussed below and throughout the remainder of this report.

Broad Perceptions of Personal Health Information

Canadians increasingly see it as important for health care providers to have easy access to patient information for the delivery of health care.

- Close to nine in ten (87 per cent) increasingly agrees that timely and easy access to personal health information is integral to the provision of quality health care.
- At least one in two Canadians is also concerned about serious mistakes in diagnoses or treatment due to incomplete, inaccurate, or illegible patient information.
- Hand in hand with these views is the enormous premium Canadians place on the necessity for safeguards to be in place to protect their health information. We find strong (and modestly rising) agreement with the perception that there are few types of personal information which are more important to protect than personal health information.

Safety & Security of Personal Health Information

Canadians have strong concerns about the safety and security of their personal health information (defined as at the broadest level) but reasonable confidence that responsible stewardship of personal health data is in place (e.g., 79 per cent considers the health information that exists about them to be at least moderately safe / secure).

Further, there is little evidence that the public expect improper use by those collecting or holding personal health information.

- Trust in health professionals (e.g., doctors, nurses, pharmacists) is very high; but slightly lower for other groups (e.g., administrators, government departments).
- Trust levels are more mixed outside the realm of immediate health care providers (e.g., computer technicians, insurance companies, researchers).

Protection of Personal Health Information

Confidence in the protection of health information is mixed, but significantly higher than confidence in protection of personal information in general (i.e. while 37 per cent feel they have less protection of their health information than five years ago, 53 per cent feel this way about their personal information in general).

- We find very small numbers (four per cent) reporting their health information having been used inappropriately or without their consent.

Direct awareness of oversight is modest.

- Two in five (39 per cent) have clear / vague awareness of laws; it is likely that many more believe that such protection is in place.
- Recognition of the existence of protective agencies is very low (76 per cent “no awareness”), which is a fairly typical finding.
- Awareness relates more to privacy protection in general, than to protection of personal health information specifically (e.g., Privacy Act and Canada’s Privacy Commissioner are the most top-of-mind).
- Clear awareness of laws that protect personal health information is highest in Alberta and lowest in Quebec.
- Importantly, Canadians who have interacted with an electronic health information system have a greater awareness of legislation and institutions intended to protect this information.

While Canadians enthusiasm for privacy laws may be high, overall low levels of familiarity with legislation in this area suggests that many may not be aware of their rights when it comes to the protection of their health information. Moreover, even if they are aware of their rights, it seems that few would know where to turn if they ever experienced a violation of their personal health information.

Support for EHRs

Awareness and support for EHRs is on the rise.

- Nearly one in two Canadians (49 per cent) has heard of EHRs (up eight per cent since 2003) and one in three (31 per cent) has interacted with this type of system.
- Assessments of interactions with EHRs lean strongly positive (e.g., faster service, information more accessible). Among those who have interacted with an EHR, top-of-mind assessments lean strongly towards the positive.
- Close to nine in ten Canadians (88 per cent) support the development of EHRs (up five percentage points since 2003).
- Access to patient information and improved efficiency remain the most compelling reasons to support EHRs, whereas concerns about security lead reasons for opposing.

EHRs are seen as increasingly superior to the paper-based system.

- More than eight in ten Canadians rate EHRs as better than paper-based systems in terms of their effectiveness for doctors, pharmacists, patients, and nurses. A smaller majority (53 per cent) also believes EHRs to be less costly.
- When it comes to the privacy / security of patient information, those seeing EHRs as better than a paper-based system outnumber those who see EHRs as worse by a margin of over two to one.
- Interestingly, those with firsthand experience with EHRs (31 per cent of Canadians) are more likely to see the benefits of this type of system for patients and health care providers. In a top-of-mind assessment of EHRs – beyond a predominantly positive impression – these patients spontaneously cite faster service and accessibility of information as benefits.

Arguments in favour of EHRs are all strong and strengthening, while arguments against this type of system are weaker than in 2003. At least eight in ten Canadians agree with all the arguments in favour (e.g., improved access to and better information, more rapid diagnosis, etc.).

Canadians' overall level of comfort with EHRs is strong and continues to rise. Importantly, those who have interacted with an electronic health information system report higher levels of comfort with EHRs.

The EHR & Comfort Levels

Concerns about EHRs are more limited (i.e. fewer than half agrees with arguments against EHRs). When there are concerns, the idea that personal health information could somehow be compromised predominates. For example, pluralities agree that they worry that their information could be accessed for malicious or mischievous reasons (45 per cent) or that it could be used for purposes not related to their health (42 per cent). Over one in three (37 per cent) also worries that privacy and security procedures will not be followed by those with access to their records.

There exists a host of potential initiatives that could be introduced as a way of increasing the general public's comfort with this technology.

- Having the ability to find out who accessed your health record and when tops the list of ways to increase comfort levels (77 per cent say this would make them "more comfortable").
- This is followed closely by introducing new legislation that would make unauthorized access of personal health records a serious criminal offence (74 per cent say this would make them "more comfortable"). It is worth reiterating that most Canadians are not aware of the privacy legislation that currently exists.

A range of other options are also seen as effective:

- *Privacy assurances.* The option of being informed of any privacy or security breaches is new to the list this year and ranks third overall, with seven in ten (70 per cent) Canadians saying this would make them "more comfortable". The other new item on the list – having procedures to respond to such breaches – would make two-thirds of Canadians (68 per cent) "more comfortable". Likewise, two in three (66 per cent) also say that a clear and accessible privacy policy on how this information is to be handled would make them "more comfortable".
- *Access to records.* Another way of increasing comfort levels would be to allow Canadians to access their health record at any time in order to make any necessary corrections (68 per cent "more comfortable"). A majority (55 per cent) would also like to be able to hide or mask sensitive information.
- *Endorsements.* Knowing that their doctor supported a system of EHRs would make two in three Canadians (66 per cent) "more comfortable" with the technology. Other forms of endorsement (i.e. from the federal, provincial or territorial governments) would also increase feelings of comfort for about one in two (49 per cent for the federal government and 45 per cent for the provincial or territorial governments).

- *Oversight.* The idea that the entire system would be evaluated or audited after a period of time would also make about one in two (54 per cent) “more comfortable” with EHRs.

Of note, support for any of the aforementioned initiatives is generally somewhat stronger among the 31 per cent of Canadians who reported that they have interacted with an electronic health information system in the past year.

Secondary Use of Health Information

Health research is another area in which electronic health information could potentially be put to use. More than eight in ten Canadians (84 per cent) support the use of EHRs in such research, provided that details such as their name and address are not known to the researcher. This finding is particularly impressive as it mirrors overall support for the EHR (88 per cent). Support for the use of EHRs in health research drops dramatically, however, if personal details are *not* removed from the record (50 per cent). If consent is obtained ahead of time, there also exists support for the health researchers to link personal health information to other records that may be related to health outcomes (e.g., education, income), but this is considerably more tepid than overall support for EHRs (66 per cent).

At least three in four says they would be comfortable with EHRs being used to anticipate health crises, or to monitor / evaluate or prevent improper uses of the health care system.

One volunteered quote from a survey respondent perhaps encapsulated the essence of the majority view on these issues: “If you can protect my privacy, I am okay with [electronic health records].”

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2. Sommaire

Selon le Conseil consultatif sur l'Infostructure de la santé, le dossier de santé électronique (DSE) – dossier de santé d'un patient qu'il est possible de consulter en ligne, au moyen de nombreux systèmes automatisés interopérables, dans les limites d'un réseau électronique sécurisé – est un élément essentiel d'un système intégré de prestation des soins de santé.

#1 Inforoute Santé du Canada, Santé Canada et le Commissariat à la protection de la vie privée du Canada sont les commanditaires de la présente étude, qui visait à aborder les attitudes des Canadiens à l'égard des renseignements de santé électroniques et de la protection de leur vie privée. Plus particulièrement, le sondage visait à examiner les attentes des Canadiens pour ce qui a trait à la protection, à la confidentialité et à la sécurité des renseignements de santé personnels, tout en tenant compte de facteurs précis dans le contexte des soins de santé (p. ex., utilisation, qualité et accessibilité).

Chacun des commanditaires a déjà réalisé, auprès de la population en général, des travaux de recherche sur ce genre de questions :

- 2003, Inforoute Santé du Canada, *Public Attitudes to Electronic Health Records and its Linkages*;
- 2004, Santé Canada, *Cadre pancanadien de protection de la confidentialité des renseignements personnels sur la santé*;
- 2007, Commissariat à la protection de la vie privée du Canada, *Les Canadiennes et Canadiens et la protection de la vie privée*.

Les commanditaires ont demandé aux Associés de recherche EKOS de se fonder sur ces précédents travaux de recherche sur l'opinion publique afin d'examiner l'évolution de certaines tendances, et afin de faire progresser les connaissances en la matière et d'approfondir la compréhension de ces sujets.

Plus particulièrement, la présente étude avait pour objectifs d'évaluer les éléments décrits ci-dessous :

- #3 • les perceptions au sujet de la protection de la vie privée et de la protection des renseignements de santé personnels;
- #4 • la connaissance des lois ou des instances de surveillance dans le contexte des renseignements de santé personnels;

- #5 • les perceptions et les expériences pour ce qui a trait aux renseignements de santé électroniques;
- #6 • les applications secondaires des renseignements de santé électroniques;
- #7 • la confiance, le sentiment d'aise et la tolérance de la population dans le contexte du dossier de santé électronique.

Les résultats découlant de la présente étude sont fondés sur la réalisation d'un sondage téléphonique de 20 minutes auprès d'un échantillon aléatoire de 2 469 Canadiens de 16 ans et plus. Les activités de sondage effectuées dans le cadre de l'étude se sont déroulées entre le 22 juin et le 19 juillet 2007. Vous trouverez ci-dessous et tout au long du rapport une analyse des principales observations liées à la présente étude.

Perceptions générales au sujet des renseignements de santé personnels

Les Canadiens sont de plus en plus d'accord pour dire qu'il est important, dans la prestation des soins de santé, que les professionnels de la santé puissent consulter facilement les renseignements sur leurs patients.

- Dans une proportion de près de neuf pour dix (87 p. 100), les Canadiens estiment que l'accès facile, en temps opportun, aux renseignements de santé personnels, fait partie intégrante de la prestation de soins de santé de qualité.
- Au moins la moitié des Canadiens se préoccupent en outre des erreurs graves commises sur le plan des diagnostics ou des traitements à cause de renseignements de santé incomplets, inexacts ou illisibles.
- Dans le droit fil de ce qui précède, les Canadiens attachent une très grande importance à la nécessité d'établir des mesures de protection de leurs renseignements de santé. En particulier, nous avons observé des résultats vigoureux (en légère progression) témoignant de l'adhésion à la perception selon laquelle peu de renseignements personnels revêtent plus d'importance que les renseignements de santé, pour ce qui concerne la protection de la confidentialité.

Mesure dans laquelle les renseignements médicaux personnels sont bien protégés

Les Canadiens se préoccupent vivement de la mesure dans laquelle leurs renseignements médicaux personnels (au sens le plus large) sont bien protégés.

Par ailleurs, les Canadiens se révèlent plutôt convaincus que des pratiques de gestion responsable des données personnelles sur la santé sont adoptées (p. ex., 79 p. 100 sont d'avis que les renseignements de santé qui existent à leur sujet sont au moins modérément bien protégés).

En outre, il n'y a guère de données indiquant que les membres de la population s'attendent à ce que les personnes qui recueillent ou détiennent les renseignements de santé personnels s'en servent à mauvais escient.

- Les Canadiens accordent une très grande confiance aux professionnels de la santé (p. ex., médecins, infirmières, pharmaciens). Le niveau de confiance accordée aux membres des autres groupes de professionnels (p. ex., les gestionnaires, les ministères du gouvernement) est toutefois un peu plus faible.
- En dehors de la sphère des prestataires de soins de santé de première ligne, les niveaux de confiance sont plus nuancés (p. ex., techniciens en informatique, compagnie d'assurance, chercheurs).

Protection des renseignements de santé personnels

Les résultats témoignant de la mesure dans laquelle la protection des renseignements de santé inspire confiance aux Canadiens sont mitigés. Ils sont néanmoins considérablement supérieurs aux résultats sur la confiance qu'inspire la protection des renseignements personnels en général (en particulier, tandis que dans une proportion de 37 p. 100, les Canadiens sont d'avis que leurs renseignements de santé sont moins bien protégés qu'il y a cinq ans, 53 p. 100 d'entre eux sont de cet avis pour ce qui concerne les renseignements personnels en général).

- Dans le cadre du sondage, une très faible proportion des personnes interrogées (quatre p. 100) ont signalé que leurs renseignements de santé ont été utilisés à mauvais escient ou divulgués sans leur consentement.

D'autre part, les résultats témoignant de la connaissance directe des mécanismes de surveillance sont modestes.

- Dans une proportion de deux pour cinq (39 p. 100), les Canadiens affirment être « certainement » ou « vaguement » au courant des lois. En outre, il est probable qu'un grand nombre d'autres Canadiens soient d'avis qu'il existe pareilles mécanismes de protection.

- La reconnaissance de l'existence des organismes de protection est très peu répandue (76 p. 100 des personnes interrogées disent ne pas connaître ces institutions). Il s'agit d'une observation plutôt typique.
- Les Canadiens sont plus au courant de la protection de la vie privée en général que de la protection des renseignements de santé personnels en particulier (p. ex., la Loi sur la protection des renseignements personnels et le Commissariat à la protection de la vie privée du Canada sont les premières réponses citées lorsque nous interrogeons les Canadiens sur ces questions).
- Les résultats témoignant d'une connaissance claire des lois protégeant la confidentialité des renseignements de santé sont le plus élevés en Alberta et le plus faibles au Québec.
- Fait important, les Canadiens qui ont eu une forme d'interaction avec un système de renseignements de santé électronique connaissent davantage les lois et les institutions visant à protéger la confidentialité de ces renseignements.

Tandis que les Canadiens semblent afficher un vif enthousiasme à l'égard des lois sur la protection des renseignements, les niveaux de connaissance des lois de cette nature, qui sont généralement faibles, font penser qu'un grand nombre d'entre eux pourraient ne pas connaître leurs droits pour ce qui concerne la protection de leurs renseignements de santé personnels. De plus, même dans les cas où ils connaissent leurs droits, il appert qu'un faible nombre de Canadiens seulement sauraient où s'adresser s'ils subissaient une infraction au chapitre de la protection de leurs renseignements de santé personnels.

Appuis pour les DSE

Les résultats témoignant de la connaissance des DSE et des appuis que cette technologie recueille sont en pleine progression.

- Près de la moitié des Canadiens (49 p. 100) disent avoir entendu parler des DSE (résultat témoignant d'une augmentation de huit p. 100 par rapport à 2003). De plus, le tiers des Canadiens (31 p. 100) ont eu une interaction avec un système de cette nature.
- Les évaluations des interactions avec des DSE ont tendance à se révéler très favorables (p. ex., le service est plus rapide, il est plus facile de consulter l'information). Chez les Canadiens qui ont eu une interaction avec un système de DSE, les premières évaluations présentées sont le plus souvent favorables.

- Dans une proportion de près de neuf pour dix (88 p. 100), les Canadiens appuient la mise au point des DSE (résultat témoignant d'une augmentation de cinq p. 100 par rapport à 2003).
- L'accessibilité des renseignements sur les patients et l'amélioration de l'efficacité demeurent les raisons invoquées le plus souvent pour expliquer les appuis que reçoivent les DSE, tandis que les préoccupations liées à la sécurité constituent les principales raisons de s'opposer à la mise au point de ce système.

Les Canadiens estiment de plus en plus que les DSE sont supérieurs aux systèmes de dossiers papier.

- Dans une proportion supérieure à huit pour dix, les Canadiens indiquent que les DSE sont supérieurs aux systèmes de dossiers papier pour ce qui a trait à leur efficacité pour les médecins, les pharmaciens, les patients et les infirmières. Dans une plus faible proportion, néanmoins majoritaire (53 p. 100), les personnes interrogées estiment en outre que les DSE sont moins coûteux.
- Au chapitre de la protection et de la sécurisation des renseignements des patients, le nombre de répondants d'avis que les DSE sont supérieurs aux systèmes de dossiers papier surpasse de plus de deux fois le nombre de répondants qui estiment que les DSE sont moins bons à cet égard.
- Fait intéressant, les Canadiens qui ont eu une expérience pratique des DSE (31 p. 100 de la population) sont plus susceptibles de percevoir les avantages qui se rattachent à ce genre de système, tant pour les patients que pour les prestataires de soins de santé. Dans le cadre de l'évaluation des DSE, en outre de présenter des impressions principalement positives, ces patients signalent spontanément le service plus rapide et l'accessibilité des renseignements au nombre des avantages du système.

Les résultats témoignant de l'adhésion aux arguments à l'appui des DSE sont de plus en plus forts, tandis que les résultats au sujet de l'adhésion aux arguments contre l'adoption d'un système de cette nature sont plus faibles qu'en 2003. En particulier, c'est dans une proportion d'au moins huit pour dix que les Canadiens sont d'accord avec l'un ou l'autre des arguments à l'appui des DSE (p. ex., meilleure accessibilité et meilleure information, diagnostics plus rapides, etc.).

Dans l'ensemble, le niveau de confort des Canadiens à l'égard des DSE est fort et en pleine progression. Fait important, les personnes interrogées qui ont eu une interaction avec un système de renseignements de santé électronique font état de niveaux de confort supérieurs dans le contexte des DSE.

Le DSE et le sentiment d'aise

Les préoccupations au sujet des DSE sont de portée plus limitée (c.-à-d. que moins de la moitié des Canadiens adhèrent aux arguments contre les DSE). Dans les cas où des préoccupations persistent, c'est la crainte que l'intégrité des renseignements de santé personnels soit mise en péril qui prévaut. Par exemple, c'est presque en majorité que les personnes interrogées s'entendent pour dire qu'elles craignent que quelqu'un de mal intentionné s'empare de renseignements personnels les concernant (45 p. 100) ou que leurs renseignements puissent servir à d'autres fins que leur santé (42 p. 100). Dans une proportion supérieure au tiers (37 p. 100), les Canadiens s'inquiètent aussi de la possibilité que les personnes ayant accès à leurs renseignements de santé ne suivent pas la procédure établie en matière de protection et de sécurité des renseignements lorsqu'elles consultent leurs dossiers.

Toute une série d'initiatives possibles pourraient servir à améliorer le sentiment d'aise de la population à l'égard de cette technologie.

- La possibilité de savoir qui a consulté leur dossier de santé et à quel moment figure en tête de la liste de mesures qui pourraient améliorer les niveaux de confort des Canadiens (77 p. 100 disent qu'ils se sentiraient ainsi « plus à l'aise »).
- Cette première mesure est suivie de près par l'adoption d'une nouvelle loi précisant que quiconque consultant sans autorisation un dossier de santé commettrait une infraction criminelle grave (74 p. 100 des Canadiens indiquent que cette mesure les mettrait « plus à l'aise »). Il convient de souligner de nouveau que la plupart des Canadiens ne sont pas au courant des lois déjà en vigueur dans la sphère de la protection de la vie privée.

Les Canadiens estiment aussi qu'un éventail d'autres options seraient efficaces :

- *Une assurance de la protection de la vie privée.* La possibilité d'être mis au courant de toute atteinte à la protection et à la sécurité des renseignements est une mesure qui figure pour la première fois dans la liste, cette année. Dans l'ensemble, cette mesure s'est classée troisième, étant donné que dans une proportion de sept pour dix, les Canadiens indiquent que ça les mettrait « plus à l'aise ». L'autre nouvel élément de la liste – l'établissement d'une procédure pour réagir à ce genre d'atteintes – permettrait aux deux tiers (68 p. 100) des Canadiens de se sentir « plus à l'aise ». Dans la même veine, c'est aussi dans une proportion de deux pour trois (66 p. 100) que les Canadiens indiquent que l'adoption d'une politique claire et accessible sur la protection de la vie privée, qui porterait sur la façon dont ces renseignements sont traités, leur permettrait de se sentir « plus à l'aise ».

- *L'accessibilité des dossiers.* Pour améliorer les niveaux de confort, on pourrait aussi permettre aux Canadiens de consulter leur dossier de santé en tous temps, afin d'y apporter au besoin les corrections nécessaires (68 p. 100 signalent qu'ils se sentiraient ainsi « plus à l'aise »). En majorité (dans une proportion de 55 p. 100), les Canadiens souhaiteraient également être en mesure de cacher ou de masquer des renseignements délicats.
- *Les appuis.* S'ils savaient que leur médecin appuie le système des DSE, deux Canadiens sur trois (66 p. 100) seraient « plus à l'aise » à l'égard de cette technologie. D'autres manifestations d'adhésion (de la part des gouvernements fédéral ou provinciaux et territoriaux) amélioreraient aussi le sentiment d'aise chez environ la moitié des personnes interrogées (49 p. 100 des répondants, pour ce qui concerne le gouvernement fédéral, et 45 p. 100 des répondants, pour ce qui concerne les gouvernements provinciaux et territoriaux).
- *La surveillance.* À la perspective de la réalisation, après un certain temps, d'une évaluation ou d'une vérification s'attachant au système au complet, la moitié environ des Canadiens (54 p. 100) sont « plus à l'aise » à l'égard des DSE.

Il convient de souligner que les résultats témoignant des appuis que reçoivent les initiatives dont il vient d'être question sont quelque peu plus élevés dans le groupe des Canadiens (31 p. 100) indiquant qu'ils ont eu une interaction avec un système de renseignements de santé électronique au cours de l'année qui vient de s'écouler.

Applications secondaires des renseignements de santé

La recherche en santé constitue une autre sphère dans laquelle les renseignements de santé pourraient être utilisés. C'est dans une proportion supérieure à huit pour dix (84 p. 100) que les Canadiens appuient l'utilisation des DSE dans le cadre de pareils travaux de recherche, pour autant que des détails comme leur nom et leur adresse ne soient pas communiqués au chercheur. Cette observation est d'autant impressionnante, que le résultat qui s'y rattache rappelle le niveau de soutien global du DSE (qui s'établit à 88 p. 100). En revanche, les résultats témoignant de la mesure dans laquelle les Canadiens appuient l'utilisation des DSE dans le cadre de la recherche en santé affichent une baisse spectaculaire (et s'établissent à 50 p. 100) si les détails personnels ne sont pas éliminés des dossiers. Dans la mesure où le consentement des personnes intéressées a été obtenu à l'avance, la possibilité que les chercheurs en santé associent les renseignements de santé personnels avec d'autres informations qui peuvent avoir une incidence sur la santé (p. ex., la scolarité, le

revenu) recueille aussi certains appuis, qui sont toutefois plus tièdes en comparaison du soutien global à l'égard des DSE (66 p. 100).

Dans une proportion s'élevant au moins aux trois quarts, les Canadiens indiquent qu'ils seraient à l'aise avec l'utilisation des DSE pour prévoir les crises de santé publique, pour surveiller ou évaluer le système de santé ou encore pour prévenir les utilisations abusives du système.

Une affirmation spontanée d'un(e) répondant(e) du sondage renferme peut-être l'essence même du point de vue de la majorité pour ce qui a trait à ces questions : « Si vous êtes capable de protéger ma vie privée, je suis à l'aise avec les [dossiers de santé électroniques]. »

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Afin d'obtenir de plus amples renseignements au sujet de la présente étude, veuillez communiquer avec Santé Canada

3. Methodology

The research findings for this study have been drawn from the results of a telephone survey with a random sample of 2,469 Canadians, aged 16 years and older. Surveying on the study was undertaken between June 22nd and July 19th, 2007. The interviews averaged approximately 20 minutes in length.

The survey instrument was designed in close consultation with the partnership of Health Canada, the Office of the Privacy Commissioner of Canada, and Canada Health Infoway. The purpose of the research was to update previous work undertaken on health information and privacy and contribute to the development of new knowledge and understanding of Canadians views on these topics. Several other basic indicators dealing with interaction with the health care system were included as profiling variables (i.e., variables which could be used to examine the core survey indicators). The results of these indicators are provided in Appendix A.

Once the questionnaire items were finalized, the questionnaire was programmed into EKOS' computer assisted telephone interviewing (CATI) software. In addition to programming the actual text of each question, the software includes a series of instructions to interviewers on how to administer each question (by reading or not reading the available categories, or prompting with a specified or randomized set, etc.), as well as the available categories or scaled responses to include.

test du questionnaire
After the questionnaire was programmed, it was pre-tested over the telephone in English on June 6th, 2007. A total of 15 interviews were conducted to ascertain the clarity of the questions, the flow of the sequencing, the overall length of the interviews and any other factors that may affect the response rate. The average length of the survey was found to be much longer than anticipated. As such, a number of revisions were made to the survey instrument. The revised questionnaire was pre-tested with 20 cases in English on June 20th. Following the second pre-test it was determined that no additional changes were required. The French version of the questionnaire was then pre-tested with 15 cases. The fieldwork for this project officially began on June 22nd, 2007. The final version of this survey is provided in Appendix B.

Once data collection was complete, the results were statistically weighted by age, gender, and region to ensure that the findings were representative of the Canadian population 16 years of age and over. With a sample size of 2,469, results from questions asked of the full sample of this survey may be considered statistically accurate to within +/- 2.0 percentage points, 19 times out of 20. A more detailed field report is provided in Appendix C.

A note on the presentation of results

Baseline studies on issues related to the current project have been undertaken by each of the partners in the past. Aspects of each of these other studies have been reproduced in the current research in order to determine whether or not views have changed over time. Tracking indicators are denoted throughout the report by the year in which the research was initially conducted.

It should also be noted that there are quotes in italicized lettering scattered throughout the report. These verbatim statements are drawn from the four open-ended questions respondents were asked over the course the survey, and are used to exemplify some of the views held by respondents.

Many of the questions were asked on a seven-point intensity scale, with "1" as the lowest score, "7" as the highest and "4" as the mid-point. Where the mid-point is discrete, such as on agree/disagree scales where it denotes "neither agree nor disagree", it is presented on its own with the low (1 to 3 on the 7-point scale) and high (5 to 7 on the 7-point scale) ends collapsed. Where the intensity scale represents a continuum, such as from low to high trust, the lowest (1 on the scale), highest (7) and mid-point (4) scores are presented separately, with the remaining lower (2 and 3) and higher (5 and 6) scores collapsed.

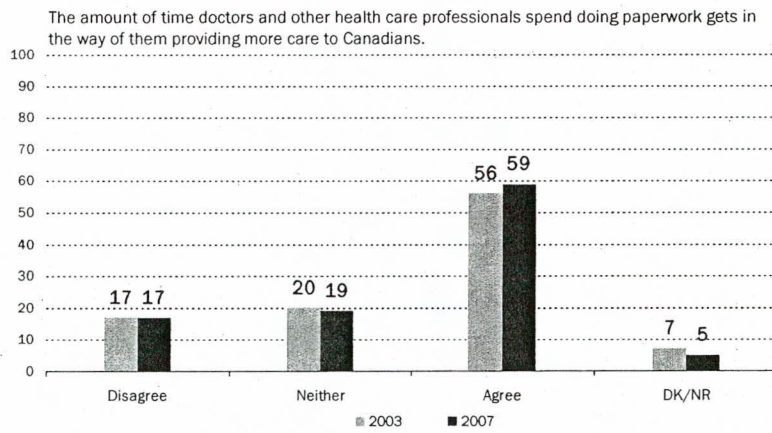
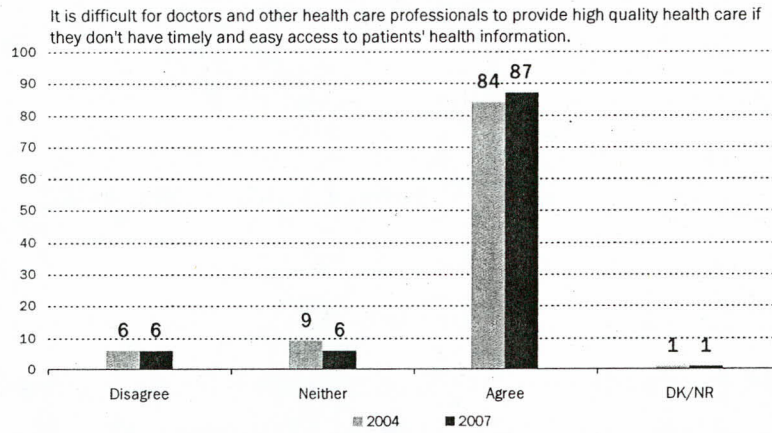
All results were analyzed by cross-tabular examination of sub-groups. Only statistically significant variations (using a chi-square test with a threshold of .5 or lower) are presented in these findings. The reader should assume, for example, that when one or more sub-groups such as provinces are highlighted in the report that the other sub-groups not mentioned are not statistically different from the overall (or average) responses.

With respect to regional analysis, "Prairies", in this document, refers to Manitoba and Saskatchewan. Responses from Albertans are reported separately.

4. Broad Perceptions of Personal Health Information

Health care providers' access to timely patient health information is seen as critical to the provision of quality health care. There are also rising fears that diagnoses and treatments are compromised by health information difficulties.

General attitudes:



Q:
Please rate the degree to which you agree or disagree with the following statements.
(Base: All Canadians; June/July 2007, n=2469)

General attitudes

Concerns about the privacy, confidentiality and security of patient information have intensified somewhat over the past several years.

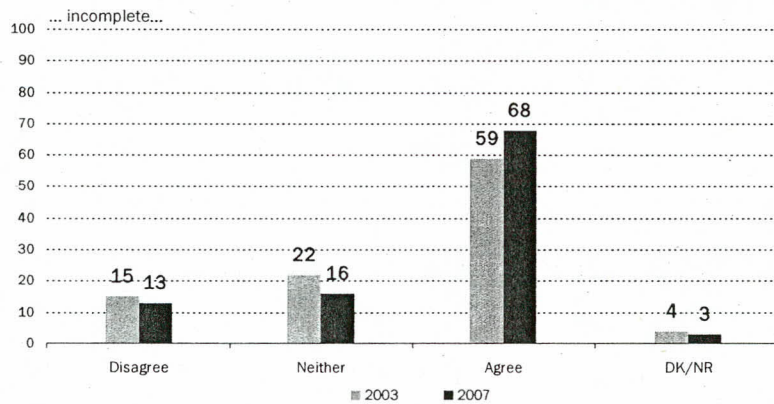
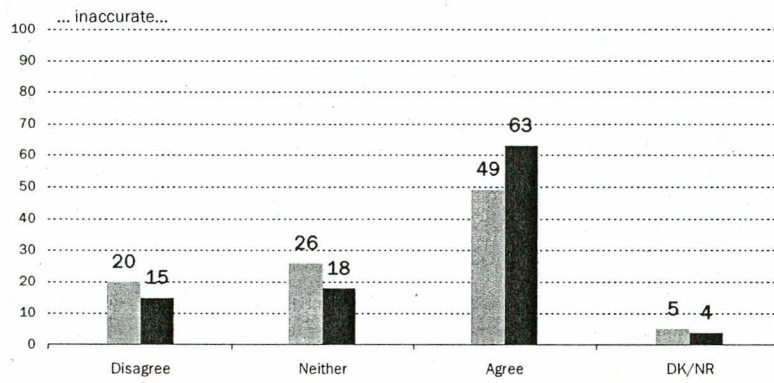
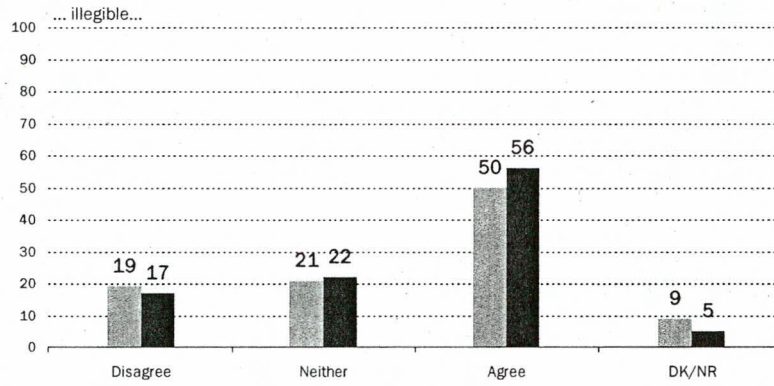
Canadians increasingly feel it is important for health care professionals to have easy access to patient information, seeing this as integral to the provision of quality health care. Indeed, close to nine in ten (87 per cent) agrees that it is difficult for health care professionals to provide quality care without timely and easy access to patient information. Agreement with this statement has strengthened slightly since this question was first asked in 2004 (up three percentage points).

- The belief that health care professionals require easy access to health information is highest in Ontario (90 per cent) and lowest in Quebec (83 per cent).

Administrative requirements of the current health care system are also seen as potentially impeding the delivery of services. A majority of the public (59 per cent) takes the view that the amount of time doctors and other health care professionals spend doing paperwork gets in the way of their providing care to Canadians. Overall, less than one in five (17 per cent) do not believe this to be the case. The proportion of Canadians agreeing with this statement has also increased over the past several years (up three percentage points since 2003).

- Regionally, residents of Quebec are more likely to indicate that the time spent by health care professionals doing paperwork is getting in the way of providing care (64 per cent).
- Women are more likely to believe that paperwork is an impediment to the delivery of quality care (61 per cent compared to 56 per cent of men).
- These concerns also rise significantly and consistently with age (46 per cent of those under the age of 25 take this view compared to 65 per cent of those over 65 years of age).

Mistakes in patient information:



Q: Serious mistakes do in fact occur due to doctors and other health care professionals incorrectly diagnosing or treating a patient because they have... patient information.
 (Base: All Canadians; June/July 2007, n=1/3 sample)

Mistakes in patient information

There are rising fears that diagnoses and treatments are being compromised by incomplete, illegible and / or inaccurate health information.

One of the arguments originally put forward in favour of the development of electronic health records was that this type of system would be able to reduce mistakes in patient information. When Canadians were first asked about this issue in 2003, many were willing to accept the argument that serious mistakes in the diagnosis and treatment of patients did indeed occur because doctors and other health care professionals were relying on information that was incomplete, illegible and inaccurate.

The results of the current study suggest that Canadians are now even more concerned that mistakes are being made due to flawed patient records. Presently, more than one in two says these mistakes occur because patient information is illegible (56 per cent), and two in three because information is inaccurate (63 per cent) or incomplete (68 per cent).

While there has been an across the board rise in concern about illegible, inaccurate and incomplete patient information, Canadians seem particularly worried about patient information that is inaccurate, with the proportion saying these are to blame for mistakes in diagnoses and treatments rising 14 percentage points since 2003.

- Canadians with household incomes of less than \$20,000 annually are more likely than those with higher annual incomes to be worried about serious mistakes occurring due to inaccurate, illegible, and incomplete information.
- Those concerned about health care providers' access to patient's health information are consistently more likely to agree that incomplete, illegible, and inaccurate information are likely causes of incorrect diagnoses and treatment, as are those that feel doctors spend too much time doing paperwork.

5. Safety and Security of Personal Health Information

Canadians hold positive assessments of the safety and security of their health information and accord high degrees of trust to those with access to their information, especially health care professionals.

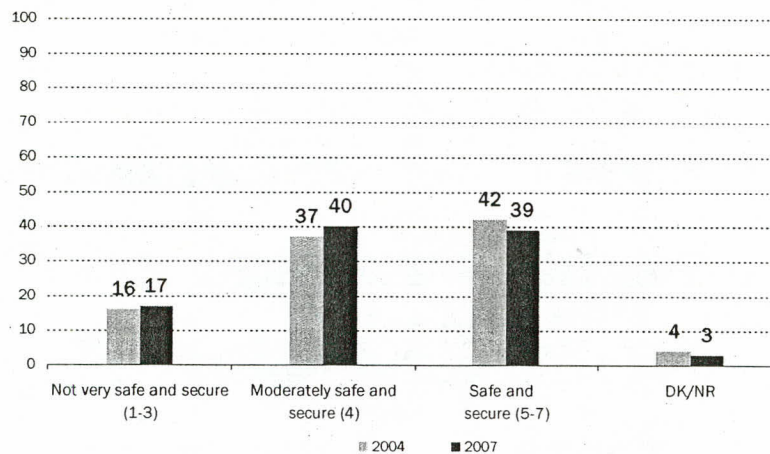
Perceived safety and security of health information

Positive perceptions of the safety and security of health information persist.

Two in five Canadians (39 per cent) believes that the health information that exists about them is “safe and secure” (5 to 7 on a 7-point scale) and an additional 40 per cent says that the information is at least “moderately safe and secure”. On the other end of the spectrum, there is less than one in five (17 per cent) that worries that the information is “not safe and secure” (1 to 3 on a 7-point scale). With the exception of a few more Canadians preferring to indicate that health information is “moderately safe and secure” as opposed to just “safe and secure”, these results are virtually unchanged from 2004.

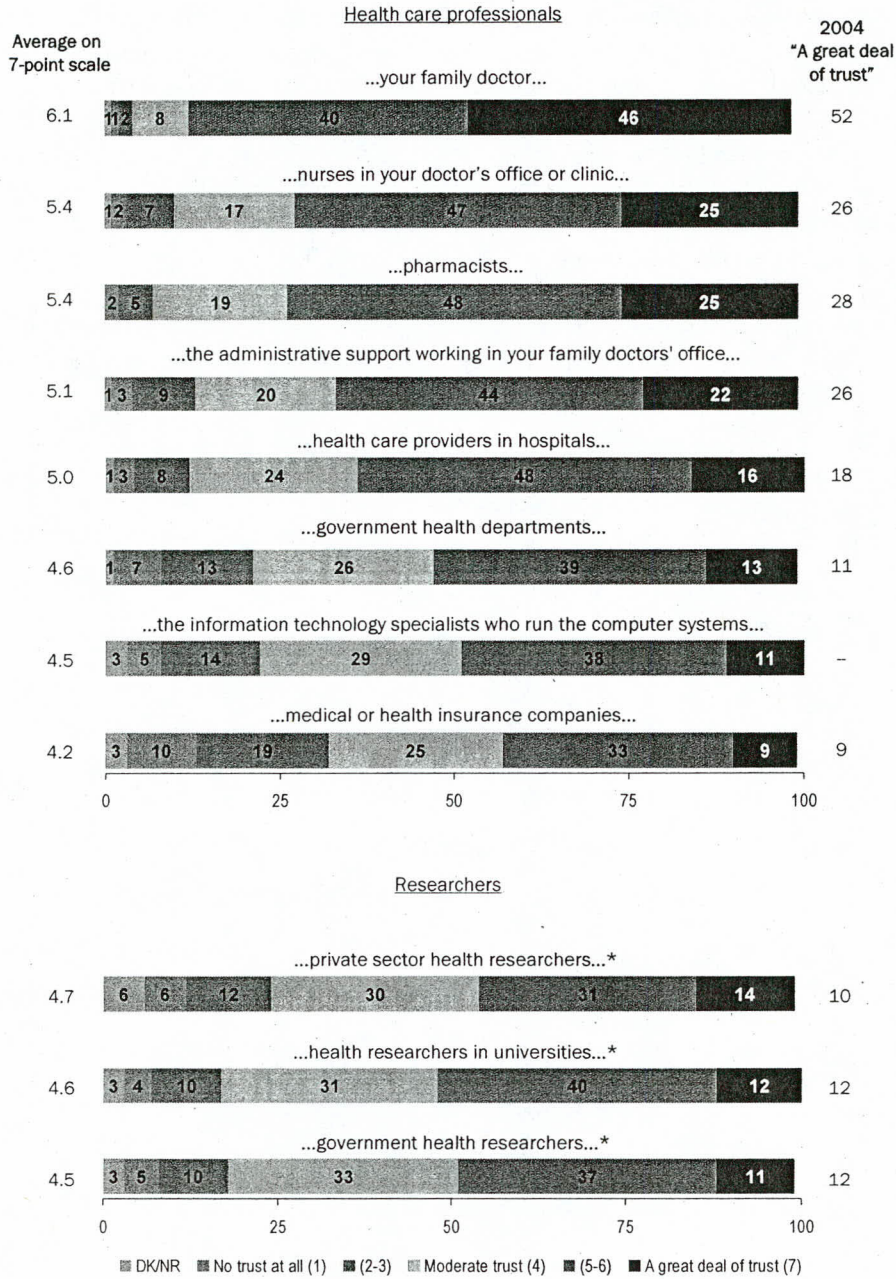
- Perceptions of the security of health information vary across the country, with residents of Alberta (46 per cent) and Atlantic Canada (44 per cent) the most likely to consider the information “safe and secure”.
- The perceived safety of health information also declines rapidly with age (60 per cent of youth consider their health information “safe and secure” compared to 34 per cent of seniors).

Perceived safety and security of health information:



Q:
In your opinion, how safe and secure is the health information which EXISTS about you?
(Base: All Canadians; June/July 2007, n=2469)

Trust in those with access to health information:



Q: How much trust do you have in . . . to keep your / Canadians health information safe and secure?
 (Base: All Canadians; June/July 2007, n=half sample / * 1/3 sample)

Trust in those with access to health information

Canadians continue to express a high degree of trust in health care professionals to preserve the safety and security of their personal health information.

Given that Canadians express a great deal of confidence in the safety and security of their health information in general, it is not unexpected to find that they are also highly trusting of those with access to this information. While there have been some variations in the level of trust afforded to these different professions since 2004, the overall hierarchy has remained virtually unchanged.

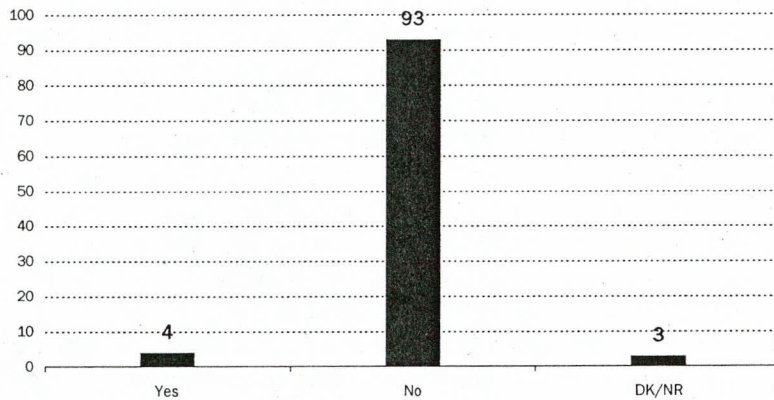
By a wide margin, doctors are still the most trusted, with just about half of all respondents (46 per cent) saying they have “great deal of trust” in these individuals (a 7 on a 7-point scale). Other frontline caregivers also score extremely well, with about one in four affording nurses (25 per cent), pharmacists (25 per cent), and administrators in family doctor’s offices (22 per cent) the highest trust scores. Health care providers in hospitals score slightly lower (16 per cent “a great deal of trust”), but they are still highly trusted overall. For all of these professionals, there is at least an additional 40 per cent that assigns high trust (a score of 5 or 6 on the same scale), while fewer than one in ten typically assigns low trust (a score of 1 to 3).

For the most part, health care researchers score somewhat lower than health care professionals. For example, only about one in ten gives government health departments (13 per cent), information technology specialists (11 per cent), or insurance companies (nine per cent) the highest trust rating. The same is true for health researchers: 14 per cent have a “great deal of trust” in those working for the private sector, 12 per cent for universities, and 11 per cent for the government. For the most part, however, all non-frontline workers – including researchers – are seen as largely trustworthy with at least four out of ten Canadians giving them a score of 5 or above on a 7-point scale.

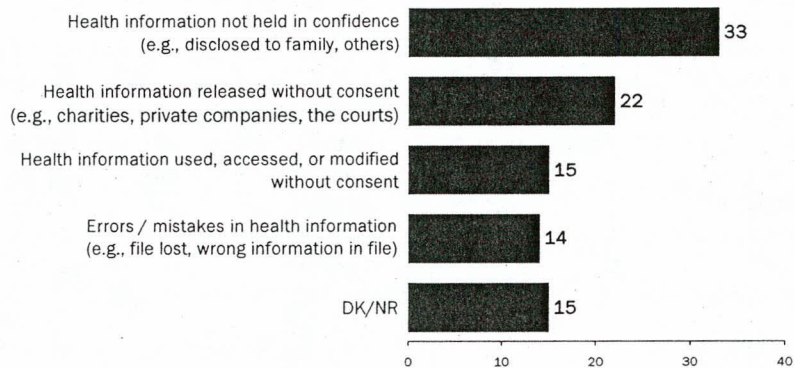
- Generally speaking, those Canadians with lower incomes and levels of educational attainment tend to display higher levels of trust in any of the tested professions.
- Across the country, residents of Quebec are more likely than those living elsewhere to place the highest level of trust in researchers.
- Those Canadians that already believe that health information is protected display higher levels of trust in health care professionals.

“I trust my family doctor.”

Breach of personal health information:



Type of Breach:



Q:
 Have you or a member of your family ever experienced a serious breach where your personal health information was used inappropriately or released without your consent? [IF yes] What was the breach? *
 (Base: All Canadians; June/July 2007, n=2469 / * those who had experienced a serious breach; June/June 2007, n=108)

"[A] receptionist was talking about me to a mutual friend."

"I was sent a letter for a fundraiser for a specific disease which I had and it came [from] the hospital I was treated, so someone used the information to see if I would donate money."

"My doctor released my health information to a lawyer without a court order."

Breach of personal health information

Reports of inappropriate use or release of Canadians' personal health information are almost non-existent among survey respondents.

In addition to asking about the perceived safety and security of health information, the current research also sought to determine whether or not Canadians have experience with their personal health information either being used inappropriately or released without their consent. Encouragingly, results reveal that an overwhelming majority of the public (93 per cent) had not had this type of experience. A very small minority of Canadians (four per cent) reports that either they or a member of their family has had their health information compromised by a security breach.

- Reports about the security of health information being compromised are most common in the Prairies (nine per cent) and Alberta (six per cent), and least common in Quebec (one per cent).
- Not surprisingly, individuals reporting breaches are much less likely to believe that their health information is secure. Accordingly, they are also less likely to trust health care professionals to keep this information safe.¹
- Interestingly, individuals who have had experience with EHRs over the past year are more likely to report a breach.

The four per cent of Canadians reporting inappropriate use or release of their health information were then asked the nature of this breach. The most common complaint was that their health information had not been held in confidence. Others indicated that their information had been released, accessed, or modified without their consent. There were also those that reported errors or mistakes as a breach of their personal health information, and almost as many did not provide the nature of the breach.²

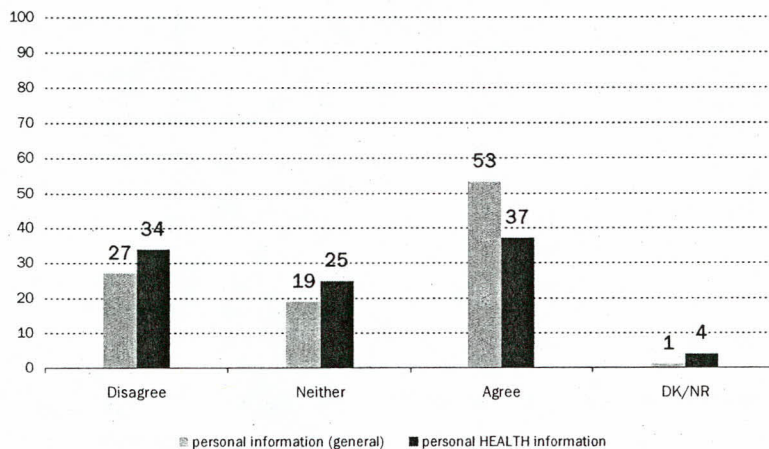
¹ Due to the very small number of respondents experiencing a breach (n=108), results on the subgroups should be interpreted with some caution.

² Ibid

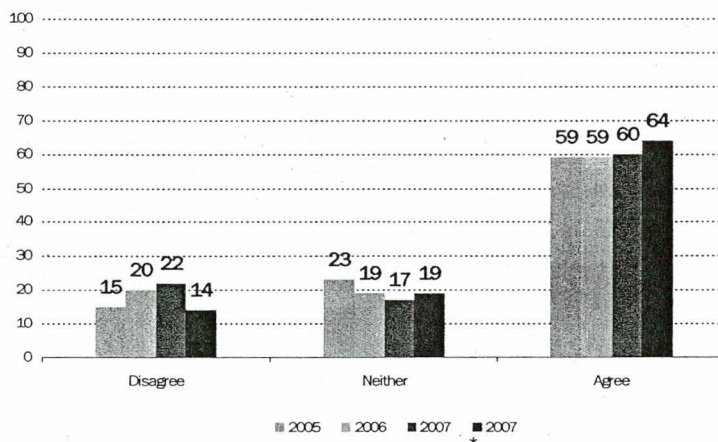
6. Protection of Personal Health Information

There are few types of personal information accorded a higher priority for privacy protection than health information. There is modest awareness among Canadians of existing privacy legislation and institutions.

Privacy and the protection of personal health information:



Q:
I feel I have less protection of my personal [information / health information] in my daily life than I did five years ago.
(Base: All Canadians; June/July 2007, n= half sample)



Q:
There are few types of personal information that are more important for privacy laws to protect than personal health information.
(Base: All Canadians; June/July 2007, n=2469 [* March 2007])

Privacy and the protection of personal health information

Health information is perceived as more secure than other types of personal information; however, laws protecting this information are still seen as important.

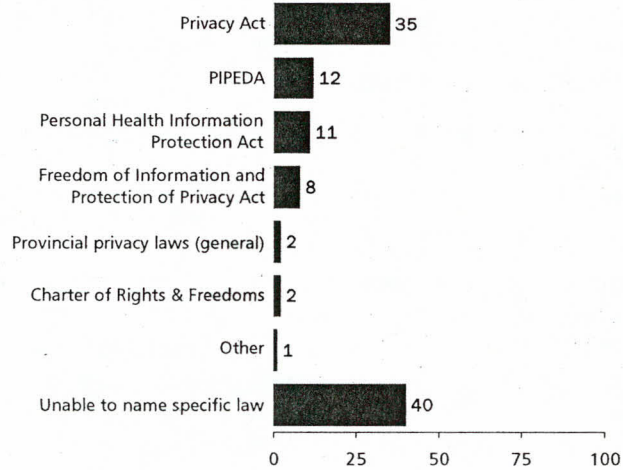
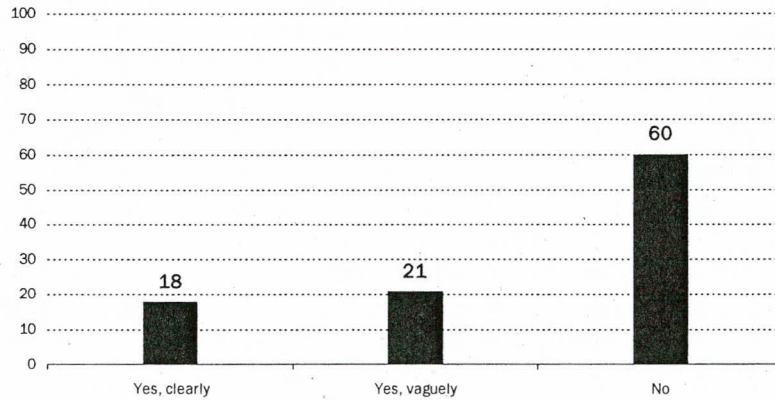
As noted earlier, Canadians generally feel that their health information is safe and secure. When asked to consider the protection of this information compared to just five years ago, however, the results are more mixed. While just over one in three (37 per cent) agrees that they have less protection of their health information than they did in the recent past, almost as many disagree with this statement (34 per cent).

What is clear is that Canadians are more likely to feel that their health information is safer than other types of personal information. Indeed, when asked about the protection of their personal information in general, it is one in two (53 per cent) – as opposed to one in three – that feels that this information is less secure than it was five years ago.

- Residents of British Columbia are the most likely to say they have less protection of their health information (47 per cent).
- Concerns about the security of personal information (in general and health information specifically) increase with age, but decrease as educational attainment rises.
- As might be expected, Canadians who have had a breach in their personal health information are significantly more likely to say they have less protection of their information (both health and otherwise) than those who have not had this type of experience.
- There are no differences of note with respect to frequency of use of the health care system.

While Canadians may express fewer concerns with respect to their personal health information, they nonetheless see the importance of having strong legislation in place to protect this information. In fact, close to two in three (64 per cent) believes that there are few other types of personal information that are more important to protect. This is a sentiment that has grown consistently stronger since this question was first asked in 2005 (up five percentage points).

Awareness of laws protecting the privacy of health information:



Q:
 Are you aware of any laws that help Canadians deal with privacy and the protection of personal health information? [If yes] Which laws are you aware of? *
 (Base: All Canadians; June/July 2007, n= half sample / * those that report "vague" to "clear" awareness of privacy laws n=537)

Awareness of laws protecting the privacy of health information

Few Canadians are aware of the laws intended to protect the privacy of personal health information.

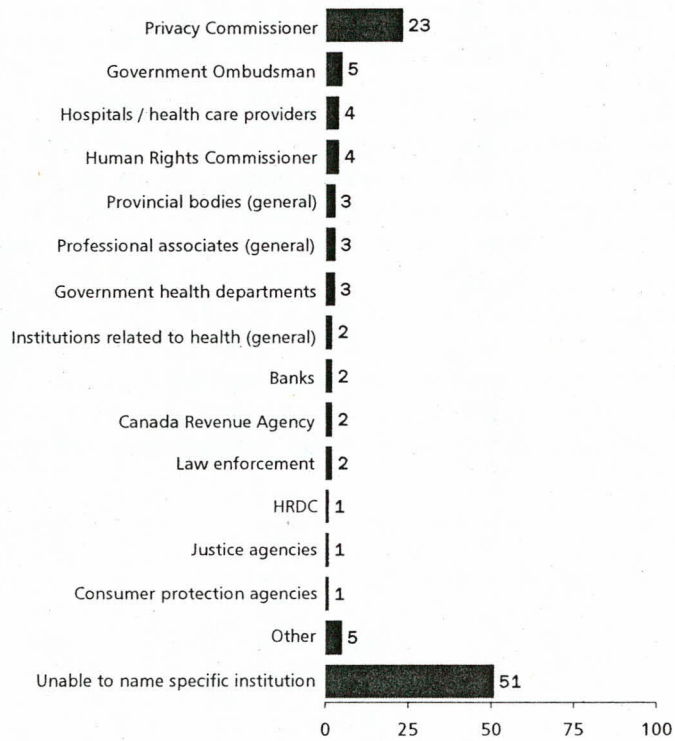
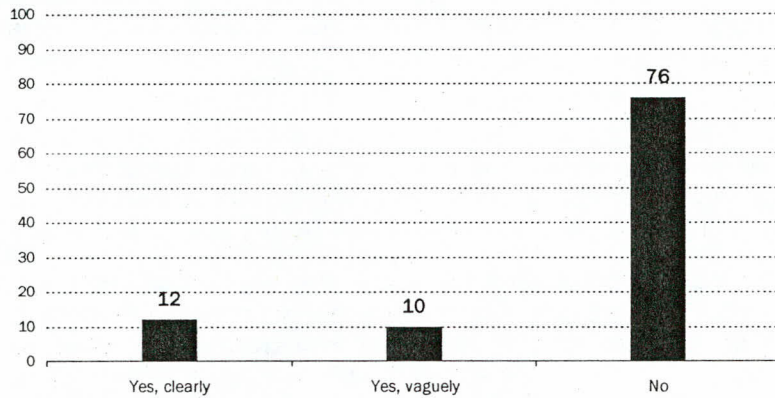
Even though Canadians increasingly stress the importance of having laws to protect the privacy of personal health information, it is only a minority that says they are aware of the laws that currently exist (18 per cent “clear” awareness and 21 per cent “vague” awareness).

- Across Canada, residents of Alberta are the most likely to say they are “clearly aware” of these kinds of laws (24 per cent). Quebeckers, on the other hand, register the lowest awareness levels (78 per cent “no awareness”).
- As is typical of indicators measuring awareness, Canadians of higher socioeconomic standing (i.e. those with higher levels of education and income) are more likely to report that they are aware of laws protecting privacy.
- Awareness of privacy laws is also significantly greater among Canadians who have had some form of interaction with an electronic health system in the past 12 months (27 per cent “clear” and 24 per cent “vague” awareness).

When those with at least a vague awareness were asked to provide the name of a specific law, federal privacy legislation is mentioned most frequently, with about one in three (35 per cent) citing The Privacy Act, and about one in ten (12 per cent) The Personal Information Protection and Electronic Documents Act (PIPEDA). Even though not all provinces have such legislation³, a Personal Health Information Protection Act is mentioned by about one in ten (11 per cent) at the national level (and by 18 per cent in Alberta). A few others also mention laws such as the Freedom of Information and Protection of Privacy Act, provincial privacy laws (in general), and the Charter of Rights and Freedoms. It should also be noted, however, that a plurality (40 per cent) are actually unable to name a specific piece of legislation.

³ At the time of this research, there were four provinces with health information protection acts in force: Alberta, Manitoba, Saskatchewan, and Ontario.

Awareness of institutions protecting the privacy of health information:



Q: Are you aware of any federal, provincial or territorial institutions that help Canadians deal with privacy and the protection of personal health information? [If yes] Which federal institutions are you aware of?*

(Base: All Canadians; June/July 2007, n= half sample / * those that report "vague" to "clear" awareness of institutions n=277)

Awareness of institutions protecting the privacy of health information

Even fewer Canadians say they are aware of institutions responsible for protecting their personal health information.

Awareness of federal, provincial or territorial institutions that are intended to help Canadians with the privacy and protection of personal health information is rather modest and significantly lower than awareness of privacy laws. In fact, only about one in five says they have heard of these institutions (12 per cent "clear" awareness and 10 per cent "vague" awareness), compared to two in five who have heard of privacy laws.

- Residents of Quebec also have the lowest awareness of institutions protecting personal health information (85 per cent "no awareness").
- Once again, Canadians of higher socioeconomic standing are more likely to report that they are aware of institutions protecting the privacy of health information.
- Interaction with electronic health information systems is also linked to higher awareness institutions with a role in this area (16 per cent "clear" awareness and 14 per cent "vague" awareness).

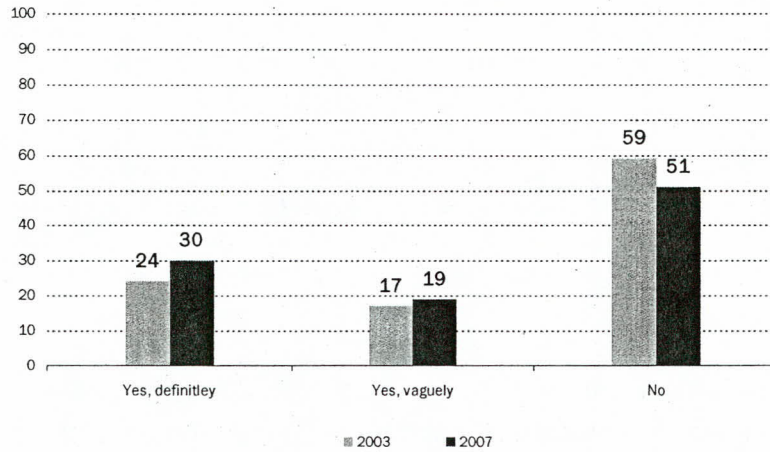
When those with at least a vague awareness are asked to name a specific institution, The Office of the Privacy Commissioner is cited most often (23 per cent). Most of the other responses are more general in nature (e.g., government ombudsmen, hospitals/health care providers, provincial bodies, professional associations), and all are named by less than one in ten overall. Interestingly, a few also reported non-health related institutions such as banks and the Canada Revenue Agency as institutions meant to protect the privacy of their health information. Awareness of these types of establishments is also overstated, as a majority (51 per cent) are unable to name a specific institution.

While Canadians enthusiasm for privacy laws may be high, overall low levels of familiarity with legislation in this area suggests that many may not be aware of their rights when it comes to the protection of their health information. Moreover, even if they are aware of their rights, it seems that few would know where to turn if they ever experienced a violation of their personal health information.

7. Perceptions of the Electronic Health Record (EHR)

Canadians have modest, but growing, awareness of EHRs, and a good number have personal experience to draw from. Assessments of, and support for, EHRs is robust.

Awareness of electronic health records (EHRs):



	Overall	Gender		Age				Education		
		Male	Female	<25	25-44	45-64	65+	HS	Coll	Uni
Yes, definitely	30	31	30	19*	29	38*	30	18*	32	40*
Yes, vaguely	19	19	18	22	19	18	18	17	19	20
No	51	50	51	60*	52	45*	52	64*	49	39*

	Overall	Region						
		BC	AB	MB/SK	ON	QC	ATL	TER
Yes, definitely	30	28	32	28	30	32	31	25
Yes, vaguely	19	20	19	19	17	21	18	11*
No	51	52	50	52	53	48	50	64*

* denotes differences that are statistically different from the average

Q:
One way that governments intend to improve the health care system in Canada is to move to electronic health records.
Have you ever heard anything about so called electronic health records?
(Base: All Canadians; June/July 2007, n=2469)

Awareness of electronic health records (EHRs)

Awareness of EHRs – although still rather modest – is growing.

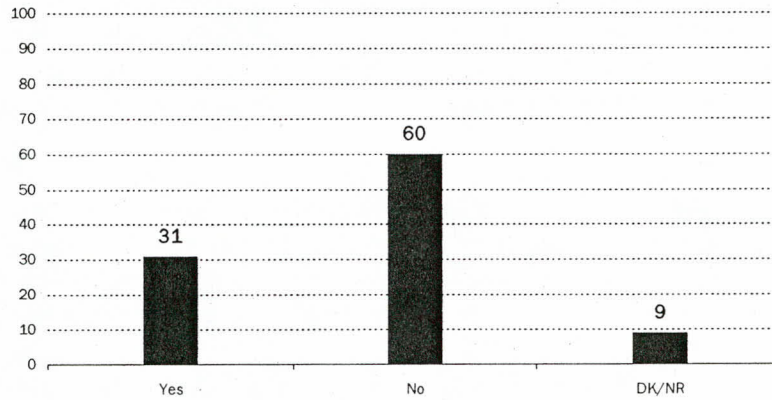
The 2003 study, *Public Attitudes to Electronic Health Records and Its Linkages*, established that public fluency on the EHR was quite low, which was not surprising, given the early stage of its development. Since that time, however, more than 200 EHR-related projects have been launched across the country⁴ and efforts to promote the technology appear to be registering with the Canadian public.

Today, it is nearly one in two Canadians (49 per cent) that have heard of EHRs (30 per cent “definite” awareness and 19 per cent “vague” awareness). This represents an eight percentage point increase in awareness since 2003. Notably, most of this rise has occurred in clear awareness (up six percentage points).

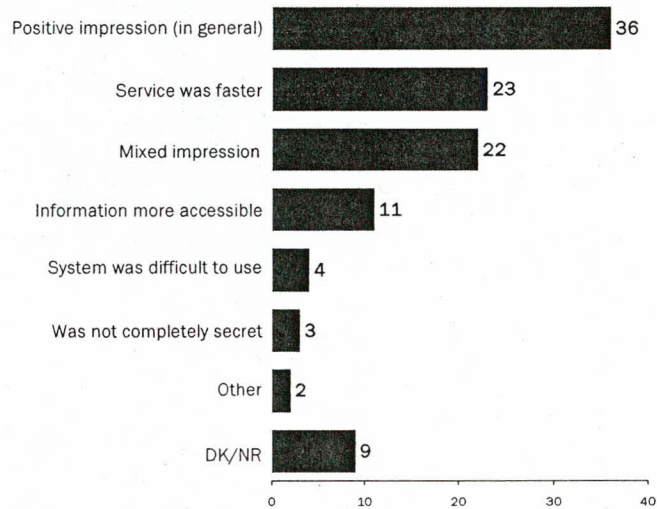
- Despite different rates of uptake, awareness of EHRs is fairly consistent across the regions, with the notable exception of the Territories (where close to two in three has not heard of this technology).
- Familiarity with EHRs is greater among older Canadians, particularly the 45 to 64 age cohort.
- The university educated are by far the most aware of EHRs (60 per cent have a definite / vague awareness). This is compared to 51 per cent with a college education and 35 per cent without any post secondary education.
- Awareness also rises with income (42 per cent of those with annual reported incomes of \$20,000 or less report some awareness compared to 58 per cent those with annual reported incomes of more than \$100,000).
- Canadians who have had the most interaction with health care providers over the past year (i.e. 20 or more personal or family visits) are more likely to be familiar with EHRs than those with fewer visits.

⁴ Canada Health Infoway, 2006-2007 Annual Report: *EHR...at the crossroads of success*.

Interactions with electronic health information systems:



Impression of interaction:



Q: In the past year, have you had any interactions with a health care provider that used some type of electronic health information system? Please do not include those interactions where someone verified your name, address and health card information using computers upon your arrival. [IF yes] What was your impression?*

(Base: All Canadians; June/July 2007, n=2469 / * Those who had an interaction n=775)

Interactions with electronic health information systems

Experiences with electronic health information systems are rated positively.

In addition to gauging overall awareness of the concept of EHRs, Canadians were also asked whether or not they have had any interaction with an electronic health information system in the past year.

Overall, it is about one in three (31 per cent) Canadians that reports having come across this type of system. Interestingly, there is also about one in ten (nine per cent) that reports not knowing if they had such an interaction, suggesting that exposure to electronic health systems may actually be higher.

- Across the country, interaction with electronic health information systems varies from a high of 43 per cent in Alberta to a low of 18 per cent in Quebec.
- Interestingly, men are more likely to report having had some type of interaction (36 per cent compared to 25 per cent of women).
- Interaction with electronic health information systems is also more common among Canadians of higher socioeconomic standing.

For the most part, Canadians are optimistic about their interactions with electronic health information systems. About one in three (36 per cent) describes the experience as generally positive, and some note that the service was faster (23 per cent) and that their information was more accessible (11 per cent). There is also about one in five (22 per cent) that has a more mixed or neutral impression. There are a few others, however, that have some concerns, although these are relatively minor overall (e.g., four per cent think the system is difficult to use and three per cent say the system is not completely secret or private).

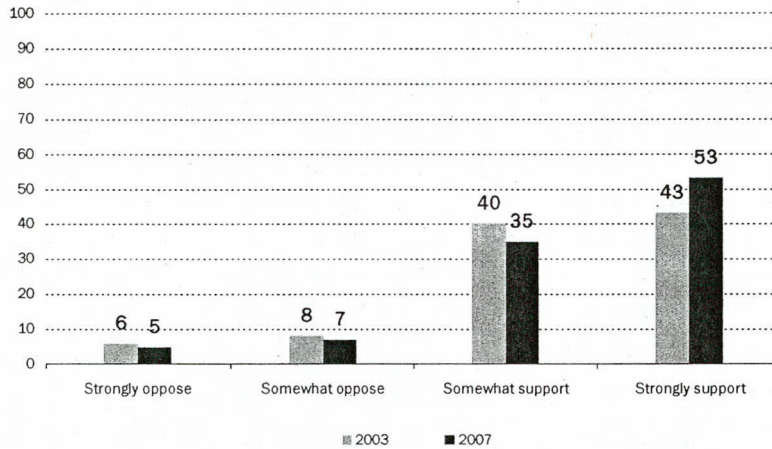
"It was communicative. It was specific and it zeroed in on my history."

"I loved it because it was easy...there were computers in every exam room...they typed up your name and your whole file, everything, came up."

"It was fine; makes everything faster."

"I'm a skeptic. Until it is centralized and access is limited, I'm not impressed."

Support for EHRs:



	Overall	Gender		Age				Education		
		Male	Female	<25	25-44	45-64	65+	HS	Coll	Uni
Strongly oppose	5	5	6	3	4*	6*	8*	7*	3*	5
Somewhat oppose	7	7	7	8	7	6	8	9*	7	5*
Somewhat support	35	34	35	40	34	33	34	36	36	32*
Strongly support	53	54	51	50	56*	53	50	47*	53	58*

	Overall	Region						
		BC	AB	MB/SK	ON	QC	ATL	TER
Strongly oppose	5	5	1*	9*	7*	4*	5	9
Somewhat oppose	7	7	6	6	7	8	6	16*
Somewhat support	35	38	33	32	31*	43*	27	21*
Strongly support	53	50	58	51	55*	45*	61*	52

* denotes differences that are statistically different from the average

Q:

Overall, do you strongly support, somewhat support, somewhat oppose or strongly oppose the development of a system of electronic health records that would allow health care professionals to be able to access your records no matter where in Canada you are receiving care?

(Base: All Canadians; June/July 2007, n=2469)

Support for EHRs

As awareness of EHRs grows, so does support for this technology.

Support for a system of electronic health information is robust, with close to nine in ten indicating that they support the development of EHRs (53 per cent “strongly support” and 35 per cent “somewhat support”). By comparison, only about one in ten opposes the development of this technology (five per cent “strongly” and seven per cent “somewhat”). While opposition to the EHR has remained relatively entrenched since 2003, overall support has climbed a total of five percentage points. Notably, much of this increase can be attributed to a conversion of weak support into strong support.

- Although support for EHRs is elevated across all regions, residents of Alberta, Ontario and Atlantic Canada hold the most favourable views.
- Strong support for EHRs increases with level of educational attainment.
- Those more familiar with EHRs – including those who have interacted with this type of system over the past year– are considerably more likely to support their development.

“Makes it easier for nurses and doctors to access health records and prevent abuse of the system.”

“We travel out of province and access to all health information in case of an emergency would be valuable.”

“I like the idea of having my complete information in one place.”

“Being able to access [information] in a timely fashion would save lives.”

“Just makes sense to have access for whomever you are being treated by. More likely to get all the necessary information from one [place].”

“It’s just a good idea.”

“There would be no delay in treatment because my records will be easily accessible.”

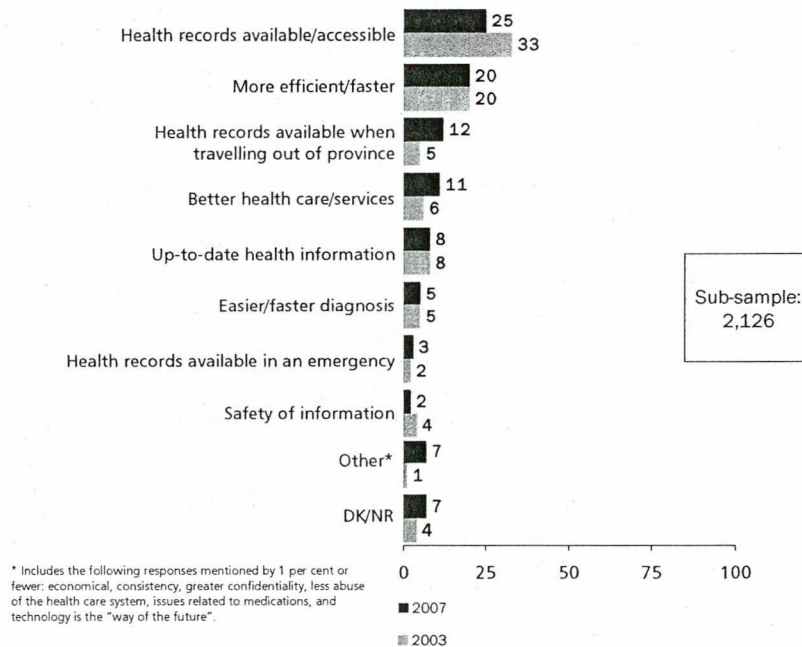
“It will make the health care system cheaper and more efficient.”

Reasons for supporting the development of EHRs

Accessibility / efficiency remain the most compelling reasons to support EHRs.

Canadians were asked, through an open-ended question, to explain their position on EHRs. (The reader should bear in mind that those supporting EHRs far outnumber those opposed). As was the case in 2003, support for the development of EHRs continues to centre on two primary factors: 1) making health records more accessible, and 2) improving the efficiency of the health care system. Related issues, such as having health records available when traveling out of province or in an emergency, are seen as increasingly attractive features of this technology. A few also continue to support EHRs for the simple fact that they believe that this type of system will improve health care (e.g., faster diagnosis, more up-to-date patient information).

Reasons for supporting the development of EHRs:



Q: What is the MAIN reason you would support the development of electronic health records?
(Base: Those that SUPPORT the development of EHRs n=2126)

"I want health care personnel to have instant access to my health records whenever and wherever I am."

"My impression was that it was faster service using electronic information."

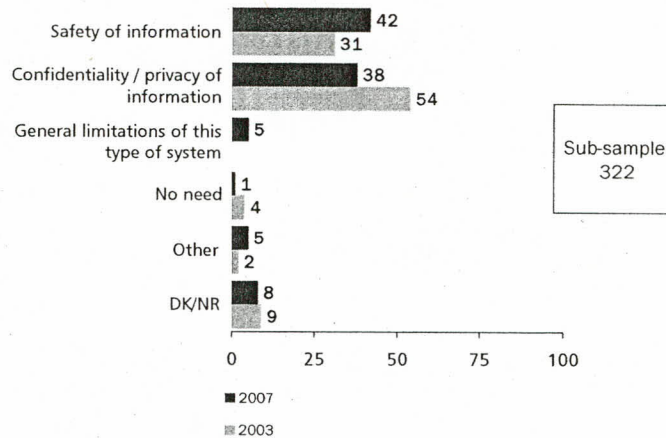
"In order for doctors to make important decisions, they must have all the information available."

Reasons for opposing the development of EHRs

Concerns about the security of EHRs lead reasons for opposing the development of this type of system.

Opposition to the development of EHRs, on the other hand, continues to be rooted almost entirely in concerns regarding the integrity of personal health information (i.e. the security and confidentiality of this information). Only a few oppose the system because they think it is generally limited or serves no real purpose. Although it is a stable group that opposes EHRs, if more can be done to demonstrate how information will be safeguarded in this type of system, it is possible that their views may change.

Reasons for opposing the development of EHRs:



Q: What is the MAIN reason you would oppose the development of electronic health records?
 (Base: Those that OPPOSE the development of EHRs n=322)

"There is no such thing as secure networks. If one person [can] have access to it, then everyone can have access to it."

"Look at identity theft, for example. Access to your health records makes it easier."

"I don't think it's necessary. Any doctor could [already] have access to any patient's information."

8. Comparison of EHRs and Paper-Based Systems

EHRs are seen as superior to paper-based records across a great many dimensions.

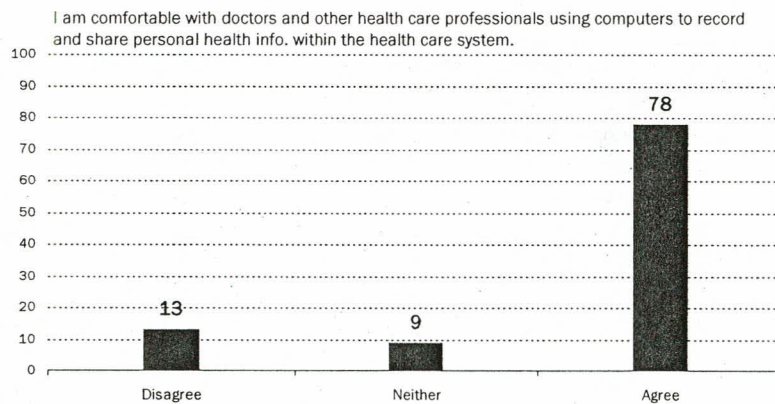
Comfort with electronic storage of health information

Canadians have few concerns with the electronic storage of health information.

Given that most already support the idea of the EHR, it is not unexpected to find that four in five Canadians (78 per cent) says they are comfortable with doctors and other health professionals using computers to record and share personal health information within the health care system. At 13 per cent, opposition to this practice seems to mirror reservations with EHRs in general (12 per cent oppose their development).

- Regionally, residents of the Prairies are the least comfortable with this practice (68 per cent).
- As level of education and household income increases, so do comfort levels.
- As might be expected, those Canadians who support EHRs are much more comfortable with the use of computers to store and share their personal health information (82 percent compared to 46 per cent opposed to EHRs).

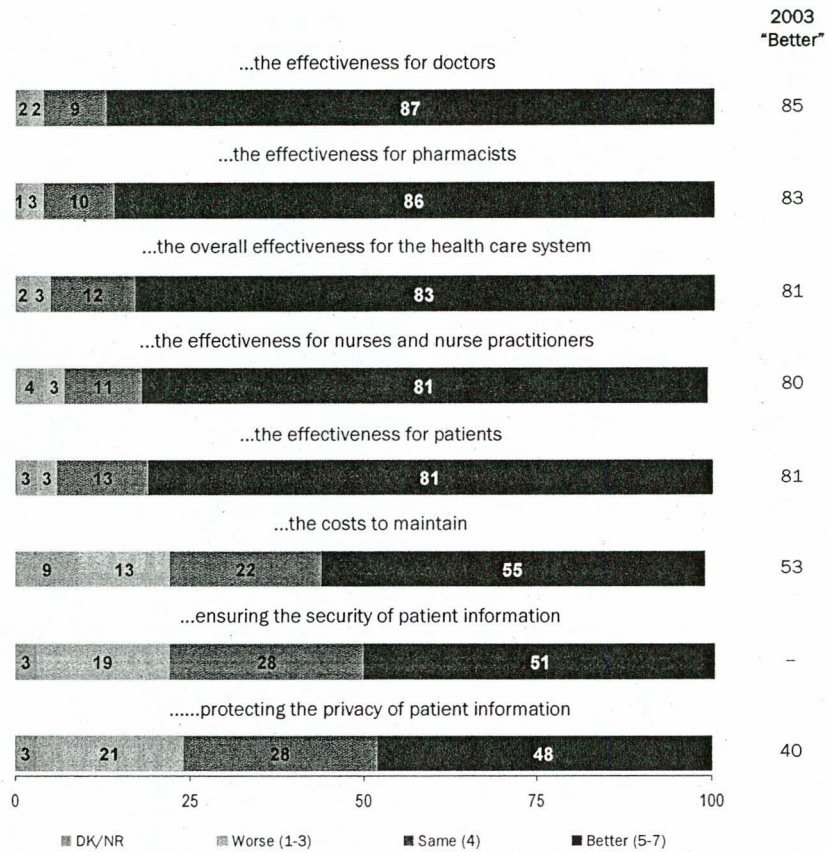
Comfort with electronic storage of health information:



Q:
Please rate the degree to which you agree or disagree with the following statements.
(Base: All Canadians; June/July 2007, n=2469)

"We trust banking electronically, so we can trust electronic health records using proper encryption and proper storage."

EHR v. paper-based systems:



Q: How would an electronic health record system compare to a paper based system) when it comes to ...
 (Base: All Canadians; June/July 2007, n= half sample)

"[Electronic health information systems] save time and the information is there permanently and accurately."

"[It's] quite efficient on the computer. Everything is readily available."

"I want doctors to have access to my records as fast as possible. The more knowledge the doctor has, the better the treatment."

"It would cut down on double doctoring and misuse of the drug system."

"[It is] much easier to manage the shear volume of information with an electronic system."

EHR vs. paper-based system

EHRs are increasingly perceived as being superior to paper-based systems.

When asked to compare the effectiveness of the two types of patient record systems, more than eight in ten Canadians rate EHRs as better than the paper-based system for all those involved in the delivery of health care (i.e. doctors, pharmacists, nurses and nurse practitioners, and patients) and for the health care system as a whole. Fewer, but still a majority (53 per cent), also believe that the electronic systems will be less costly to maintain. The perception that the EHR is a "better" option has increased marginally across all of these indicators since 2003, with the exception of the perceived effectiveness for patients (which has remained stable at 81 per cent).

Ensuring the privacy and security of patient information is the one area that continues to present a challenge for the health care system as a whole, with close to half of Canadians indicating that electronic-based systems would be worse or no better than paper-based systems. That said the public still leans to seeing the EHR as the preferred system in these areas. The perception that the EHR is "better" at protecting privacy has improved significantly since this question was last asked in 2003 (up eight percentage points).

- Generally speaking, Canadians with higher incomes and levels of educational attainment are more inclined to view the EHR as "better" for all frontline health care professionals (e.g., doctors, pharmacists, nurses).
- Those who support EHRs are, not surprisingly, more likely to consider electronic systems superior to paper-based systems across all areas tested.
- Importantly, Canadians with firsthand experience with electronic health information systems are more likely to see the benefits of EHRs for patients and health care providers. When asked how the EHR system compared to the paper system in terms of overall effectiveness for the health system, an overwhelming majority (89 per cent) said the electronic system was better.

"[The electronic health information system] made it easier. The receptionist didn't have to find and sort through a file; it was all readily available."

"[EHRs] are fast, efficient, and reliable; papers often get lost."

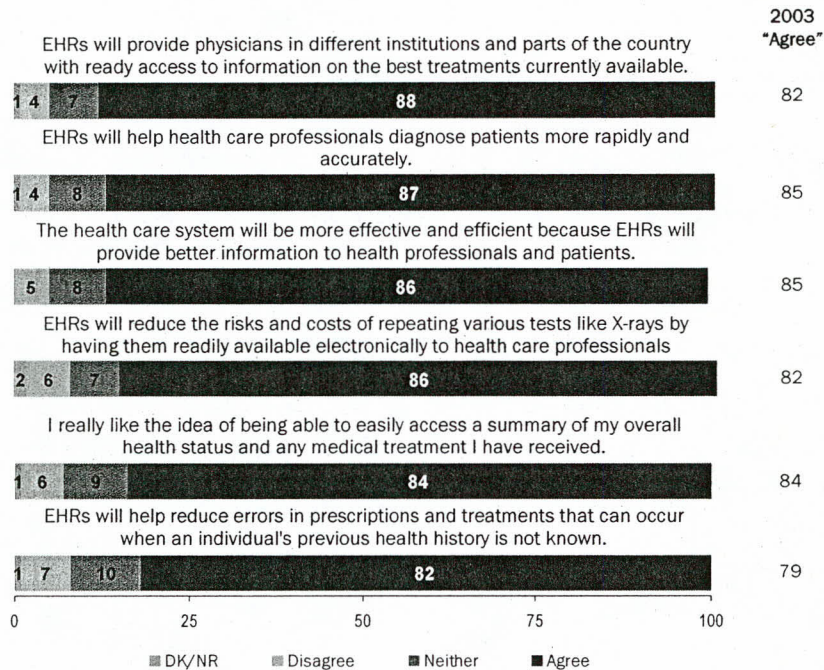
"Having a paper-based system is more secure. Nobody breaks into a doctor's office to steal records, but they break into computer systems."

"[Electronic health information systems are] more efficient than trying to go through a bunch of paper reports looking for information; providing it is kept up to date."

9. Potential Advantages & Disadvantages of EHRs

A host of arguments in favour of EHRs hold a great degree of resonance for Canadians. Arguments against EHRs gain less traction, with security concerns garnering the most agreement.

Potential advantages:



Q: There are a number of arguments made for and against electronic health records. How much do you agree or disagree with the following arguments
(Base: All Canadians; June/July 2007, n= half sample)

"Everything is in the record; history and test results always available."

"Easier to keep track; reduces chances of errors in diagnosis and prescriptions."

"It is cutting down on paperwork and workload."

"They had everything right there...saved me from a drug interaction that may have cost me my life..."

Potential Advantages

Arguments in favour of the EHR continue to resonate with most Canadians.

Canadians clearly recognize the potential advantages of the EHR. In fact, at least eight in ten consistently agree with all the arguments in favour of such a system, and fewer than one in ten disagrees.

The public is most onside with the notion that EHRs will provide physicians across the country with ready access to patient information. This is followed closely by the arguments that EHRs will assist health care professionals to make faster and more accurate diagnosis, will provide better information to doctors and patients, and will reduce redundancies within the system. The idea of being able to access a summary of their health status is also appealing to most Canadians, as is the potential for reducing errors in prescriptions and treatments.

With the exception of a patient being able to access their own summary (which has remained stable at 84 per cent), agreement with each prospective advantage of EHRs has risen since 2003. This is particularly true when it comes to the potential for improving physicians' access to patient information, which has climbed six percentage points over the past several years to become the top rated advantage.

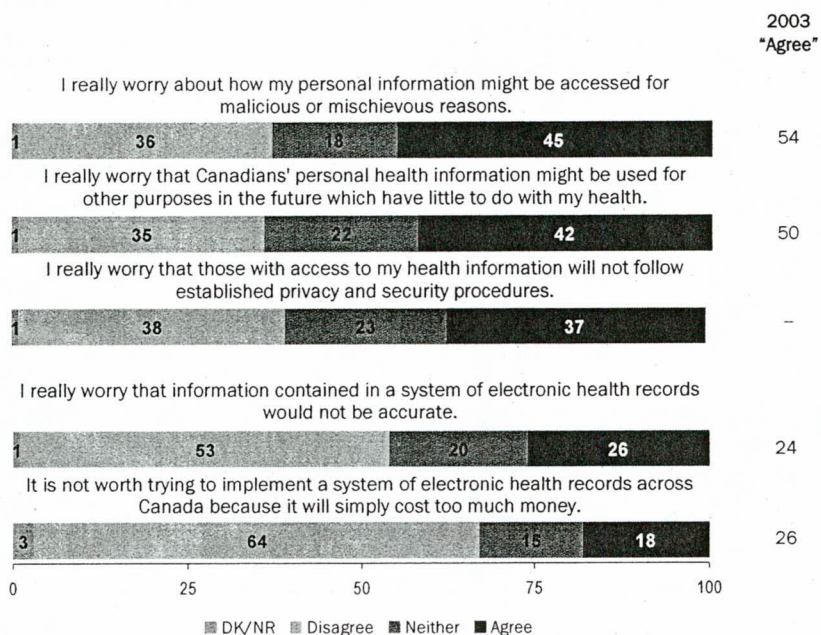
While the overall high levels of agreement are consistent across demographic groups, there are some noteworthy differences based on other attitudinal indicators.

- Canadians who support the development of EHRs are significantly more likely than those who oppose it to accept the arguments in favour of this type of system (by at least 30 percentage points).
- Those who have had some interaction with electronic health information systems are also somewhat more likely to acknowledge certain benefits of an EHR system (e.g., reducing errors in prescriptions, reducing costs from redundancies, and having access to a health status summary).

"Better health care due to better access to information."

"Prevented repeating x-rays."

Potential disadvantages:



Q:
There are a number of arguments made for and against electronic health records. How much do you agree or disagree with the following arguments
(Base: All Canadians; June/July 2007, n= half sample)

"It's not as efficient as it should be."

"Not all paper information can be properly entered; occasional errors in the computer system."

"It is a good idea. It is easier to access information, but [I am] concerned about unauthorized usage."

"The electronic systems are not foolproof. Someone could enter the system with malicious intent."

Potential Disadvantages

Canadians' concerns with EHRs continue to focus primarily on the safety and security of the system.

Although most are convinced of the benefits of the EHR, Canadians also express some apprehension with this type of system. For the most part, however, concerns about EHRs are far more limited (i.e. fewer than half agrees with any of the potential disadvantages).

The public is most concerned that their personal information could somehow be compromised. For example, pluralities agree that they worry that their information could be accessed for malicious or mischievous reasons (45 per cent) or that it could be used for purposes not related to their health (42 per cent). Canadians are less worried that privacy and security procedures will not be followed by those with access to their records, although it is still a concern for about one in three (37 per cent). Arguments that a system of EHRs would not be accurate or would be too costly to implement resonate with few Canadians (26 per cent and 18 per cent, respectively).

As noted earlier, Canadians are more likely to accept the arguments in favour of developing EHRs than they were in 2003. Conversely, the public is less likely to agree with any of the arguments presented against EHRs than they were when these issues were first explored.

- As might be expected, Canadians who oppose the development of the EHR are significantly more likely than those who support it to agree with each of the potential disadvantages of this type of system (by at least 27 percentage points).
- It is important to note that Canadians who have not had first hand experience with an electronic health system are more likely to accept each of the arguments against the EHR.
- Not surprisingly, a majority of those who have experienced a breach in their personal health information have concerns with the privacy of this type of system (e.g., that privacy procedures are not followed, that their information is being used for other purposes).

“If I had things I didn't want people to know, I would be more concerned about that information getting out.”

10. The EHR & Comfort Levels

We find strong and rising comfort with EHRs, and a number of specific initiatives which could serve to bolster comfort levels.

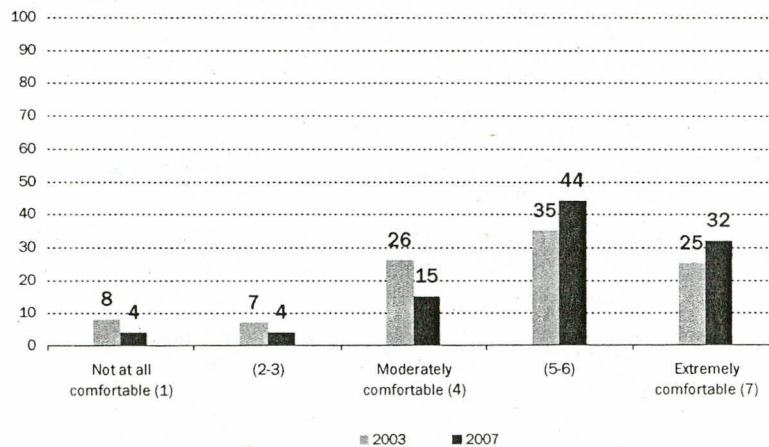
Comfort with EHRs

Level of comfort with the idea of EHRs is strong and rising.

Most Canadians indicate that they are, at the very least, moderately comfortable with the EHR (92 per cent rate their level of comfort between 4 and 7 on a 7-point scale), and an impressive three in four (76 per cent) are "very comfortable" with this type of system (a 5-7 on the 7-point scale). Overall, fewer than one in ten expresses a low level of comfort. Moreover, comfort with the idea of an electronic health record has increased significantly since 2003, with the proportion reporting that they are "very comfortable" rising 16 percentage points.

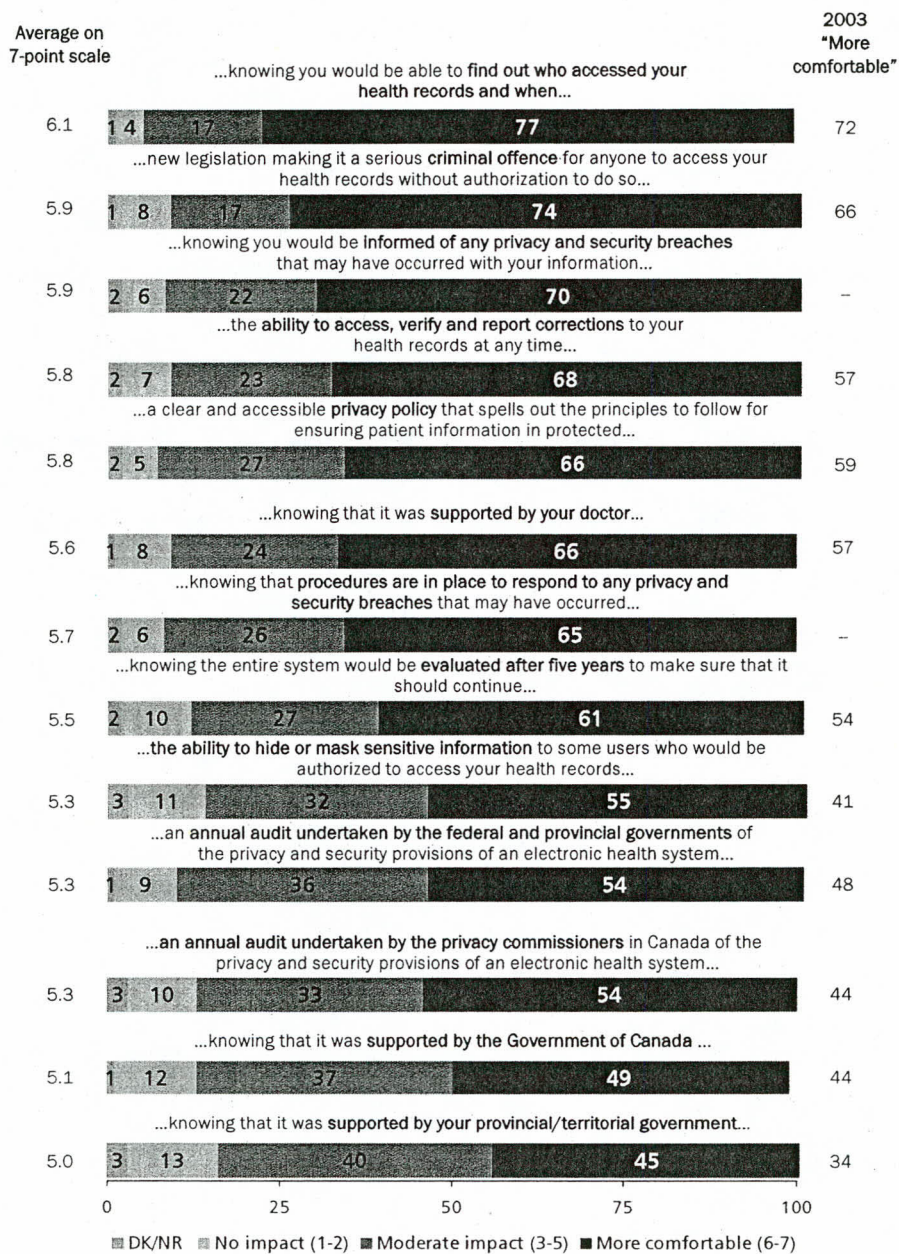
- Across all regions of Canada, the highest comfort levels are found in Quebec (40 per cent rate their comfort a 7 on a 7-point scale).
- Older Canadians are the least comfortable with the idea of EHRs (66 per cent "very comfortable" compared to 80 per cent of youth).
- Not surprisingly, those who support the development of EHRs are more comfortable with this type of system.
- Importantly, those who have interacted with an electronic health information system also report higher levels of comfort with EHRs.

Comfort with EHRs:



Q:
Overall, how comfortable are you with the idea of electronic health records?
(Base: All Canadians; June/July 2007, n=2469)

Potential ways of increasing comfort with EHRs:



Q: What impact would ... have on your comfort levels with an EHR?
 (Base: All Canadians; June/July 2007, n= half sample)

Increasing comfort with EHRs

There are a number of measures that will help to greatly improve comfort levels.

Although Canadians already express a high level of comfort with EHRs there remain some concerns with the implementation of this type of system. Respondents were asked their opinion of how a number of measures may impact their level of comfort with an EHR. Although certain measures are more effective than others, all options examined had some positive impact on comfort levels. Moreover, the proportion of Canadians indicating that any one of these measures would make them feel more comfortable has increased across the spectrum.

As was the case in 2003, a clear hierarchy emerges, with having the ability to find out who accessed your health records and when, topping the public's list of things that could be done to make them "more comfortable" with EHRs. This is followed closely by introducing new legislation that would make unauthorized access of personal health records a serious criminal offence. It is worth reiterating that most Canadians are not aware of the privacy legislation that currently exists. A range of other options are also seen as effective. These are grouped by theme and discussed below.

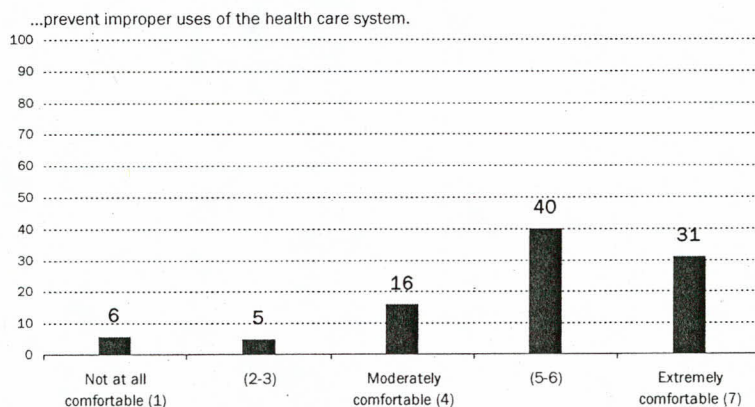
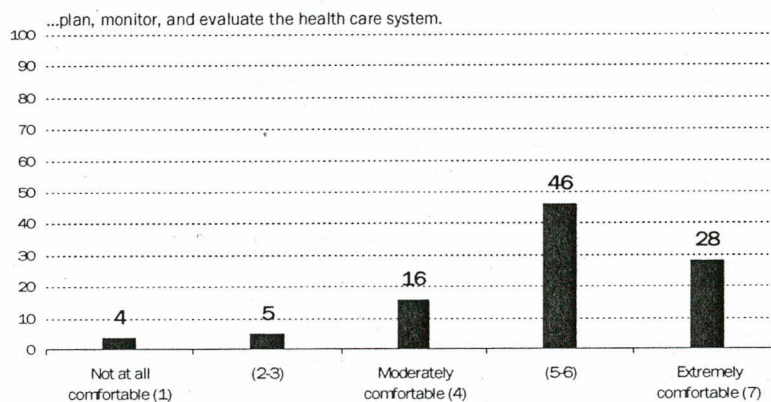
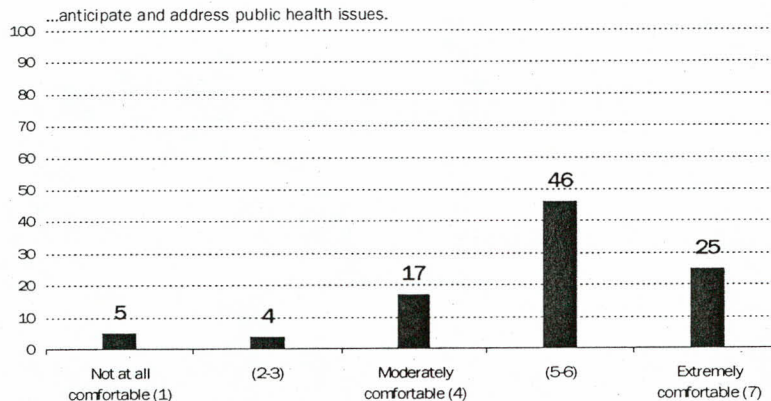
- *Privacy assurances.* The option of being informed of any privacy or security breaches is new to the list this year and ranks third overall, with seven in ten Canadians saying this would make them "more comfortable". The other new item on the list – having procedures to respond to such breaches – would make two-thirds of Canadians "more comfortable". Likewise, two in three also say that a clear and accessible privacy policy on how this information is to be handled would make them "more comfortable".
- *Access to records.* Another way of increasing comfort levels would be to allow Canadians to access their health record at any time in order to make any necessary corrections (68 per cent "more comfortable"). A majority (55 per cent) would also like to be able to hide or mask sensitive information.
- *Endorsements.* Knowing that their doctor supported a system of EHRs would make two in three Canadians "more comfortable" with the technology. Other forms of endorsement (i.e. from the federal, provincial or territorial governments), would also increase feelings of comfort for about one in two.
- *Oversight.* The idea that the entire system would be evaluated or audited after a period of time would also make about one in two "more comfortable".

Of note, support for any of these initiatives is generally somewhat stronger among those who have interacted with an electronic health information system. It should also be noted that, slightly different versions of many of these measures were tested in a 2004 EKOS survey. While not directly comparable, those findings showed the strongest measures as security safeguards for health professionals, including fines and measures to empower individuals with some measure of control over their health information.

11.Secondary Uses of EHRs

There exists high comfort levels with and strong support for secondary uses of EHRs, particularly under certain conditions.

Comfort with other uses of electronic health information:



Q:
Using the same scale, how comfortable are you with electronic health information being used to...?
(Base: All Canadians; June/July 2007, n= half sample)

Comfort with other uses of electronic health information

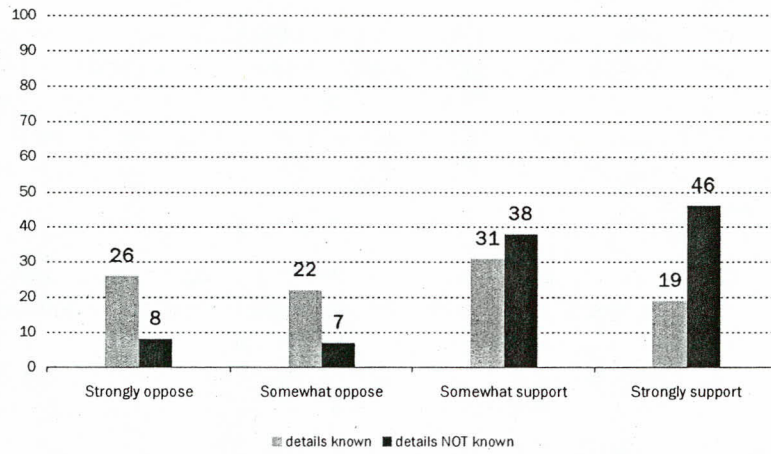
Canadians are also fairly comfortable with EHRs being used for a variety of other administrative purposes.

The Canadian public is highly comfortable with the basic premise of electronic health information systems (i.e. more accurate and accessible health records for improved health care delivery). There are, however, a number of other ways in which the EHR could be used to benefit the health care system more broadly. This year's survey sought to test Canadians receptivity to other uses of electronic health information.

Using EHRs to prevent improper use of the health care system holds the broadest appeal, with one in three saying they would be "extremely comfortable" (a 7 on a 7-point scale) making use of health information to achieve this objective. About one in four, would also feel "extremely comfortable" with health information being used to anticipate / address health issues or to plan, monitor and evaluate the health care system. Overall, close to three in four Canadians say they are "very comfortable" (5-7 on the 7-point "comfortable" scale) with any of these other uses of electronic health information, and only about one in ten expresses a low level of comfort. It should be noted that these comfort levels are only slightly lower than overall comfort with the EHR.

- Residents of Quebec are more likely than those living elsewhere in the country to be comfortable using EHRs to plan and evaluate the health care system and to anticipate and addressing public health issues (respectively, 40 per cent and 36 per cent "extremely comfortable").
- Predictably, those opposed to the development of EHRs are much less comfortable with any secondary use of this technology.

Support for using electronic health information in health research:



Q: Would you strongly support, somewhat support, somewhat oppose, or strongly oppose your electronic health information being used for health research purposes if details such as your name and address were [known / NOT known] to the researcher.
(Base: All Canadians; June/July 2007, n= half sample)

Support for using electronic health records in health research

Support exists for using EHRs in health research – especially if personal details are not shared or linked to other records.

Health research is another area in which electronic health information could potentially be put to use. More than eight in ten Canadians (84 per cent) support the use of EHRs in such research, provided that details such as their name and address are not known to the researcher. This finding is particularly impressive as it mirrors overall support for the EHR (88 per cent). Support for the use of EHRs in health research drops dramatically, however, if personal details are *not* removed from the record (50 per cent).

- Even those who support the EHR are less enthusiastic about using this information in health research if their personal details are not protected (i.e. only 54 per cent support compared to 87 per cent when name and address are removed).

If consent is obtained ahead of time, there also exists support for the health researchers to link personal health information to other records that may be related to health outcomes (e.g., education, income), but this is considerably more tepid than overall support for EHRs (66 per cent).

⋮ *“If you can protect my privacy, I am okay with [electronic health records]...”*

Appendix A: Interaction with the Health Care System

Interaction with the Health Care System

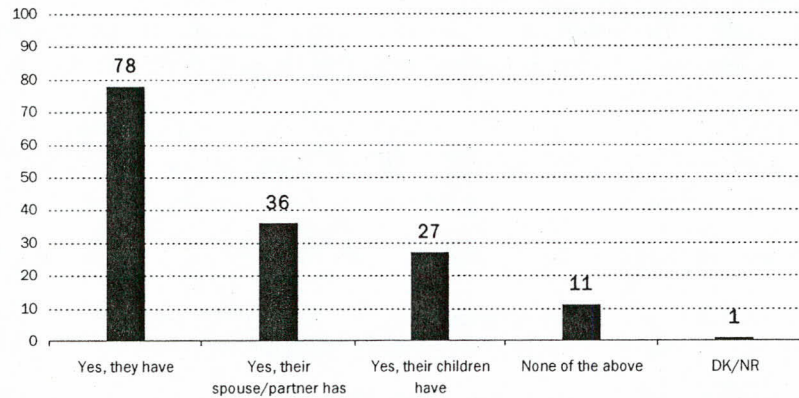
Questions in this section were asked with the express purpose of determining whether or not interaction with the health care system has an impact on Canadians' views of electronic health records or of the protection and confidentiality of their personal health information. Generally speaking, there are relatively few differences in broad attitudes. The areas where differences do exist are highlighted throughout the report.

The following is a brief summary of the Canadian public's self-reported interaction with the health care system over the past year.

- Contact with the health care system: Most Canadians report having been in direct contact with the health care system over the past 12 months.
- Source of medical care: Family doctors and physicians are the most common sources for health care in the country.
- Frequency of after-hours care: A majority of Canadians have never before sought care outside of regular working hours, but about 1 in 3 have done so on occasion.
- Frequency of contact with health care provider: During the course of a year, Canadians report an average of eight family and/or personal consultations with health care providers.
- Self-rated health: Most Canadians consider themselves to be in fairly good health.

Additional details, including regional and demographic variations, are provided in the remainder of this section.

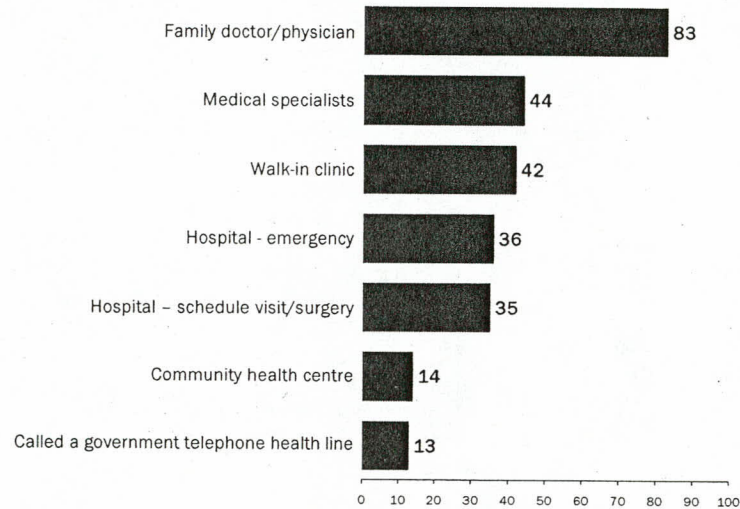
Contact with the health care system:



Q:
Over the past 12 months have you, or a member of your immediate family, visited a family physician or clinic?
(BASE: All Canadians; June/June 2007, n=2469)

- Three in four Canadians (78 per cent) report that they have visited a family physician or clinic over the past 12 months.
- About 1 in 3 also says that their spouses / partners (36 per cent) or their children (27 per cent) have been to the doctor in the past year.
- Only about 1 in 10 (11 per cent) says that neither they nor a member of their family have had contact with the health care system over this timeframe.
- Visits are most common among women, seniors, and Canadians of higher socioeconomic standing.

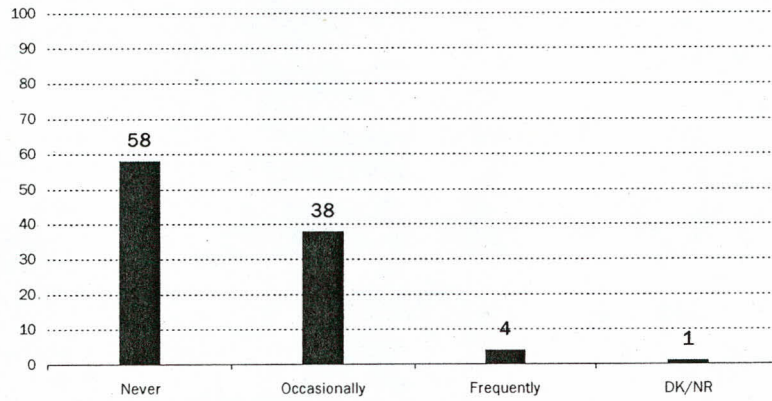
Source of medical care:



Q: Thinking about the past 12 months, where have you or a member of your immediate family received medical care from?
(BASE: Those who had or an immediate family member had an interaction with a family physician or clinic; June/June 2007, n=2232)

- Family doctors / physicians are, by a wide margin, the most common sources of medical care for Canadians (mentioned by 83 per cent of those who have received care over the past 12 months).
- Medical specialists and walk-in clinics are the next most common sources, each mentioned by approximately 2 in 5 (44 and 42 per cent, respectively).
- About 1 in 3 Canadians has received medical assistance at hospitals (36 per cent for emergency care and 35 per cent for scheduled surgeries).
- Only about 1 in 10 report either going to a community health centre (14 per cent) or called a government telephone health line (13 per cent).

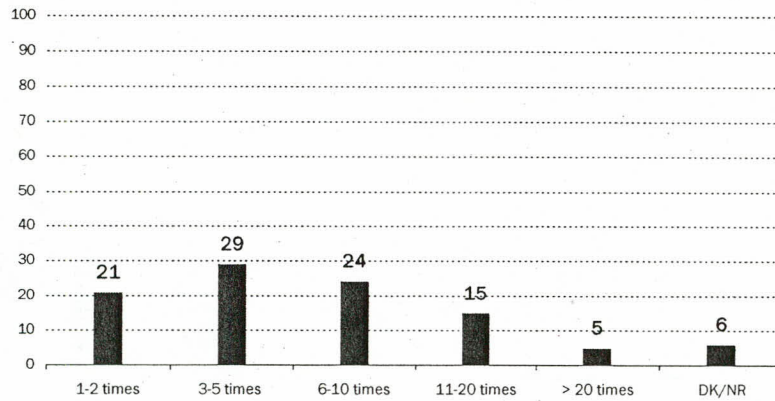
Frequency of after-hours care:



Q: How often, if ever, have you or a member of your immediate family tried to obtain medical assistance or information from your doctor or clinic after hours or on weekends? Would you say never, occasionally, or frequently?
(Base: All Canadians; June/July 2007, n=half sample)

- A majority of Canadians (58 per cent) says they have never tried to obtain care from a health care provider after-hours or on weekends.
- For those that have sought after-hours care, the tendency is to have done this occasionally rather than frequently.
- After-hours care varies by region, with residents of Quebec least likely to report using this service (71 per cent “never”).
- Canada’s seniors are also less inclined to visit after-hour clinics (69 per cent “never”).

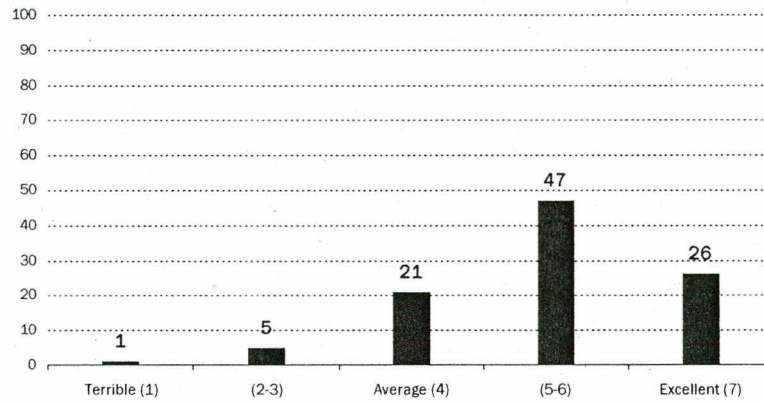
Frequency of contact with health care provider:



Q:
How many times have you or your immediate family consulted a health care provider in the past twelve months?
(BASE: All Canadians; June/June 2007, n=2230)

- The average number of personal and/or family visits to health care providers is 8.6 times in a 12 month period.
- Across Canada, the average number of yearly visits varies from a low of 5.9 in Quebec, to highs of 9.9 in Ontario and 11.6 in the Territories.
- The average number of visits also varies by age, with those between the ages of 25 and 44 reporting the fewest visits, and seniors reporting the most visits.

Self-rated health:



Q:
In general, how would you rate your health? Please use a scale from 1 terrible, to 7 excellent, where the mid-point 4 is average.
(BASE: All Canadians; June/June 2007, n=2469)

- When asked to rate their health on a 7-point scale, where 1 is “terrible” and 7 is “excellent”, Canadians average score is 5.4.
- Seniors and Canadians of lower socioeconomic standing rate their health slightly lower (with average scores of 4.9).

Appendix B: Survey Instrument

Electronic Health Information and Privacy Survey 2007

→ ON DOIT NUMÉROTÉ LES QUEST.

INTRO

Hello, my name is...and I work for EKOS Research Associates. We have been hired by the federal government and government funded organizations to speak to Canadians 16 years and older about the use of personal health information to provide health care. This is an opportunity to express your views on things that affect all of us. All of your responses are confidential. May I begin?

****If asked, the survey will take 20 minutes.****

SEX

DO NOT ASK

Record gender of respondent

Male..... 1
Female..... 2

PRE1

In this survey there are questions about privacy and personal health information. By privacy, we mean the right of individuals to control information about themselves. By personal health information, we mean information about your physical and mental health and about the health services that you receive.

PCF

PRE1B

Please rate the degree to which you agree or disagree with the following statements using a 7 point scale where 1 means you strongly disagree, 7 means you strongly agree and the mid-point 4 means you neither agree nor disagree.

FT6

There are few types of personal information that are more important for privacy laws to protect than personal health information.

OPCC TRACKING

1 Strongly disagree..... 1
2..... 2
3..... 3
4 Neither agree nor disagree..... 4
5..... 5
6..... 6
7 Strongly agree..... 7
DK/NR..... 9

IMPR

It is difficult for doctors and other health care professionals to provide high quality health care if they don't have timely and easy access to patients' health information.

PCF

DA16B

1/2 SAMPLE W/DA16H

I feel I have less protection of my personal information in my daily life than I did five years ago.

OPCC TRACKING

①

exemple

V59I-? ②
→ info personnelle et protection

③

(2) 4a→b

④a

⑤

(1)

DAI6H

1/2 SAMPLE W/DAI6B

4b

I feel I have less protection of my personal HEALTH information in my daily life than I did five years ago.

PWORK

5

The amount of time doctors and other health care professionals spend doing paperwork gets in the way of them providing more care to Canadians.
EHR

MIST1

1/3 SAMPLE W/MIST2-3

(3) ba → c

6a

Serious mistakes do in fact occur due to doctors and other health care professionals incorrectly diagnosing or treating a patient because they have incomplete patient information.
EHR

MIST2

1/3 SAMPLE W/MIST1-3

6b

Serious mistakes do in fact occur due to doctors and other health care professionals incorrectly diagnosing or treating a patient because they have inaccurate patient information.
EHR

MIST3

1/3 SAMPLE W/MIST1-2

6c

Serious mistakes do in fact occur due to doctors and other health care professionals incorrectly diagnosing or treating a patient because they have illegible patient information.
EHR

7

CPHIR

I am comfortable with doctors and other health care professionals using computers to record and share personal health information within the health care system.

SKP3

=> SKP4 else => +1 if NOT (ROT2=#1); 1/2 SAMPLE W/AW3B-4B

8

AW1B

Are you aware of any laws that help Canadians deal with privacy and the protection of personal HEALTH information? V52

- Yes, clearly 1
- Yes, vaguely 2
- No 3
- DK/NR 9

AW2B

=> +1 if NOT (AW1B=#1-#2)

9

DO NOT READ - DO NOT PROMPT

Which laws are you aware of? V52

- Personal Information Protection and Electronic Documents Act (PIPEDA) 01
- The Privacy Act 02
- DK/NR 99 X

SKP4

=> SKP5 else => +1 if NOT (ROT2=#2); HALF SAMPLE W/AW1B-2B

10

AW3B

Are you aware of any federal, provincial or territorial institutions that help Canadians deal with privacy and the protection of personal HEALTH information?

- Yes, clearly 1
- Yes, vaguely 2
- No 3
- DK/NR 9

INSTITUTIONS
V52? v
Policy knowledge

AW4B

=> +1 if NOT (AW3B=#1-#2)

11

DO NOT READ - DO NOT PROMPT

Which INSTITUTIONS are you aware of?

- Privacy Commissioner of Canada 01
- Response 77
- DK/NR 99

O
X

PRE2

12

Canadians' health information is used to provide care to pay for health services and to manage the health care system in general. This information is stored in numerous locations such as doctors' offices, hospitals, or places such as labs or clinics.

DEF?

SAF

13

In your opinion, how safe and secure is the health information which EXISTS about you? Please use a scale from 1 to 7, where 1 is not at all safe and secure, 7 is extremely safe and secure, and 4 is moderately safe and secure.

- 1 Not at all safe and secure 1
- 2 2
- 3 3
- 4 Moderately safe and secure 4
- 5 5
- 6 6
- 7 Extremely safe and secure 7
- DK/NR 9

TRU

V59D

Preamble

How much trust do you have in the following groups to keep your health information safe and secure? Please use a scale from 1 to 7, where 1 is no trust at all, 7 is a great deal of trust, and 4 is a moderate amount of trust.

TRU1

1/2 SAMPLE W/TRU5

14a-h

14a

18)

How much trust do you have in . . . your family doctor . . . to keep your health information safe and secure?

- PCF
- 1 No trust at all 1
- 2 2
- 3 3
- 4 Moderate amount of trust 4
- 5 5
- 6 6
- 7 A great deal of trust 7
- (DO NOT READ) Not applicable 8
- DK/NR 9

12

TRU2

1/2 SAMPLE W/TRU4

1Ab

How much trust do you have in . . . nurses in your doctor's office or clinic . . . to keep your health information safe and secure?

PCF

TRU3

1/2 SAMPLE W/TRU8

1Ac

How much trust do you have in . . . the administrative support working in your family doctors' office, such as a receptionist . . . to keep your health information safe and secure?

PCF

TRU4

1/2 SAMPLE W/TRU2

1Ad

How much trust do you have in . . . health care providers in hospitals . . . to keep your health information safe and secure?

PCF

TRU5

1/2 SAMPLE W/TRU1

1Ae

How much trust do you have in . . . pharmacists . . . to keep your health information safe and secure?

PCF

TRU6

1/2 SAMPLE W/TRU7

1Af

How much trust do you have in . . . government health departments . . . to keep your health information safe and secure?

PCF

TRU7

1/2 SAMPLE W/TRU6

1Ag

How much trust do you have in . . . Medical or health insurance companies . . . to keep your health information safe and secure?

PCF

TRU8

1/2 SAMPLE W/TRU3

1Ah

How much trust do you have in . . . the information technology specialists who run the computer systems . . . to keep your health information safe and secure?

NEW

TRMR1

1/3 SAMPLE W/TRMR2-3

15a → 1c

15a

Using the same scale, how much trust do you have in health researchers in universities to keep Canadians' health information safe and secure?

PCF

⑤

②

TRMR2

1/3 SAMPLE W/TRMR1-3

15b

Using the same scale, how much trust do you have in government health researchers to keep Canadians' health information safe and secure?
PCF

TRMR3

1/3 SAMPLE W/TRMR1-2

15c

Using the same scale, how much trust do you have in private sector health researchers to keep Canadians' health information safe and secure?
PCF

PAP

Today, Canadians' health records are paper-based and stored in numerous locations depending on how many doctors, hospitals, labs or clinics you have visited. This also means that some health care providers may not have access to a person's complete history when they are providing care.

16

DEFN

One way that governments intend to improve the health care system in Canada is to move to electronic health records.
EHR

instrument

DEFN1

Have you ever heard anything about so called electronic health records?
EHR

17

- Yes, definitely 1
- Yes, vaguely 2
- No 3
- DK/NR 9

DEFN2

An electronic health record would enable health care providers to view a person's medical history, and to send test results using a secure computer system. The electronic health record is expected to contain information such as your name and address, test results, medications and diagnoses.

18

IPOS2

Overall, do you strongly support, somewhat support, somewhat oppose or strongly oppose the development of a system of electronic health records that would allow health care professionals to be able to access your records no matter where in Canada you are receiving care?
EHR

19

- Strongly oppose 1
- Somewhat oppose 2
- Somewhat support 3
- Strongly support 4
- DK/NR 9

IPOSS

=> +1 if NOT (IPOS2=#3,#4)

DO NOT PROMPT

What is the MAIN reason you would support the development of electronic health records?
EHR

20

- Response, please specify 77 O
- DK/NR 99

IPOS0

=> +1 if NOT (IPOS2=#1,#2)

DO NOT PROMPT

21

What is the MAIN reason you would oppose the development of electronic health records?

- EHR
- Response, please specify 77 0
- DK/NR 99

PSAF

For the next questions, I would like you to tell me how you think electronic health records would compare to the current paper-based system. Please use a scale from 1 to 7, where 1 is much worse, 7 is much better, and the mid-point 4 means about the same.

COMPARAISON DE 2 METHODES SUR DIFFERENTS PTS?

PSAF1

1/2 SAMPLE W/PSAF6

(How would an electronic health record system compare to a paper based system) when it comes to the costs to maintain

- EHR
- 1 Much worse 1
- 2 2
- 3 3
- 4 About the same 4
- 5 5
- 6 6
- 7 Much better 7
- DK/NR 9

22a-h
8

22a

PSAF2

1/2 SAMPLE W/PSAF3

(How would an electronic health record system compare to a paper based system) when it comes to the effectiveness for doctors

EHR

22b

PSAF3

1/2 SAMPLE W/PSAF2

(How would an electronic health record system compare to a paper based system) when it comes to the effectiveness for patients

EHR

22c

PSAF4

1/2 SAMPLE W/PSAF5

(How would an electronic health record system compare to a paper based system) when it comes to the effectiveness for nurses and nurse practitioners

EHR

22d

PSAF5

1/2 SAMPLE W/PSAF4

(How would an electronic health record system compare to a paper based system) when it comes to the effectiveness for pharmacists

EHR

22e

9

PSAF6

1/2 SAMPLE W/PSAF1

22f

(How would an electronic health record system compare to a paper based system) when it comes to the overall effectiveness of the health care system
EHR

PSAF7

1/2 SAMPLE W/PSAF8

22g

(How would an electronic health record system compare to a paper based system) when it comes to protecting the privacy of patient information
REVISED EHR

PSAF8

1/2 SAMPLE W/PSAF7

22h

(How would an electronic health record system compare to a paper based system) when it comes to ensuring the security of patient information
NEW QUESTION

PR_AR

There are a number of arguments made for and against electronic health records. How much do you agree or disagree with the following arguments on a scale from 1 to 7, where 1 means strongly disagree, 7 means strongly agree, and 4 means neither agree nor disagree.
EHR

ARGUMENT
V54A

PRO1A

1/2 SAMPLE W/PRO1B

23a → K
(11)

23a

Electronic health records will help reduce errors in prescriptions and treatments that can occur when an individual's previous health history is not known.

- 1 Strongly disagree..... 1
- 2..... 2
- 3..... 3
- 4 Neither agree nor disagree..... 4
- 5..... 5
- 6..... 6
- 7 Strongly agree..... 7
- DK/NR..... 9

PRO1B

1/2 SAMPLE W/PRO1A

23b

Electronic health records will help health care professionals diagnose patients more rapidly and accurately.
EHR

CON1

1/2 SAMPLE

23c

It is not worth trying to implement a system of electronic health records across Canada because it will simply cost too much money.
EHR

11

PRO2

1/2 SAMPLE W/CON2

23d

The health care system will be more effective and efficient because electronic health records will provide better information to health professionals and patients.

EHR

CON2

1/2 SAMPLE W/PRO2

23e

I really worry that information contained in a system of electronic health records would not be accurate.

EHR

PRO3

1/2 SAMPLE

23f

Electronic health records will provide physicians in different institutions and parts of the country with ready access to information on the best treatments currently available.

EHR

PRO4

1/2 SAMPLE W/CON4

23g

Electronic health records will reduce the risks and costs of repeating various tests like X-rays by having them readily available electronically to health care professionals providing care to a patient.

EHR

CON4

1/2 SAMPLE W/PRO4

23h

I really worry about how my personal information might be accessed for malicious or mischievous reasons.

EHR

CON5

1/2 SAMPLE

23i

I really worry that Canadians' personal health information might be used for other purposes in the future which have little to do with my health.

EHR

PRO6

1/2 SAMPLE W/CON6

23j

I really like the idea of being able to easily access a summary of my overall health status and any medical treatment I have received.

EHR

CON6

1/2 SAMPLE W/PRO6

23k

I really worry that those with access to my health information will not follow established privacy and security procedures.

NEW

IMP

There are a number of things that could be done to make Canadians comfortable with a system of electronic health records. What impact would the following have on your overall comfort levels? Please use a scale from 1 to 7, where 1 is no impact and 7 is they would make you much more comfortable.

EHR

154A
↓

24a → m

13

24a

IMP1

1/2 SAMPLE W/IMP2

What impact would ... have on your comfort levels with an EHR

the ability to access, verify and report corrections to your health records at any time

EHR

- 1 No impact 1
- 2 2
- 3 3
- 4 4
- 5 5
- 6 6
- 7 Makes you much more comfortable 7
- DK/NR 9

IMP2

1/2 SAMPLE W/IMP1

What impact would ... have on your comfort levels with an EHR

the ability to hide or mask sensitive information to some users who would be authorized to access your health records

EHR

24b

IMP3

1/2 SAMPLE W/IMP5

What impact would ... have on your comfort levels with an EHR

new legislation making it a serious CRIMINAL offence for anyone to access your health records without authorization to do so

EHR

24c

IMP4B

1/2 SAMPLE W/IMP4C

What impact would ... have on your comfort levels with an EHR

an annual audit undertaken by the federal and provincial governments of the privacy and security provisions of an electronic health system

EHR

24d

IMP4C

1/2 SAMPLE W/IMP4B

What impact would ... have on your comfort levels with an EHR

an annual audit undertaken by the privacy commissioners in Canada of the privacy and security provisions of an electronic health system

EHR

24e

IMP5

1/2 SAMPLE W/IMP3

What impact would ... have on your comfort levels with an EHR

a clear and accessible privacy policy that spells out the principles to follow for ensuring patient information is protected

EHR

24f

13

IMP6B

1/2 SAMPLE

24g

What impact would ... have on your comfort levels with an EHR
knowing that an electronic health system was supported by your doctor
EHR

IMP6C

1/2 SAMPLE W/IMP6D

24h

What impact would ... have on your comfort levels with an EHR
knowing that an electronic health system was supported by the Government of
Canada
EHR

IMP6D

1/2 SAMPLE W/IMP6C

24i

What impact would ... have on your comfort levels with an EHR
knowing that an electronic health system was supported by your provincial/territorial
government
EHR

IMP7

1/2 SAMPLE W/IMP8

24j

What impact would ... have on your comfort levels with an EHR
knowing the entire system would be evaluated after five years to make sure that it
should continue
EHR

IMP8

1/2 SAMPLE W/IMP7

24k

What impact would ... have on your comfort levels with an EHR
knowing you would be able to find out who accessed your health records and when

IMP9

1/2 SAMPLE W/IMP10

24l

What impact would ... have on your comfort levels with an EHR
knowing you would be informed of any privacy and security breaches that may have
occurred with your information

IMP10

1/2 SAMPLE W/IMP9

24m

What impact would ... have on your comfort levels with an EHR
knowing that procedures are in place to respond to any privacy and security breaches
that may have occurred

Ø

25

OC

Overall, how comfortable are you with the idea of electronic health records? Please respond using a 7-point scale where 1 means not at all comfortable, 7 means extremely comfortable, and the mid-point 4 means moderately comfortable.

- EHR
- 1 Not at all comfortable..... 1
- 2..... 2
- 3..... 3
- 4 Moderately comfortable..... 4
- 5..... 5
- 6..... 6
- 7 Extremely comfortable..... 7
- DK/NR..... 9

V53 or V54? A specific

OC2

1/2 SAMPLE W/OC3

(3) 26a-c

26a

Using the same scale, how comfortable are you with electronic health information being used to plan, monitor and evaluate the health care system?

OC3

1/2 SAMPLE W/OC2

26b

Using the same scale, how comfortable are you with electronic health information being used to anticipate and address public health issues?

OC4

1/2 SAMPLE

26c

Using the same scale, how comfortable are you with electronic health information being used to prevent improper uses of the health care system?

PRSU

27

The next series of questions are about using electronic health information for health research. In all cases, assume that no personal information about you would ever be publicly released.

Common info / many

SU1

1/2 SAMPLE W/SU2

(2) 28a-b

28a

Would you strongly support, somewhat support, somewhat oppose, or strongly oppose your electronic health information being used for health research purposes IF details such as your name and address were KNOWN to the researcher?

- Strongly oppose..... 1
- Somewhat oppose..... 2
- Somewhat support..... 3
- Strongly support..... 4
- DK/NR..... 9

V58

SU2

1/2 SAMPLE W/SU1

28b

Would you strongly support, somewhat support, somewhat oppose, or strongly oppose your electronic health information being used for health research purposes IF details such as your name and address were NOT KNOWN to the researcher?

- Strongly oppose..... 1
- Somewhat oppose..... 2
- Somewhat support..... 3
- Strongly support..... 4
- DK/NR..... 9

7

29

PR_L
Health researchers could also link your health information with other records, such as education and income, that might be related to health outcomes.

Common also meany

LIA

1/2 SAMPLE

30

Would you strongly support, somewhat support, somewhat oppose, or strongly oppose the linkage of your health information with other records if consent was obtained ahead of time?

V58?

- Strongly oppose..... 1
- Somewhat oppose..... 2
- Somewhat support..... 3
- Strongly support..... 4
- DK/NR 9

31

PR_HC
The next questions deal with health care that you and your immediate family may have received. By immediate family, I mean your spouse/partner and your children.

def. common meany

32

HC_A
Over the past 12 months have you, or a member of your immediate family, visited a family physician or clinic?

- Yes, they have..... 1
- Yes, their spouse/partner has..... 2
- Yes, their children have..... 3
- None of the above..... 4X
- DK/NR 9X

33

HC B

=> +1 if NOT (HC_A=#1-#3)

READ LIST; SELECT ALL THAT APPLY

Thinking about the past 12 months, where have you or a member of your immediate family received medical care from?

- Family doctor/physician..... 01
- Walk-in clinic..... 02
- Medical specialists..... 03
- Community health centre..... 04
- Called a government telephone health line..... 05
- Hospital - scheduled visit/surgery..... 06
- Hospital - emergency..... 07
- (DO NOT READ) Other, specify..... 77 O
- (DO NOT READ) DK/NR 99 X

34

HC_C
How often, if ever, have you or a member of your immediate family tried to obtain medical assistance or information from your doctor or clinic after hours or on weekends? Would you say never, occasionally, or frequently?

- Never..... 1
- Occasionally..... 2
- Frequently..... 3
- DK/NR 9

35

HC D

=> +1 if NOT (HC_A=#1-#3)

RECORD NUMBER

How many times have you or your immediate family consulted a health care provider in the past twelve months?

- PCF.....
- DK/NR 999

36

HC_F2

In the past year, have you had any interactions with a health care provider that used some type of electronic health information system? Please do not include those interactions where someone verified your name, address and health card information using computers upon your arrival.

NEW

Yes	1
No.....	2
DK/NR	9

HC_F4

=> +1 if NOT (HC_F2=#1)

37

ACCEPT UP TO THREE RESPONSES

What was your impression?

NEW

Response (specify).....	77	O
DK/NR	99	X

S1

38

Have you or a member of your family ever experienced a serious breach where your personal health information was used inappropriately or released without your consent?

NEW

Yes	1
No.....	2
DK/NR	9

S12

=> +1 if NOT (S1=#1)

39

What was the breach?

NEW

Response (specify).....	77	O
DK/NR	99	X

HEALT

40

In general, how would you rate your health? Please use a scale from 1 terrible, to 7 excellent, where the mid-point 4 is average.

PCF

1 Terrible	1
2.....	2
3.....	3
4 Average.....	4
5.....	5
6.....	6
7 Excellent.....	7
DK/NR	9

STATS

These final questions are used for statistical purposes only.

sociodemog

41

LAN

What is the language that you first learned at home in childhood and still understand?

English.....	01	
French.....	02	
Arabic.....	03	
Chinese.....	04	
German.....	05	
Italian.....	06	
Japanese.....	07	
Polish.....	08	
Russian.....	09	
Vietnamese.....	10	
SPANISH.....	11	
UKRANIAN.....	12	
DUTCH.....	13	
PERSIAN.....	14	
Other (specify).....	77	O
DK/NR.....	99	

42

USE

In the past 3 months, have you used the Internet, either at home or elsewhere?

Yes.....	1
No.....	2
DK/NR.....	9

43

CSK

How comfortable are you using computers, using a scale where 1 is not at all comfortable, 7 is extremely comfortable and 4 is somewhat comfortable?

1 Not at all comfortable.....	1
2.....	2
3.....	3
4 Somewhat comfortable.....	4
5.....	5
6.....	6
7 Extremely comfortable.....	7
DK/NR.....	9

44

HOU

Which of the following types best describes your current household? ** IF THEY SAY THEY ARE LIVING WITH THEIR PARENT(S) THEN THE HOUSEHOLD IS EITHER 02 (ONE ADULT WITH CHILD/CHILDREN) OR 04 (MARRIED OR COMMON-LAW COUPLE, WITH CHILDREN)

One person, living alone.....	01
One adult with child/children.....	02
A married or common-law couple, without children.....	03
A married or common-law couple, with children.....	04
Two or more unrelated persons.....	05
Living with relatives other than parents.....	06
More than one adult with child/children.....	07
Other.....	98
DK/NR.....	99

45

CHI

=> +1 if HOU=#1,#3,#9

How many children under the age of 18 are living in your household?

None.....	00
DK/NR.....	99

46

EDUC

What is the highest level of schooling that you have completed?

Some high school or less.....	01
High school graduate.....	02
Some college.....	03
Community/Technical college or CEGEP graduate.....	04
Private college graduate.....	05
Some university.....	06
Bachelor's degree.....	07
Graduate degree.....	08
DK/NR.....	99

47

INC20

What is your annual HOUSEHOLD income from all sources before taxes?

<\$10,000.....	01
\$10,000-\$19,999.....	02
\$20,000-\$29,999.....	03
\$30,000-\$39,999.....	04
\$40,000-\$49,999.....	05
\$50,000-\$59,999.....	06
\$60,000-\$79,999.....	07
\$80,000-\$99,999.....	08
\$100,000-\$119,999.....	09
\$120,000 or more.....	10
DK/NR.....	99

48

AGE2X

IF HESITANT MOVE ONTO NEXT QUESTION

In what year were you born? NOTE: ANSWER THE FULL YEAR, I.E. 1977 as "1977"

HESITANT.....	9999
---------------	------

AGE2Y

=> +1 if	NOT (AGE2X=#1)
----------	----------------

49

May I place your age into one of the following general age categories?

Under 25.....	01
25-34 years.....	02
35-44 years.....	03
45-54 years.....	04
55-64 years.....	05
65-74 years.....	06
75 years or older.....	07
(DO NOT READ) DK/NR.....	99

50

BORN

In what country were you born?

Canada.....	01
U.K. (England, Ireland, Scotland, Wales).....	02
Western Europe (Italy, France, Spain, etc.).....	03
Northern Europe (Scandinavia, Sweden, Denmark, etc.).....	04
Eastern Europe (Poland, Russia, Yugoslavia, etc.).....	05
Middle East (Lebanon, Turkey, Iraq, etc.).....	06
South Asia (Pakistan, India, Sri Lanka, etc.).....	07
Southeast Asia (China, Vietnam, Korea, etc.).....	08
Oceania (Australia, New Zealand, Fiji, etc.).....	09
Latin America (Mexico, Brazil, Chile, etc.).....	10
Caribbean (Jamaica, Trinidad, Haiti, etc.).....	11
United States.....	12
Africa (South Africa, Nigeria, Somalia, etc.).....	13
Other (please specify).....	77
DK/NR.....	99

O
X

5

51

MINOR

READ LIST, CHOOSE ALL THAT APPLY

Do you consider yourself to belong to any of the following groups? PROMPT IF NECESSARY: A member of a visible minority by virtue of your race or colour

- A member of a visible minority..... 1
- An Aboriginal person 2
- A disabled person 3
- (DO NOT READ) None 4X
- (DO NOT READ) DK/NR 9X

FG

=> THINK if NOT (HC_F2=#1); ONLY THOSE WHO HAVE HAD ELECTRONIC HEALTH INTERACTION_

52

Occasionally, we hold group discussions with members of the general public on a variety of topics of interest to most Canadians. These are typically one and a half to two hour discussions with eight to ten participants who are given an honorarium for their time. If we were to hold such a group discussion in your city, would you be interested in participating?

- Yes 1
- No 2
- DK/NR 9

NAME1

=> +1 if NOT FG=#1

RECORD NAME, INITIAL or some other type of IDENTIFIER here for when we call back.

THNK

End of Interview

Thank you for your cooperation and time!

Completion 1D

Appendix C: Field Report

The research findings for this study have been drawn from the results of a telephone survey with a random sample of 2,469 Canadians, aged 16 years and older. Surveying on the study was undertaken between June 22nd and July 19th, 2007. The interviews averaged approximately 20 minutes in length.

Sampling Strategy

The study involved a random sample of Canadians, 16 years of age and older. The sample was stratified to ensure a certain sub-sample in each province and in the territories.

EKOS used Survey Sample software to produce the sample for this project. This software samples by Random Digit Dial (RDD) methodology and checks its samples against published phone lists to divide the RDD into "Directory Listed" (DL) and "Directory Not Listed" (DNL) RDD components.

Once the sample was determined, the telephone numbers were imported into our CATI system. Additional criteria were then added to the introduction of the questionnaire to select the individual respondent in the household. For this survey, the respondent had to be at least 16 years of age.

Survey Administration

Fieldwork for this project was conducted by highly trained interviewers at EKOS' call centres in Ottawa and Edmonton. Throughout the data collection, survey supervisors continuously monitored interviewing to ensure consistency of questionnaire administration and interviewing techniques.

Up to 10 call-backs were made to each member of the sample for which initial attempts at contact were unsuccessful. Call-backs were made to each selected case in the original sample before retiring a case and substituting another household. Follow-up calls were made on subsequent days, at varying time periods, to maximize the potential for reaching a given respondent. Appointments were made for respondents wishing to reschedule a survey. Daily records were kept of all calls made, whether successful (i.e. interviews completed or appointments made) or not.

Weighting

Once data collection was complete, the results were statistically weighted by age, sex and region to ensure that the findings were representative of the Canadian population 16 years of age and over.

Weighting was done using the statistical software package, StatXP. This program carries out this task on the basis of the distribution of the population for each variable considered in the weighting scheme (i.e., age, sex, region). Weights were developed so that the differences between the survey sample and the actual population were reduced. With a sample size of 2,469, results from questions asked of the full sample of this survey may be considered statistically accurate to within +/- 2.0 percentage points, 19 times out of 20. The sample sizes broken down by region, gender, and age as well as the associated margins of error are summarized in Table 1.

Table 1 – Composition of Sample and Associated Margins of Error

	Sample Size	Margin of Error	Unweighted %	Weighted %
Region				
Territories	100	+/-9.8	4.1	13.0
British Columbia	301	+/-5.7	12.2	10.0
Alberta	300	+/-5.7	12.2	7.0
The Prairies	203	+/-6.9	8.2	38.3
Ontario	806	+/-3.5	32.6	23.8
Quebec	506	+/-4.4	20.5	7.6
Atlantic Canada	253	+/-6.2	10.2	0.3
Sex				
Male	1078	+/-3.0	43.7	48.8
Female	1391	+/-2.8	56.3	51.2
Age				
Less than 25 years	163	+/-7.7	6.6	15.0
25-44 years	738	+/-3.6	29.9	38.6
45-64 years	1125	+/-2.9	45.6	29.5
65 years and older	413	+/-4.8	16.7	15.6
Overall	2,469	+/-2.0	100.0	100.0

Response Rate

The response rate for this survey was 10.5 per cent. This is calculated by dividing the cooperative call backs (i.e. those who completed the survey, those who we spoke to but were ineligible, and the quota filled) by the functional sample. The functional sample is the sample remaining after numbers not in service, business/fax numbers, duplicate numbers and numbers blocked by the phone company are removed. Details are provided in Table 2.

Table 2 – Call Results and Response Rates

Total sample	30,438
Numbers not in service	3,723
Business/fax lines	855
Duplicates	8
Numbers blocked by telephone companies	84
Total functional sample	25,768
No answers	12,247
Retired (i.e., called 10 times without success; no one reached)	1,535
Language difficulty (i.e., do not speak either official language)	471
Other (e.g., require TDD telephone for deaf or hearing impaired)	107
Unavailable	41
Break-offs (i.e., survey started but not completed)	49
Refusals	8,610
Cooperative call-backs	2,708
Completes (i.e., all completed surveys)	2,469
Ineligible (e.g., no one old enough to complete survey)	113
Quota filled (i.e., needed sample distribution filled)	126
Response rate	10.5