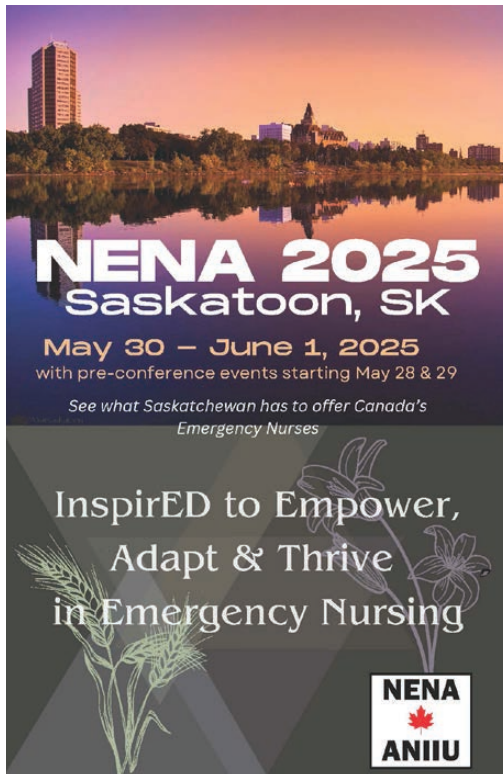




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Emergency department patients' willingness to participate in low-risk health research during the COVID-19 pandemic

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Background: Conducting health research during a health emergency, such as a pandemic, is important to manage public health responses and recovery (Lurie et al., 2013; Canadian Institute of Health Research [CIHR], 2024). Prior to the COVID-19 pandemic, a survey by Gobat et al. (2019) showed strong public support for health research during a hypothetical pandemic and discussed patient willingness to participate in pandemic-relevant health research. Conducting research in the emergency department (ED) is challenging due to various barriers, including time constraints for patients (Irani et al., 2015) and patient concerns about trust, risk (Limkakeng, 2014), and confidentiality (Irani et al., 2015) in regard to research participation.

Study Aims: A cross-sectional study design and convenience, criterion sampling was used. Adult patients (≥ 18 years) registered in two urban tertiary EDs at University Health Network (UHN), who met the study inclusion criteria, were invited to complete a structured, anonymous, electronic survey. Surveys were collected from August to December 2020. Research Ethics Board approval was obtained by UHN.

The survey included a) demographic questions; b) binary questions (yes/no) on whether the patient would consent to donate biospecimens (blood specimens, throat swab, nasopharyngeal (NP) swab, and urine sample) for research; and c) five-point Likert scale questions on patient motivation(s) to donate biospecimens based on four key domains (altruism, trust, personal

benefit, and social). These domains were formulated based on the Theory of Consumption Values (Sheth et al., 1991) and literature review. Biospecimens were not collected as part of this study.

Results: Two hundred and twenty-five participant surveys were collected. There was a near equal number of male (51%) to female (48%) participants. Most adult age groups were well-represented: 19% were 18–29 years old, 30% were 30–49 years old, 35% were 40–59 years, and 25% were 60–79 years old. The sample had higher levels of education as 13% were high school graduates, 27% completed undergraduate education, and 30% completed graduate or post-graduate education. Those who reported their gender as other (1%), were 80 years of age or older (2%), and had no schooling (1%) or a kindergarten to grade 12 education (7%), were underrepresented.

The majority of study participants described themselves as generally healthy (60%). Of those who reported health concern(s; 40%), cancer was most reported (22%), followed by cardiac disease (17%), liver or kidney disease (13%), neurological issues (10%), and respiratory disease (8%). Most (62%) survey participants reported no prior participation in health research.

Willingness to provide biospecimens for research

Most (85%) ED patients were willing to provide at least one biospecimen for research purposes and the majority (55%) agreed to provide all four samples. Of those agreeing to donate biospecimens, the majority were willing to provide a urine sample (78%), throat swab (77%), blood sample (75%), or NP swab (65%). Those who previously participated in health research were more likely to agree to donate a urine sample ($p = .002$), NP swab ($p = .005$), small blood sample ($p = .04$), and throat swab ($p = .04$).

Participants largely (71%) reported that their decision to donate biospecimens for research would not be influenced by the presence of a global pandemic. The remaining 29% reported that their decision to take part would be different if there was not a present pandemic. Sixty percent reported that the decision to take part would be different if more risk was involved (e.g., taking a medication, having an x-ray, or skin biopsy) while 40% reported their decision would not be different.

Motivation to donate biospecimens for research

Two domains, altruism and trust, were shown to be internally consistent and reliable via Cronbach's alpha (<0.7). Sum scores were created and then tested against demographic variables. Demographic characteristics of sex, age, education, and health status (generally healthy; health concern[s]) were not statistically significant. Those who reported previous participation in health research had a higher total altruism score ($p = .004$) and trust score ($p = .005$) than those who had not previously participated in health research.

Implications and Future Directions: This study's results support engaging ED patients in health research recruitment during a pandemic. The results show that the ED may be a suitable location to seek adult participant consent for the collection of low-risk biospecimens for research purposes during a pandemic.

Since the majority (60%) of participants reported a willingness to accept more risk (such as taking a medication, having an x-ray, or skin biopsy), further research is required to explore ED patient participation in research involving more risk during a pandemic.

As results show participants have a high willingness to partake in low-risk health research, further research is needed to explore ED patient participant recruitment facilitators and barriers within a pandemic context. Demographic variables not collected in this study, such as ethnicity or socioeconomic status, could also be explored further in relation to ED patient participation in low-risk health research during a pandemic.

Conclusion: This study found that most adult ED patients were willing to donate low-risk biospecimens during the COVID-19 pandemic. It also found that altruism and trust were key domains that influenced ED patients' willingness to donate biospecimens for low-risk health research during the COVID-19 pandemic.

Volonté des patients des urgences à participer à des recherches en santé à faible risque durant la pandémie de COVID-19

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Contexte : Mener des recherches en santé lors d'une urgence sanitaire, comme une pandémie, est essentiel pour orienter les interventions de santé publique et la reprise (Lurie et al., 2013; IRSC, 2024). Avant la pandémie de COVID-19, une enquête menée par Gobat et coll. (2019) avait démontré un fort appui du public pour la recherche en santé dans le cadre d'une pandémie hypothétique et avait examiné la volonté des patients à participer à des recherches pertinentes en situation de pandémie.

La recherche menée dans les départements d'urgence (DU) présente plusieurs défis en raison de divers obstacles, notamment le manque de temps pour les patients (Irani et al., 2015) ainsi que leurs préoccupations liées à la confiance, au risque (Limkakeng, 2014) et à la confidentialité (Irani et al., 2015) en ce qui a trait à la participation à la recherche.

Objectifs de l'étude : Une étude transversale avec un échantillonnage de commodité et par critères a été réalisée. Les patients adultes (≥ 18 ans) inscrits dans deux départements d'urgence tertiaires urbains du University Health Network (UHN) répondant aux critères d'inclusion ont été invités à remplir un questionnaire structuré, anonyme et électronique. Les données ont été recueillies entre août et décembre 2020. L'approbation éthique a été obtenue auprès du comité d'éthique de la recherche de l'UHN.

Le questionnaire comprenait a) des questions démographiques; b) des questions binaires (oui/non) sur la volonté du patient de consentir au don de biospécimens (échantillon de sang, écouvillon de gorge, écouvillon nasopharyngé et échantillon d'urine) à des fins de recherche; et c) des questions utilisant une échelle de Likert à 5 points sur la motivation du patient à donner des biospécimens selon quatre domaines clés : altruisme, confiance, bénéfice personnel et social. Ces domaines ont été formulés à partir de la *Theory of Consumption Values* (Sheth et coll., 1991) et d'une revue de la littérature. Aucun biospécimen n'a été recueilli dans le cadre de cette étude.

Résultats : Un total de 225 questionnaires ont été recueillis. Les participants étaient presque également répartis selon le sexe (51 % hommes; 48 % femmes). La plupart des groupes d'âge adulte étaient bien représentés : 19 % avaient entre 18 et 29 ans, 30 % entre 30 et 49 ans, 35 % entre 40 et 59 ans et 25 % entre 60 et 79 ans. Le niveau d'éducation était élevé : 13 % étaient diplômés du secondaire, 27 % avaient complété des études de premier cycle et 30 % des études supérieures ou postuniversitaires. Les participants ayant indiqué un autre genre (1 %), âgés de 80 ans ou plus (2 %), sans scolarité (1 %) ou ayant un niveau de la maternelle à la 12^e année (7 %) étaient sous-représentés.

La majorité des participants se sont décrits comme généralement en bonne santé (60 %). Parmi ceux ayant déclaré un ou plusieurs problèmes de santé (40 %), le cancer était le plus fréquent (22 %), suivi des maladies cardiaques (17 %), hépatiques ou rénales (13 %), neurologiques (10 %) et respiratoires (8 %). La plupart (62 %) n'avaient jamais participé à une recherche en santé auparavant.

Volonté de fournir des biospécimens à des fins de recherche
La majorité (85 %) des patients des urgences étaient disposés à fournir au moins un biospécimen à des fins de recherche, et plus de la moitié (55 %) acceptaient de fournir les quatre échantillons. Parmi ceux qui acceptaient de donner, la majorité étaient prêts à fournir un échantillon d'urine (78 %), un écouvillon de gorge (77 %), un échantillon de sang (75 %) ou un écouvillon nasopharyngé (65 %). Les participants ayant déjà pris part à des recherches en santé étaient plus susceptibles d'accepter de fournir un échantillon d'urine ($p = .002$), un écouvillon NP ($p = .005$), un petit échantillon de sang ($p = .04$) et un écouvillon de gorge ($p = .04$).