Women's College Hospital Network on Uninsured Clients

Qualitative Research Project on Health-Care Access for the Uninsured

Prepared by: Carolyn Steele Gray, Michaela Hynie, Linda Gardner and Angela Robertson
July 2010

WOMEN'S COLLEGE HOSPITAL
Health care for women | REVOLUTIONIZED

Qualitative Research Project on Health Care Access for the Uninsured

Table of contents

Qualitative Research Project on Health Care Access for the Uninsured

Executive summary

The Research Committee of the Women's College Hospital Network on Uninsured Clients set out to capture the richness of experience and knowledge held by the network's members. This research project documented these experiences in order to help members share and learn from each other's unique experiences and knowledge. Twenty-four interviews were conducted with members of the network. These interviews were then transcribed, coded and analyzed, and central themes were identified and are outlined in this report. The following key issues were identified and discussed by interviewed network members.

Defining the population

Multiple definitions for the uninsured and undocumented were provided by participants. Three definitions provided most often by participants were: those that fall in the three-month waiting period, those with lost or stolen OHIP cards, and those with no legal status.

Health issues

Participants identified many health issues facing this population. The two most prominent health issues that affected this population as identified by participants in this study are mental health issues and health issues around pregnancy. Mental health issues are cited as being the most prevalent health issue encountered by some participants. Stress and social isolation that accompanied an individual's status further exacerbated the mental health and health problems more generally. Pregnancy is the second most cited health issue facing this population. Pregnancy was a key concern to participants in this study because of the barriers experienced by women attempting to access prenatal care. Other women's health issues mentioned by a few participants included gynecological and hormonal issues. Women who are undocumented or uninsured faced additional challenges and vulnerabilities given their place in society. The uninsured and undocumented also tended to present with a higher severity of health issues than other populations. Nearly half of participants stated that the uninsured/undocumented population have often delayed seeking care and so have presented with more severe health issues, some of which could have been avoided.

Accessing services

Another key issue discussed by participants is how the uninsured and undocumented population were able (or unable) to access health-care services. Multiple sites of care have been accessed by this population including community health centres, hospitals, private physicians, Toronto Public Health, and walk-in clinics. The uninsured and undocumented population received a variety of forms of treatment at these different sites and have often experienced barriers to accessing care. Additionally there were issues with regards to consistency of health-care services provided within and between these different health-care sites, particularly hospitals and community health centres. Because of these barriers and consistency issues accessing care has rarely been a straightforward process and many undocumented and uninsured individuals relied on service providers to advocate and connect them to the care they needed or they sought other ineffective and even potentially harmful methods of addressing their health-care needs.

Qualitative Research Project on Health Care Access for the Uninsured

General barriers to access

Participants highlighted a number of barriers to accessing health-care services experienced by the uninsured and undocumented population. Fear (mainly of deportation), cost of care (both actual costs and perceived costs) and lack of knowledge (on the part of the uninsured/undocumented regarding what care is accessible and on the part of health-care services providers regarding how to treat this population) were the three most prominent barriers to access discussed by participants. Language barriers, cultural barriers and discrimination were also cited by participants as key barriers to accessing health care.

Networks and relationships

One of the most significant themes that came out of the interviews was the importance of informal and formal networks and relationships to providing health-care services to the uninsured and undocumented population. While informal networks were integral to providing needed care, some participants were concerned that because they were informal there was no consistency in the provision of care through these networks. More formalized relationships that provided for more consistent policies and practices also existed to provide care for this population. Participants voiced some concerns about formalized agreements as well, as they may impede the flexibility that was sometimes required to provide care to this population. Despite the limitations of both formal and informal networks, participants in the study considered these networks to be central in the delivery of health services to the uninsured and undocumented population.

Policy Change: Recommendations

Participants highlighted a number of potential policy changes that they would like to occur in order to improve access to health-care services and improve health outcomes for the uninsured and undocumented population. The top recommendations included:

1. removing the three-month wait period
2. providing additional funding directed at the uninsured and undocumented population
3. improving immigration policy to make the process easier and more equitable
4. providing universal coverage, and
5. making health-care system changes (including improving integration and simplifying access pathways)

Political will, ideology and stigma, public awareness, the fear of increased health-care costs and intersectionality that arises within and between advocacy groups for the uninsured and undocumented were identified by participants as potential barriers to policy change that must be addressed. One of the key recommendations made by some participants is to focus advocacy efforts on small policy changes (the "easy wins") that work towards a larger goal.

Information needs

There were a number of information needs identified by participants that they saw as necessary to improve health-care delivery and push for policy change. The three most cited types of information required were cost-analyses, descriptive statistics and stories. Another information need identified participants was the need to educate politicians/policy makers, the public, and particularly health-care providers about the health issues and challenges facing the uninsured and undocumented population.

Qualitative Research Project on Health Care Access for the Uninsured

Next steps

This report identifies the issues facing the uninsured and undocumented population in relation to accessing health-care services in Toronto as identified by members of the Women's College Hospital Network on Uninsured Clients. This information can be used to identify Network goals, support desired policy changes, and act as a stepping stone towards other research and information gathering activities.

Introduction

The Research Committee of the Women's College Hospital Network on Uninsured Clients set out to capture the richness of experience and knowledge held by the Network's members. This research project was intended to document these experiences in order to help members share and learn from each other's unique experiences and knowledge.

Methodology

Interview questions were developed by Michaela Hynie and Linda Gardner, and further modified by Carolyn Steele Gray during the interview process. Semi-structured interviews were conducted with 25 network members between December 2009 and May 2010. One participant dropped out of the study leaving a total of 24 final participants. Network members were contacted via email using a dedicated secure email account. Three participation request emails were sent to 57 network members, and one participation request email was sent to 7 new members (overall response rate 38 per cent). Although this is a somewhat low response rate, thematic saturation was achieved and so additional interviews were not necessary. Interviews were conducted over the phone and lasted between 20 and 55 minutes. Interviews were transcribed, anonymized and coded using NVivo 7 by Carolyn Steele Gray. The coding scheme and identification of themes from the study was developed by Carolyn Steele Gray and was discussed and modified in discussion with Michaela Hynie and Angela Robertson. The interview questions were asked in a manner that fit with the flow of the conversation to allow for the exploration of important concepts as they emerged. Interview transcripts were sent to participants at their request.

Who we are

Participants in this study came from a variety of health-care organizations representing different sectors of the health-care system including:

- community health centres (CHCs)
- hospitals
- universities
- community-based organizations, both health-related and non-health-based (often geared towards serving immigrants, women, homeless and other vulnerable populations)
- government-based health organizations (including public health)
- advocacy groups

The majority of the participants in this study are managers and directors, health-care professionals and researchers. Other participants in the study include financial officers, social workers and lawyers.

Qualitative Research Project on Health Care Access for the Uninsured

Reasons for participating in the network

Participants conveyed a variety of reasons for joining the network. Many joined the network in order to engage with individuals and groups who work with this population. Others joined in order to seek solutions to these issues or to advocate for their uninsured and undocumented clients. Many also joined the network because they work with this population and wanted to learn more about the issues facing uninsured and undocumented people in Ontario.

Involvement with this issue

Those who participated reported a varying percentage of their work devoted to this clientele ranging from as low as 5 per cent of their work activities up to over 70 per cent. Many participants also mentioned other forms of involvement with this population beyond their primary work and involvement with the WCH network, including advocacy work and advocacy group participation, involvement in government working groups and the hospital collaborative, volunteer work, and personal involvement/relationships.

Defining the population
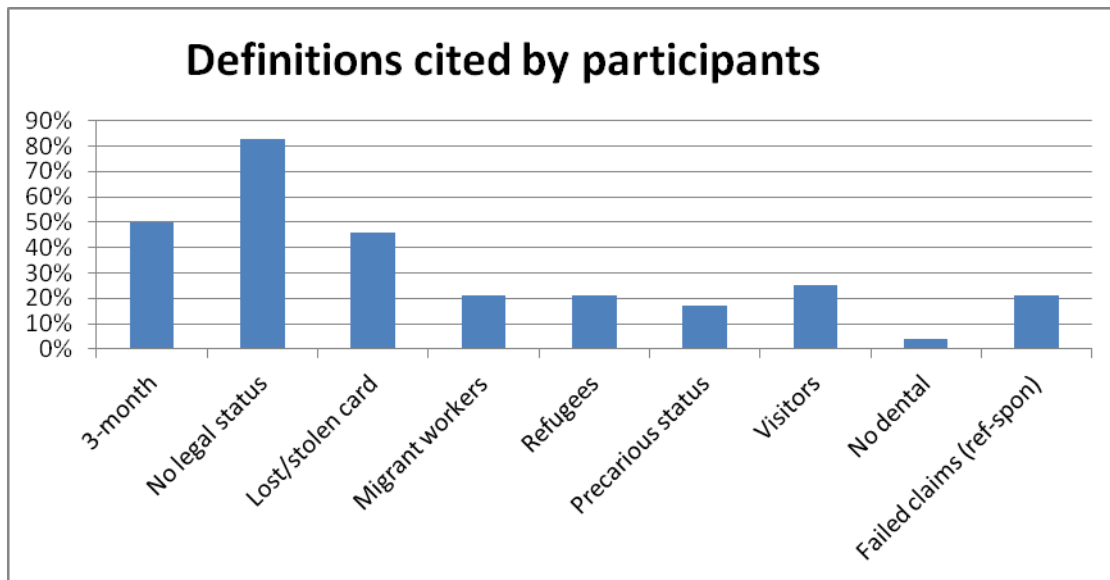
Figure 1 Percentage of participants providing each definition of the uninsured and undocumented population

Participants provided a variety of different definitions for the uninsured and undocumented population. Most participants identified this group as those who have no legal status in Canada and landed immigrants who fall within the three-month wait period in Ontario. Uninsured and undocumented individuals were also defined as those with a lost, stolen or missing OHIP card, particularly for those who are homeless. Specific groups of individuals such as migrant workers, refugees (including those with failed claims), individuals with precarious status, and visitors were also included in some participants' definition of this population. One participant argued that individuals without dental coverage should be included in the definition of uninsured, undocumented.

"... I would include that population as being part of the uninsured undocumented because ... not having basic oral health included in OHIP ... creates the situation where ... seniors, people with chronic illness, children are often left out and ... in terms of health issues, that's another one that I think is easy to ... show why people will end up in the emergency department and taking up waiting room space because they have an oral health emergency, right? And so they come in for emergency dental ... because they wait so long because there's no ... preventative care at all. As far as ... OHIP is concerned around oral health, the mouth is not part of the body." (Participant N1, Toronto hospital, policy worker)

Health issues

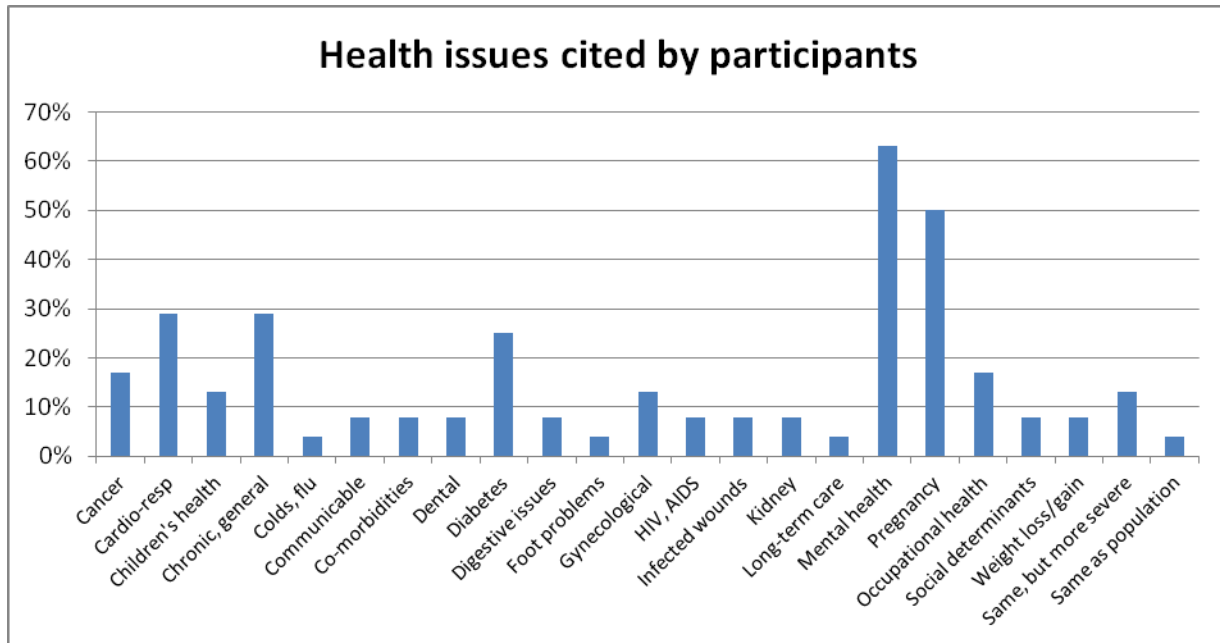**Figure 2 Percentage of participants citing different health issues facing the uninsured and undocumented population**

Participants identified a broad range of health issues, including cancer, communicable disease, STIs and sexual health issues, occupational health problems (particularly accidents in the workplace), chronic diseases such as diabetes and cardio-respiratory and cardio-pulmonary diseases, digestive issues, weight loss/gain, dental issues, and complex illnesses, which included a number of co-morbidities and health problems. The two most prominent health issues that affected this population as identified by participants in this study are mental health issues and health issues around pregnancy.

Mental health issues

Mental health problems identified by participants included a variety of disorders such as depression, anxiety, suicidality, post-traumatic stress disorder, addiction and stress. Mental health issues were cited as being the most prevalent health issue encountered by some participants. Stress and social isolation that accompanied an individual's status also exacerbated other health problems. The stress associated with being a new immigrant to Canada was compounded by the fear of being unable to access care when it was required due to cost restrictions or fear of deportation, as well as the stress of being faced

with high hospital bills after seeking care. Stress could have a significant impact on the health of an individual, leading to additional illness and additional stress.

> *"...the person is having lots of stress first because it's a new country, language barriers, lots of barriers. Secondly ... no documents; stress plus stress. If they try to find help and then they don't find it, it's more stress. The chances that this person will develop ... a very serious illness is high, so the problem will get worse in the future. Sometimes it's in the near future."* (Participant N3, community-based organization (non-health), social worker)

Social isolation was cited as potentially impacting on the health of individuals. Participants noted that some individuals who are fearful of organizations that are perceived as authorities tended to isolate themselves and avoided accessing care when required.

Pregnancy and women's health

Pregnancy was the second-most cited health issue facing this population. Pregnancy was a central concern to participants in this study because of the barriers experienced by women attempting to access prenatal care. Women often waited to access care until very late in their pregnancy due to the expense of care and the fear of being reported. While there were some formalized agreements between hospitals and community health centres (CHCs) that set out a flat fee for labour costs, these only applied to "straightforward" birthing procedures and often would not cover the cost of complications.

> *"And so we would try to work with our community hospital on ... taking people who are non-insured; specifically we had agreement with that hospital for women who are pregnant ... an agreement meaning a set fee amount ... to cover the childbirth. Now that's based on everything, you know, moving ahead in a straightforward way, right? Childbirth's unpredictable: sometimes you need caesarean to get [the] baby out, different things happen, different interventions are needed, anything."* (Participant N8, Toronto hospital, program director)

In order to address these needs some partnerships had been developed between midwives, who were able to provide free prenatal care, and CHCs, who were able to cover some of the hospital costs (including diagnostic tests and specialist referrals).

> *"They're really kind of win-win for everybody involved because ... some community health centres will provide care for pregnant women and newborns but when they work in partnership with midwives they're able to provide care for more women because essentially midwives will do all of the routine care for everyone who has a normal low-risk pregnancy and only need to kind of refer ... a women that has a complication. Or she might need to refer that woman to a hospital ... and then the CHC might cover some of those costs ... But either way it kind of allows together the midwives and the CHC to provide care for a bigger pool of women."* (Participant N25, community health organization, manager)

Despite these partnerships, women were still seeking care very late in their pregnancy – in some cases waiting until they went into labour, at which point they would go to an emergency room. Barriers to access would also lead women to seek alternative care or have home births, which could be very risky for both mother and child. Waiting to access care also meant that women miss important screening tests that could help prevent complications for the mother and/or baby during and after birth.

Other women's health issues mentioned by a few participants included gynecological and hormonal issues. Furthermore, undocumented or uninsured women face additional challenges and vulnerabilities given their place in society. One participant noted that women would take on more tasks which exacerbated their health issues, and would also fall victim to abusive relationships. Abuse was a particular concern for uninsured and undocumented women as their fear of being reported by an abusive partner prevented them from seeking help or leaving the abusive relationship.

> *"Okay, when ... for example the woman is sponsored by her partner, and ... if he, he's abusing, if she calls the police, you know they are not living together anymore, they have to report immigration, sometimes the guy stop the* [sponsorship] *process... And on top of that, if they come by themselves and they get involved with an abusive partner it's something else. And sometimes they don't want to leave the relationship because they are afraid of that ... this guy can call ... immigration."* (Participant N3, community-based organization (non-health), social worker)

Severity

A few participants noted that the population didn't necessarily present with different health issues than the broader population but rather just more severe health issues. Severity of this population's health issues was a common concern across most participants. Nearly half of participants stated that the uninsured/undocumented population often delayed seeking care and so presented with more severe health issues, some of which could have been avoided. Severe health issues identified by participants included: unmanaged chronic diseases, infected wounds, and cancer. Some participants noted that this population would only seek care in an emergency situation, particularly temporary migrant workers who cannot take time off to address health concerns until it is life threatening. Individuals' presenting with high severity illnesses is noted as occurring at all points of access (i.e. CHCs or hospitals).

> *"I suppose the problem is the people without insurance may ... not go anywhere until their conditions have become quite quite serious; and ... they go to hospital because of that... I think the hypothesis at this point is that people are presenting with more severe illnesses because, you know, they put off going to see a physician; by the time they actually do go see a physician it's at a higher level of acuity ... than if they've gone before."* (Participant N6, advocacy group member)

Accessing services

The uninsured and undocumented would access health-care services in different organizations such as CHCs, hospitals and community-based organizations. This population often faced a number of barriers to accessing services in different settings, which required them to seek out alternative pathways. Accessing care was rarely a straightforward process and many undocumented and uninsured individuals relied on service providers to advocate and connect them to care, or they would seek other, potentially harmful methods of addressing their health-care needs.

Community health centres

For many uninsured and undocumented individuals, community health centres were the first point of entry to the health system. Participants identified that this population would seek many different health-care services at a CHC, including primary health care, chronic disease services, mental health

services, pre- and post-natal care, and some dental services. CHCs also acted as connectors to other services, such as specialist services and diagnostic tests, by providing funding for those individuals to access these services at other institutions; this was done by providing referrals and letters that indicated how services were to be paid for. CHCs also played a much broader role beyond the delivery of health services by providing social support (often addressing social determinants of health issues such as housing) and counselling services, but more importantly by acting as advocates for their clients. A number of participants suggested that a significant amount of the time spent by CHC care providers was in advocating and negotiating with hospitals and other care providers to waive or reduce fees CHCs couldn't cover, or just to ensure that clients would actually be able to access services outside of the CHC.

> *"... basically my motto is just keep calling around, keep calling around until I'm able to find someone who's able to see the client for whatever resource it is they need."* (Participant N21, Toronto CHC, case co-ordinator)

Consistency issues

Some participants noted discrepancies between CHCs in the delivery of care to the uninsured and undocumented population. Of particular concern to some participants was that CHCs would serve very different populations in their catchment areas, leading some CHCs to experience long wait-lists and limited funding while others did not. Some interviewees suggested that there was some work being done to help manage the entire envelope of funding for CHCs to ensure a more effective distribution of funding, reducing the need for CHCs to shut their doors due to limited capacity. Another issue identified by one participant was that as CHCs saw different populations, and so some employees of CHCs would not be aware of all the issues facing this population.

> *"...you know they may not even be aware. I had one case that a non-status ... older couple went to CHC and they were the first non-insured ever in that CHC, and they were treated so badly. But had they come to let's say my CHC where we serve so many non-status people, that would not be an issue at all."* (Participant N17, Toronto CHC and university, researcher and front-line worker)

This discrepancy between how CHCs treat clients was echoed by another participant who stated that CHCs would vary in both their accessibility and compassion towards this population.

> *"And I mean certain community health centres, certain hospitals um, are known for providing um, kind of more accessible more compassionate care."* (Participant N9, hospital, health-care worker)

Barriers

The uninsured and undocumented population experienced a number of barriers to entry in CHCs which were, in some cases, related to the discrepancies between CHCs identified by participants. The most prominent barrier identified by participants was the long wait-lists that some CHCs experienced, followed by the limited funding CHCs had available to provide services to this population. Other barriers identified by participants included: limits to access imposed by catchment area (which left some individuals without any accessible CHC), limited knowledge about CHCs by the population, language and cultural barriers, and fear/trust issues around being reported or being able to afford care.

Hospitals

Most participants cited two main reasons why an uninsured or undocumented person sought care in a hospital: emergency services and pregnancy, specifically birthing services. Undocumented and uninsured individuals were also sent to emergency services for a variety of other reasons such as heart attack, suicidality, drug overdose, and severe injuries; generally in life-threatening situations. Pregnancy was the second-most cited reason for going to a hospital. While birthing was the primary reason for attending a hospital, women also went to hospitals for prenatal complications. Other services provided to the uninsured and undocumented at a hospital included: diagnostic testing services (although a few participants noted that individuals were also able to get diagnostic testing from independent labs who also accepted payment from CHCs), mental health services, specialist services, surgeries, dental care, cancer and HIV treatments, and children's health issues.

Consistency issues

Participants reported significant consistency of care issues in the hospital sector. The two most cited consistency issues were around inconsistent admissions and billing between hospitals in Toronto. Inconsistencies regarding which hospitals admitted uninsured and undocumented patients or not were often related to a hospital's understanding of the needs of this population, or related to the culture of the hospital. For example, if the hospital was religious-based, with a value system that sought to help underprivileged and vulnerable populations, they would be more likely to admit undocumented and uninsured patients and would be more conducive to formalized agreements with partners like CHCs.

> *"So as a Catholic community teaching hospital um, people have used the expression about the preferential option for the poor and, and ... special attention to the marginalized and disadvantaged. So there's a history of ... providing services to vulnerable people ... and the uninsured have been a part of that."* (Participant N14, Toronto hospital, director)

> *"I guess it goes back to their hospital policy or just the culture of the hospital ... the business culture of the hospital, I don't know. Um ... it's hard to say – I mean historically they just have not been, you know, as reticent to take clients who are not insured."* (Participant N16, Toronto CHC, manager)

One participant stated that disparities in admission occurred within hospitals depending on which administrator was on duty.

> *"... there is a disparity, and again, it could be on any given day. So a client could walk in to [Toronto hospital] for instance on a Monday to Friday and be okay. But on the weekend when there's different finance or admissions folks there, they're not understanding the whole CHC thing, they may, you know, give them a problem ... So that happens sometimes."* (Participant N16, Toronto CHC, manager)

Many participants also stated that administrative costs (such as facility fees), the costs of care, and the propensity to waive certain fees varied significantly from hospital to hospital.

> *"But when it comes to facility fee, which is a fee that is basically the room fee that the client has to pay in order for using the room to deliver the baby, most hospitals are, it's very subjective in terms in how they determine ... how much the client pays ... There's no set guidelines, there's no polices, it's just very subjective and people do as they feel, we find."* (Participant N21, Toronto CHC, case co-ordinator)

"Some hospitals have arrangements with community health centres. So one of the issues that we noted was that, so if you are connected with a community health centre sometimes you would get a better rate at a hospital... and there needs to be some sort of situation where ... there's fair equitable rates across the board for hospitals and that there's not this gouging where one hospital will, you know, charge $3,300 a day and another hospital will charge under $1,000 a day." (Participant N10, government health organization, health-care worker)

One participant suggested that hospitals would also vary in how they pursued unpaid bills.

"... I think they're different in ... how much they pursue it. So I have heard of people who get a bill and just don't pay it ... but I have also heard of a lot of people who get a bill and are then harassed and ... really don't have any money but end up paying it back in very small amounts." (Participant N19, health-care worker and researcher)

Some CHCs were able to create formalized relationships with some hospitals to stipulate standard fee schedules, however not all hospitals were conducive to those agreements.

"It's a formal agreement between some of the CHC's yeah and [Toronto hospital]. Now some of the CHCs have that agreement also with ... [other Toronto hospital] and ... we've been less successful in having those agreements with other hospitals." (Participant N24, Toronto CHC, director)

While most participants were deeply concerned about the cost discrepancies, a couple of participants were sympathetic to the financial constraints that faced hospitals, and the broader health system, which incented hospitals to engage in revenue-seeking activities such as these.

"... so you have 300 beds ... we know that average bed cost is X and so your ... global budget from the province will be Y... it feels as if ... we have defined efficiencies ... because it feels as if there's never enough money. Hospitals will look for opportunities to generate revenue and one of the ways they do that is by charging increased rates to out-of-country. And those increased rates I think can be like three times the amount that ... they'd get from ... the province." (Participant N14, Toronto hospital, director)

Barriers

The most noted barrier to accessing hospitals was fear experienced by the uninsured and undocumented. Participants said that this population often feared hospitals and institutions more generally; particularly if they had no status and could potentially be deported from the country.

"...when you don't have status you are afraid to go to institutions because they are afraid that they will call Immigration Canada. The first thing is that the client has to feel comfortable that whenever they go to any hospital they won't be reported." (Participant 12, community-based (non-health) organization, social worker)

Another significant barrier to access was the perceived cost of care by uninsured and undocumented individuals and the fear of receiving huge bills after accessing care at a hospital.

"... they [undocumented/uninsured individuals] ... are very worried that if they need a hospital they can be charged any amount. Like ... one participant said the ... reception desk

... at emerg said if the physician falls in love with her credit card I cannot tell you how much the bill would be; meaning, you know, they can charge whatever they feel like. So ... this when he decided not to stay ... and go home, even though he was in incredible pain." (Participant N20, university, researcher)

"Well you know people can get very scared and ... they know if they go to a hospital they are not going to be able to pay or they're going to come out with this huge bill." (Participant N7, community-based (non-health) organization, director).

The actual costs of care also acted as barriers to the uninsured and undocumented receiving treatment in hospital.

"So it was really really challenging, particularly when something needed to be done urgently [in the hospital] *and they wouldn't do it without um, all the payment in place."* (Participant N10, government health organization, health-care worker)

The cost barrier not only impacted on access to care but also led to changes in how patients were cared for as compared to insured individuals, which raises concerns regarding the quality of care received by this population.

Discrimination (mostly around individuals who are perceived as "undeserving") and language also acted as barriers to access. Many participants cited the problem of hospitals identifying who they believed "deserved" care and who did not.

"Things like um, uh, discussing who deserves care and who doesn't deserve care, and the argument about legal versus illegal ... clients ... That issue in particular is actually quite large, I think it's much larger than we tend to realize." (Participant N1, Toronto hospital, policy worker)

Other participants identified specific populations, such as the homeless population, being unwelcome or treated differently than other groups:

"Well because we're right next door to [Toronto hospital] we often end up using them. Um, we find their emergency department really isn't very friendly to homeless people or you know to marginalized people. We have much better luck with [other Toronto hospital]." (Participant N13, community-based (non-health) organization, front-line staff)

"We have a lot of clients who are discharged prematurely who end up coming back here because they're considered, you know, clients that ... the emergency room would prefer not to deal with, someone who's homeless or under-housed. We've had people ... walk out with IVs in their arms, and their colostomy bags, and in their wheelchairs and wheeled back over here... we're working within a system that's not very responsiveness in general to people who are considered ... difficult to deal with. So we get that kind of thing all the time from the hospitals." (Participant N24, Toronto CHC, director)

Participants also cited hospital-level barriers to accessing health care. Issues such as catchment area, wait times and administrative barriers were found to each play a role. Participants were also concerned about hospitals lacking an understanding of the issues facing the uninsured and undocumented; there were additional concerns that hospitals were not aware of how the CHC system works. Some

participants stated that when hospitals did not have much experience with this population, they would not have the sensitivity (including cultural sensitivity) and understanding required to treat this population. A lack of sensitivity and understanding resulted in hospitals turning away CHC clients with referrals or harassing these clients to pay bills.

> *"And I can mention like a big hospital where the population is a higher population of immigrants they start trying to understand what is the situation [with people without status] ... and they can provide that service. For example, [Toronto hospital] and the [other Toronto hospital] but in some other hospitals where they don't have ... that sensitivity, especially ... with immigrants ... with a person without status, that's when ... they have some challenges."* (Participant N12, community-based (non-health) organization, social worker)

> *"Often, sometimes ... the organizations don't know that community health centres are able to pay for that so they don't trust the client. So they often have to call and ... confirm the letter or they just refuse to do it and the client pays up-front, they come to us, let us know, and we pay the client back."* (Participant N21, Toronto CHC, case co-ordinator)

The best and the worst

Participants discussed best and worst case scenarios of the undocumented and uninsured attempting to access hospitals. Best case scenarios identified by participants were when individuals received care and some or all fees are waived.

> *"Best would be... a client ... is delivering or about the deliver and we're able to get them ... into triage, and you know delivery without any ... issue."* (Participant N16, Toronto CHC, manager)

> *"Well I had in particular one woman ... she actually bought a tool to kill herself. She was ... very depressed, so I had to take her to the hospital to emerg at [Toronto hospital] and it was incredible story because I spoke with the doctors saying ... how much will this cost? And he said well the whole one week that, or 10 days, that we have to keep her would be six, seven thousand dollars and the woman said, 'I'd rather to die, I don't have money, I am suicidal because I don't have money to feed my kids.' And they waived the whole fee."* (Participant N17, Toronto CHC and university, researcher and front-line worker)

Another reported best-case scenario was when hospitals had formalized agreements with CHCs to provide care for CHC clients who are uninsured and undocumented. Of particular note were agreements for providing free or low-cost birthing services.

> *"We've had good experiences ... when that agreement was existing around ... delivery of babies, whereby a flat fee of $500 was negotiated with the hospital which covered everything for vaginal delivery. And so that was ... the best that we can negotiate ... for that situation."* (Participant N8, Toronto hospital, program director)

Worst-case scenarios identified by participants varied considerably more than the best cases. Identified worst-case scenarios included: women in labour showing up to hospitals without having any prenatal care, discrimination (around who is deserving of care) amongst hospital directors, administrators and health-care professionals, individuals being harassed and intimidated regarding paying bills, individuals

being deported, individuals denied care even with CHC referrals, individuals being held captive in hospitals until they could demonstrate they could pay bills, individuals delaying seeking care until their health was severely compromised, being discharged early, and families having to pay exorbitant hospital bills.

> *"We've had situations where someone was needing an emergency caesarean and the doctor would say that the husband go get me the cash before I start ... or wouldn't ... intervene until he had cash in his hand. So we'd have these very very distraught husbands, family members, who may or may not have been able to get money. Worried that the health of their wife or sister or brother or whatever could be in jeopardy because they couldn't come up with the money ... There were situations ... where the doctor refused to discharge the patient until she paid up all her money. Almost kept her like a prisoner, which was just crazy, and then she would ... keep building up hospital bills."* (Participant N10, government health organization, health-care worker)

> *"The worst-case scenarios that I can think of as a clinician in general or what I would consider a shame is people delaying seeking their care to the point that they have a worse outcome. To me that is, the most uh, degrading thing that you can do to a human being is to make them reconsider their health and to put the importance of their health secondary because they feel that the country that they're in doesn't think that they're health is important ... to the point that it actually ends up having lasting negative consequences in their life, whether that be financial or whether that be, you know, worse health outcomes."* (Participant N19, health-care worker and researcher)

Toronto public health

Toronto Public Health (TPH) was identified by some participants as providing some care to the uninsured and undocumented, particularly immunization services and pre- and post-natal care programs. Both of these services weren't identified as being specifically for this population but because individuals did not have to show identification to get these services, their status was not a barrier to access. Other participants noted that TPH engaged in partnerships with other organizations and health care professionals providing care to the uninsured and undocumented. Partnerships were often around obstetrical and post-natal care. Other participants, however, stated that they did not think TPH provided services to the undocumented and uninsured population; or participants were unaware of any programming provided by TPH, suggesting that more awareness about TPH services is required.

Private physicians

When asked about private physicians providing services, about half of participants said that private physicians did provide services to this population, either from their private practices or practices housed within hospitals. Participants suggested that in many cases physicians who were willing to provide care to this population had informal relationships with the referring organizations. Often, referring to an external private physician happened through an in-house physician who had relationships with other physicians, such as specialists. Other participants, however, stated that they did not necessarily carry a roster of physicians, but rather they would call around until a physician agreed to provide service to the clients. About one-third of the participants said that private physicians provided care free-of-charge to these clients either through volunteering at organizations or by waiving fees at their own practices. Other participants stated that physicians did not differentiate between insured and uninsured clients when they realized that they will have their fees paid by a CHC.

Qualitative Research Project on Health Care Access for the Uninsured

Some participants suggested private physicians did not provide care to these clients at all. Some reasons for denying care included: physicians not wanting to deal with the additional paperwork needed to provide service to these clients (particularly refugee claimants), not having the time to serve additional clients, and not having the opportunity to see clients because they can't make it in to the hospital. One participant was concerned that private physicians were not clear on the situation facing the uninsured and undocumented and would provide false information regarding billing, which would subsequently lead to uninsured clients distrusting the health-care system as whole.

> *"And generally I find that clinicians tend to not know anything about this situation, and if anything they give patients misleading information that they won't have to pay the bill because they don't really know any of the aftermath and they assume that the hospital doesn't spend any time pursuing the bill and that there's no collection agencies involved and things like that … There definitely have been a lot of cases where collections have gotten involved … it's not a formality in any way."* (Participant N19, health-care worker and researcher)

Another participant voiced concerns about tensions that have occurred between private physicians and midwives providing care to the uninsured and undocumented:

> *"… it's a relationship marked by generally a lot of tension. The reason being is that midwives are funded by the Ministry of Health to provide care for undocumented and uninsured women and physicians are not, and so midwives tend to, especially in some communities, tend to … have a very high proportion of clients who are undocumented and uninsured and when there are medical complications with those clients midwives appropriately take those clients to a hospital … to transfer their care to a physician, or they need to consult with a physician regarding a complication. Physicians feel like midwives are kind of bringing this problem to their doorstep, and that they're essentially being forced into a position where they have to provide free care because they have no way of billing for that care that they provide."* (Participant N25, community health organization, manager)

Other service providers

Participants also identified other sources of care accessed by the uninsured and undocumented. Some participants noted that this population sought care at walk-in clinics or community care access centres (if there was a partnership with another service provider). Uninsured and undocumented individuals also accessed midwifery care and legal support which are provided through partnerships with CHCs. Legal support was also accessed through community organizations, or through legal practices geared towards helping vulnerable populations (identified by one participant). A final source of care identified by a few participants was through informal networks either with friends and family from their home country, or through social networks these groups developed after moving to Canada. Some participants were concerned about individuals self-medicating with medications brought from their home country, seeking informal care through healers, or birthing at home, as these practices could have serious negative impacts on the health of these individuals.

Qualitative Research Project on Health Care Access for the Uninsured
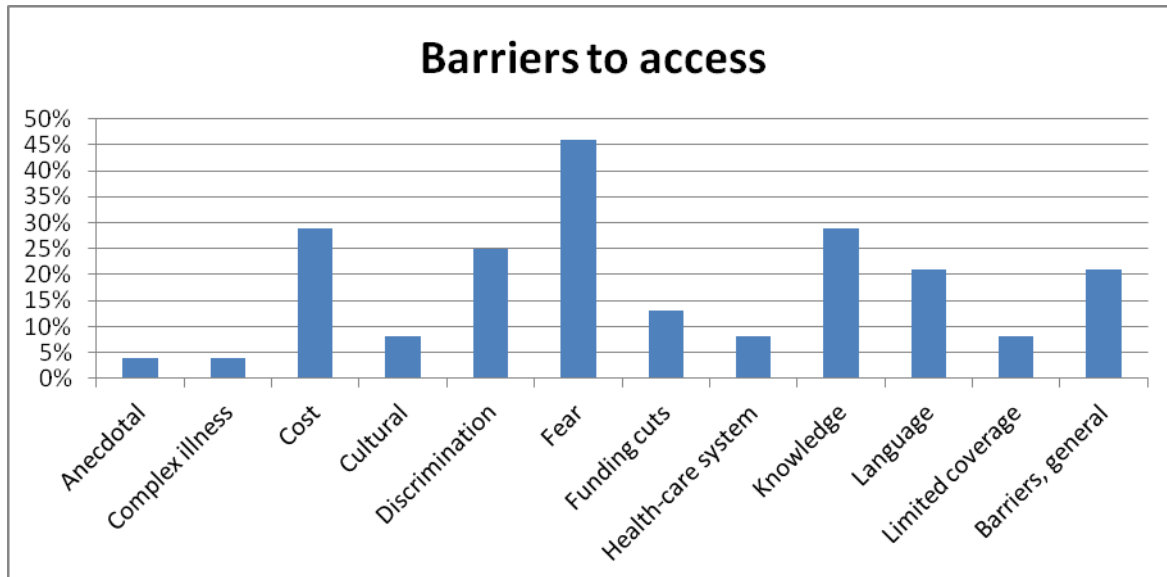
General barriers to access

Figure 3 Percentage of participants citing different barriers to accessing health-care services facing the uninsured and undocumented population

Beyond the barriers to accessing particular health-care organizations, participants noted more general barriers experienced by the uninsured and undocumented population.

Fear

The most cited barrier to access is fear, particularly fear of perceived authority figures, institutions, and government agencies (like hospitals, as noted above, and schools), and distrust. Many participants said that the uninsured and undocumented population had to feel safe before seeking out needed medical care. Fear in the uninsured and undocumented population was related to fear of deportation, fear of the cost of care, fear of being hooked into the system (which may be associated with mental illness), and fear or embarrassment or harassment due to their status. Participants in the study noted that the fear experienced by this population may have had a negative impact on their health by causing individuals to delay seeking care (leading to greater severity) or by causing stress, which itself had health impacts.

> *"So these, you know, these chronic uh illnesses were just not managed because of either fear of accessing health care or just the fact that they're without status they just never were able to address them...but it comes to a certain point where we have to refer out and a lot of times clients will not even show up to the appointments because of that ... fear of ... embarrassment and things like that happening"* (Participant N16, Toronto CHC, manager)

One participant noted that fear was experienced differently by different groups in this population, specifically that individuals without status experienced greater fear than those in the three-month wait period (who do not fear deportation).

> *"... well for undocumented clients it's a bit different ... in that there's a whole level of ... anxiety and fear around being found out. So people often don't seek help until they're maybe quite ill... that's a little different I think ... than people who are here ... for the three*

months to kind of kick in and then they would apply. So if their legal status is here they're ... are in a different space ... emotionally." (Participant N24, Toronto CHC, director)

Cost

The next most cited general barrier is the cost of care. As previously stated, the cost barrier was closely associated with the fear barrier, as it was often the fear of the cost of care which created the barrier to access):

> *"... even if people don't know ... how much the cost is, just the fact that there might be a cost; and when we're talking about new immigrants who are coming with such limited money, are looking to build a new life, are looking for a job or looking for a home, or refugees who have literally come without any previous planning and not even have any savings or may not have brought their savings, it's really a difficult thing to ask for people to just access the care and not think about the consequences."* (Participant N19, health-care worker and researcher)

Cost constraints also acted as a barrier to receiving quality care. This occurred when individuals were unable to access all services required since only some services were covered by a CHC; however, others – such as a hospital admission fee, or some tests – would not be covered.

> *"... it's not a barrier for people coming here and accessing, but when we're referring out to a specialist, for example ... we will cover off ... diagnostic costs ... But there are some instances where we can't cover off all of the costs because we don't have the budget. So it depends on, you know, the treatment that might be required of that particular person so ... we're still limited as to the amount that we actually can cover."* (Participant N24, Toronto CHC, director)

One participant suggested that physicians altered their care plans for patients when they knew the patient had to pay out of pocket, which could impact on the quality of care as well.

> *" ... when somebody for example admitted under internal medicine or neurology or some sort of service in the hospital where they may need tests performed, unless they're affiliated with a community health centre that does have some budget for that sort of thing, it's going to ... bring up a lot of discussion ... amongst the team. And I think what I've seen happen is, you know either the team will try to minimize the amount of tests that are done ... where somebody with insurance might come in and might you know end up getting a CT and this and that, somebody else might end up getting something that's cheaper because the physician is aware that this person will have to pay for everything and so they ... are trying to help the patient. But then, kind of standards of care ... aren't always applied as consistently."* (Participant N9, Toronto hospital, health-care worker)

Lack of knowledge and information

Lack of knowledge and information regarding the care available to this population was also frequently mentioned as a barrier to accessing care; for example, non-status individuals were sometimes unaware that a CHC would provide primary care services for someone without status. There was also lack of knowledge and/or miscommunications between different sectors within the health-care system with regards to providing care for this population. For example, one participant stated that some physicians

were not familiar with the interim federal health (IFH) program and would deny care to someone holding an IFH card.

> *"...a number of doctors I am told you know, don't even know what IFH is because it comes up so rarely in most practices and they ... think the only person who counts is ... one with OHIP ... even though they have an IFH which is ... a federal government document ... they have government insurance."* (Participant N6, advocacy group member)

It was also noted that physicians were sometimes unaware of the options for care for the uninsured and undocumented.

> *"Sometimes , you know, the clinicians are just like not aware of what the issues are at all and kind of what the options are, so I think that there's a lot of lack of understanding ... when somebody does end up seeing a doctor, about what the issues are in terms of payment and accessibility of care."* (Participant N9, Toronto hospital, health-care worker)

Another participant noted problems with organizations referring the wrong people to CHCs, which highlights how there has been misinformation within the health-care system regarding who CHCs serve.

Language, culture and discrimination

Language, culture and discrimination have also acted as barriers to accessing care. With regard to discrimination, some participants noted problems such as racism, sexism, and discrimination against homelessness and individuals with mental health issues. One participant believed that racism played a role in why individuals have not had access to care, or why they have been required to wait three months to access care:

> *"Especially racism, racism and sexism ... they tend to be part of this dialogue that's often underlooked ... our immigration patterns indicated that about 50 per cent come from non-white ... majority countries ... and as a result of that I think that racism is playing a role here in why people are not getting insurance or why the three-month waiting period is there. There's ... discussions around the intention ... to remain in Canada, right? Um, and ... that's a real issue because ... if people are here legally fall within the three-month waiting period but then their intention to reside in Ontario is questioned ... then they still can't access health care in a legal sense right, and have to rely on the charity of others."* (Participant N1, Toronto hospital, policy worker)

There was also mention of the stigma attached to undocumented or uninsured individuals that has acted as a barrier to accessing care. Some participants noted that uninsured and undocumented individuals were seen as taking advantage of the system,

> *"...I think to be a very popular thought that people are just here to use the health-care system; people are just here visiting and ... they're just taking advantage. And it's like well no. People are here living here ... and they have a right to be here just as much as you have a right to be here, and you know the situation in Canada is better for them and they want to live here, are we not able to provide them with health care? Do we really think that they came all the way here with their family just to use the health-care system? Like it's just the ignorance associated with it I find to be astonishing."* (Participant N21, Toronto CHC, case co-ordinator)

A few participants also mentioned instances of mistreatment of these individuals because of that stigma.

> *"... being ... sort of degrading to the clients and you know the stories like that. Like before they're being seen like ... yelling in the waiting room ... who's paying for this and ... you know like ... I didn't get my cheque yet so I don't know if I can see you this week, you know that kind of thing? Yeah so we've had some experiences."* (Participant N16, Toronto CHC, manager)

Cultural barriers were identified by two participants. Cultural barriers such as beliefs about accessing health care and the cost of health care which stem from experiences individuals had in their home countries, and cultural approaches to health issues acted as additional barriers to access.

> *"...clients are not specific about what's wrong with them ... you have to understand the culture. And the culture doesn't necessarily talk about ... they may say, 'Oh I'm having a pain in this area, and it won't go away, and I think I need to see a doctor.' But they don't necessarily come out and tell you right out what it is."* (Participant N7, community-based (non-health) organization, director)

Language barriers were also an important concern raised by interview participants. There were concerns around being able to access health-care information in different languages, finding health-care providers that speak a variety of languages, or accessing interpreters.

Other barriers

Other barriers identified by participants in the study included: funding cuts, health-care system problems generally (particularly the complexity of the system), and limitations in the services available (i.e. IFH limitations).

Networks and Relationships

One of the most significant themes to come out of the interviews was the importance of informal and formal networks and relationships. Informal networks were mentioned by 20 of the 24 participants, and were considered to be a key factor in ensuring the uninsured and undocumented received needed health-care services. Informal networks existed between: community-based organizations and health-care organizations (such as CHCs and hospitals), between private physicians and provider organizations like CHCs, between public health and CHCs and other community organizations, and partnerships around specific programs (such as obstetrical care). Informal networks were said to have come about through personal relationships, professional relationships (often through previous employment or through referrals), through advocacy (providers calling around and making the case for their clients), and through a jointly identified need by different individuals and organizations for care for this population. Some participants said that they relied heavily on informal connections with health-care providers and other organizations to serve their clients' needs. Sometimes specific individuals in organizations acted as relationship builders, using their contacts to bridge service gaps.

While it is clear from participants that informal networks had been integral to providing health care for the uninsured and undocumented, a couple of participants also noted that there was a downside to informal relationships. One participant noted that the behind-the-scenes nature of these relationships made it possible for clients to access care they otherwise would not be allowed to; for example, CHCs

are only supposed to provide services to individuals on the three-month wait, however, some will support all uninsured and undocumented clients. The downside is that because these relationships were informal there was no consistency.

> *"It's really hard to keep a roster of services because ... the clients that I see, their issues are completely all different ... situations different, time of year is different. It's really hard because while this year I might find a particular doctor who's willing to see a client for prenatal care in this area, next year he might be full, next year he might have moved. Like it's really hard to keep a consistent list and ... I don't really do that."* (Participant N21, Toronto CHC, case co-ordinator)

> *"... at least when ... you try to connect people informally... we have at least, you know, an option, or, an alternative. Otherwise, if we didn't have the informal alternative we wouldn't ... help the woman. So I see it's like fortunately and unfortunately, but at least we get something... when it's formal ... we can't because if they say we are not accepting new clients that's it, that is the answer you have."* (Participant N3, community-based (non-health) organization, social worker)

One participant highlighted the importance of network connectors in that when they were lost often informal networks were lost as well:

> *"...we used to have a much closer relationship with [other Toronto CHC] because [previous agency doctor] used to come here, now that she doesn't come here anymore because [agency doctor] comes here we don't have as close ties."* (Participant N13, community-based (non-health) organization, front-line staff)

Alternately, more formalized relationships provided for more consistent policies and practices in providing care for these individuals. About half of participants identified the existence of formal relationships such as these as well. Formal agreements between hospitals and CHCs were usually around providing birthing services, or ensuring a particular hospital rate for CHC clients. However, while these agreements may ensure better consistency, some participants noted that some agreements had been removed as hospitals were no longer able to carry a deficit. Formal agreements sometimes lead to inflexibility which could serve to impede access to care, as noted by one participant:

> *"It's kind of a double-edged sword: on the one hand ... it's good because there will be that consistency and there will be ... greater shared responsibility, right? On the other hand, those kinds of informal relationships ... might suffer ... as a result, because people won't be able to call if there's ... a clear agreement saying that, you know, planned parenthood is allowed to send 10 people, right, or whatever, in regards to that. So it's a bit of a double-edged sword."* (Participant N1, Toronto hospital, policy worker)

Formal agreements were also noted between CCACs and community organizations, between midwives and CHCs, between CHCs and other community partners (such as shelters), and between public health and community organizations and/or CHCs.
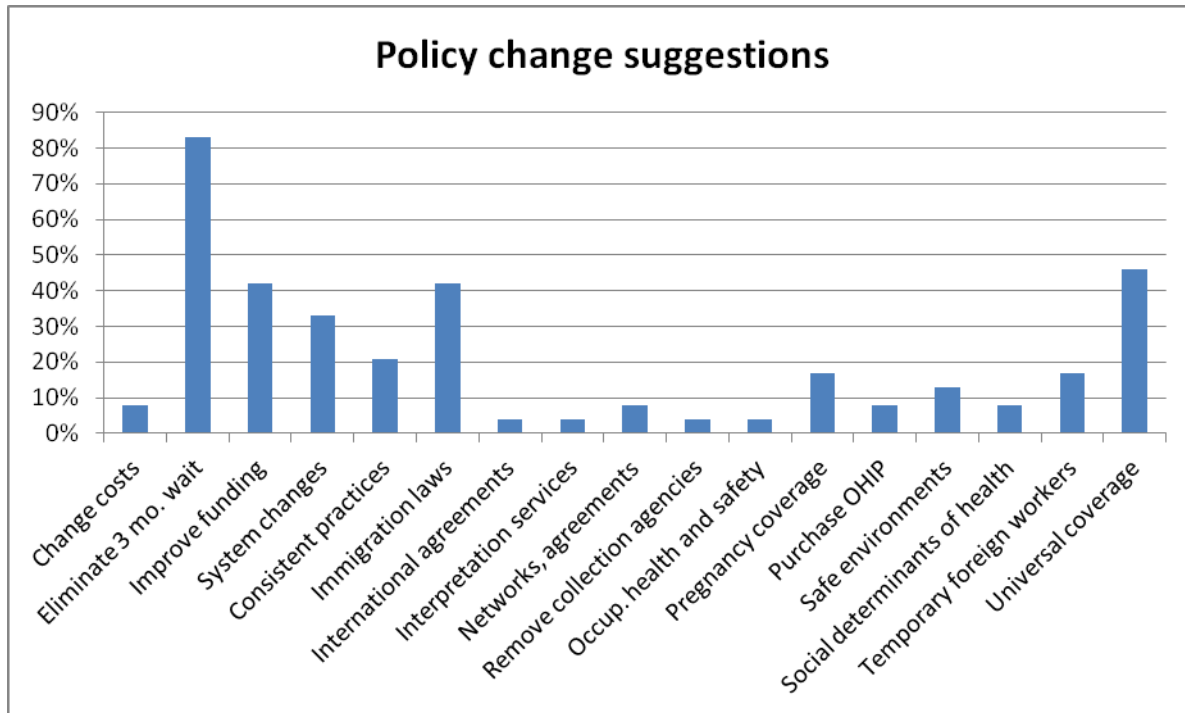
Policy changes: recommendations

Figure 4 Percentage of participants citing different policy change suggestions

Participants suggested a number of potential policy changes required to improve access to health care and to improve health outcomes for the uninsured and undocumented population. The most prominent policy change suggested by 20 of 24 participants (83 per cent) was the elimination of the three-month wait period. Many participants noted that since other provinces have already managed to eliminate or alter their three-month waiting period (New Brunswick's recent removal of the three-month wait and Quebec's exemption for pregnant women were mentioned by a number of participants), there could be a good chance that pushing for this policy change would be successful and would be a good short-term policy option. One participant noted that while the three-month waiting period should not be the sole focus of policy change, it could be an important "starting point" towards more broad policy changes that could affect more of the undocumented and uninsured population. There was also a mention of pushing for pregnancy coverage for those in the three-month wait (as is done in Quebec) and ensuring pregnancy coverage regardless of status. This was also identified as being more likely to be enacted than other policy changes. A few participants noted that this change could also act as a stepping stone towards broader, long-term policy changes for this population and increasing awareness of these issues.

> *"I think for the short term it is eliminating the three-month waiting period because that is the way to get people thinking about these issues asking the question."* (Participant N19, health-care worker and researcher)

> *"...elimination of the 90-day waiting period would be a starting point I think ... that would be the starting point to deal with one class of people, which is pretty significant, but not all of it."* (Participant N23, community-based (non-health) organization, lawyer)

The next three most cited policy changes were: providing additional funding directed at the undocumented and uninsured population, changing immigration laws, and providing universal coverage. Participants citing funding noted that there have been programs that were working to provide care for these individuals; however a key challenge for these organizations was accessing enough funding to support these existing services. Changes in how the system is funded either within organizations, such as hospitals, or between organizations and groups was included in this policy option. One suggestion provided by a participant was to redirect a small portion of pay rate increases for physicians towards services for this population.

> *"...the OMA, just ... announced that their physicians have ... settled their latest salary increases with the Ministry and they're getting 5 per cent per year for the next four years. So the people in the ... health-care system who make the most money just got the highest raise of anybody. Why ... couldn't it have been 4 per cent and then take that other 1 per cent and actually put it towards... working with uh this population?"* (Participant N5, Toronto CHC, program director)

Changing immigration policy was also noted as a potential area for change. Aspects of immigration policy identified included: improving the sponsorship and refugee claims processes (a few participants were concerned about new changes made to the refugee process), policies around immigrant workers and temporary foreign workers to support their rights and improve their access to health care, and simply making the immigration process easier and more equitable. Universal coverage as a policy was mentioned by 11 of the participants (46 per cent); however most of them recognized the significant barriers to instituting this kind of a policy change. This policy option was identified as a long-term goal, and was often associated with individuals' beliefs about health care being a human right.

Health-care system changes were also identified as a potential area requiring policy changes. Some participants mentioned moving towards partnerships and programs that have been demonstrated to work for this population,

> *"...there are certain areas where things ... are working well... The challenge across the system is they may be working on a small scale here for some of our folks who are registered, who are patients here, but ... it may not be working elsewhere in other parts of the community right? So ... there are models of service out there that are working. The challenge is ... funding ... to get more off."* (Participant N15, Toronto CHC, manager)

Ensuring access to the entire system (not just primary care through CHCs), improving integration across the system, eliminating the health card, and directing funding to other vulnerable populations (such as the poor) are other health system changes suggested by participants; these are included in the health system changes category. A prominent category within health system changes was the need to improve consistency of practice between CHCs and hospitals. The option was sufficiently dominant to warrant its own category.

> *"So there has to be some kind of accountability where they're not able to just ... for instance ... an uninsured walks in ... they see dollar signs and they charge a lot, five times the OHIP rate for a procedure that they wouldn't normally charge for. So some kind of ... law that would ... prohibit those kinds of practices."* (Participant N16, Toronto CHC, manager)

Other suggested changes related to the health system included: providing individuals with the opportunity to purchase an OHIP card, and redirecting policy focus towards a social determinants of health model.

Other policy changes identified included: changing international health-care agreements, providing interpretation services, no longer using collection agencies for individuals who are uninsured, and improving occupational health and safety policies. Finally, a few participants suggested that there need to be policies that support safe environments in order to address the fear that acts as a barrier to access; for example, hospitals making it clear that they have a "don't ask, don't tell" policy around immigration status.

Barriers to policy change

While participants identified numerous potential policy changes, they also identified a number of significant barriers to these policy changes. The most cited barrier was lack of political will to make these changes, particularly political will at the federal level. Related to this barrier were ideological barriers to policy change. In addition to individuals citing a Conservative government as one being not conducive to change, there were also concerns that dominant beliefs about who "deserves" care acted as a barrier to change. Many participants stated that politicians, policy makers and the public considered this population to be abusers of the system or drains on the system; the stigma associated with the belief that these groups cheat the system is a considerable barrier to policy change.

> *"The other kind of story or anecdote that compromises dealing with this issue in a rational way to my mind is that everybody seems to have an example of somebody who pulls up outside the Emerg in a Mercedes and then comes in claiming that they can't pay. And so the push back is always, well, actually these people can pay, they're just scamming the system. Now I suspect that's a pretty minor component of that. But because of ... the suspicion and the resentment it ... poisons the whole ... issue."* (Participant N14, Toronto hospital, director)

This stigma is related to issues of discrimination against undocumented individuals being "illegals" and undeserving of care.

> *"There are still people that would say that with respect to undocumented that they're illegals and they don't deserve to be here anyway."* (Participant N14, Toronto hospital, director)

It should be noted, however, that participants also demonstrated a tendency towards identifying groups who were more deserving of care than others; specifically many participants linked deserving care with residing in this country and contributing to this economy,

> *"... you knew with some of them ... that they wanted health-care and that they were going to go back to their country, and you know from a personal perspective sometimes I'd have more challenges with that population because they weren't living here, they weren't planning to stay here and they weren't paying taxes. Whereas the other people really did want to stay here and try and make Canada, or Toronto or whatever, their home. Whereas the other people were coming back and forth just to get free health care and that was a bit more of a dilemma; whether that's a fair thing to do."* (Participant N10, government health organization, health-care worker)

> *"... I mean it's people that they had been doing a lot of contribution to this society, because they contribute a lot in the economy. Especially in the province of Ontario because it's a big number. That's why I'm saying they deserve at least to have the health care."* (Participant N12, community-based (non-health) organization, social worker)

Participants also voiced concerns regarding adequate public awareness of, and public support for, these kinds of changes. Participants noted that a lack of public awareness potentially perpetuated beliefs about the uninsured and undocumented population being scammers and undeserving of care.

> *"Well I think the biggest barrier is just ... public opinion and support for the issue ... I think there's a lot of people, or a perception anyways, that ... this kind of whole idea that, that was really ... I remember really kind of promoted by the Harris-Eves government in Ontario, ... that people who are uninsured who are seeking health care ... are essentially like a drain on the system. Or you know they use the term of health-care fraud a lot, so this kind of ... idea that ... these people who are uninsured are kind of undeserving and somehow kind of leeching from the system. Um so I think we need to address that and I think that's kind of a ... hard piece. But I also think that ... engenders a lot of fear in politicians ... in kind of taking a stand on the issue."* (Participant N25, community health organization, manager)

It was noted by nearly half of participants that public awareness was a key barrier to policy change. A number of participants suggested that policy change could be enacted through lobbying and advocacy from the public, which is why public awareness was cited as a critical issue.

> *"It needs commitment, societal commitment rather than one hospital saying, we have this policy because that hospital also has a limit right? It has to be a societal issue rather than one CHC issue or one hospital issue or me as a front-liner..."* (Participant N17, Toronto CHC and university, researcher and front-line worker)

> *"... but any change that's going to come it will definitely require a lot of lobbying and advocacy on the part of ... the movement that we are in at this point. I don't think government is going to wake up one day and say ... we're going to change everything because I think it's more equitable. I do not see that happening. I think it has to be a kind of broader policy change that impetus will have to come from the people."* (Participant N23, community-based (non-health) organization, lawyer)

Another key barrier to policy change identified by participants in this study was fear by policy-makers of the potential cost of these policy changes. Many participants recognized the budgetary pressures facing Ontario's health-care system, which could make pushing for policy changes such as removing the three-month wait period challenging.

Two participants suggested that there were issues around intersectionality because of the diversity of the uninsured and undocumented population. One participant highlighted that the policy responses for different groups will necessarily be different; however, the other participant suggested that, while the specific needs of each sub-group may be different, there is an opportunity to address common concerns across the sub-populations. This participant was concerned that while there is indeed an opportunity for combined efforts, policy change and research efforts could be fragmented through a focus on specific subgroups.

"But I think overall what's important about doing research is kind of preventing any further division amongst groups because oftentimes ... people without status or people who are uninsured get divided up into kind of the people who are deserving and the people who are not deserving and there's kind of a fragmentation of the groups into ... kind of sub-population which actually ... losing some of the strength in numbers ... kind of divides the advocacy and divides the research into smaller and smaller pieces. Whereas there are a lot of links that can be made, for example, between ... the temporary foreign workers and the ... live-in caregivers who come and the agricultural workers and you know the people who are working here in the construction industry and ... people who come as refugees. I mean there are a lot of commonalities in terms of the marginalization they face and so kind of drawing ... on those commonalities while at the same time looking at specific groups I think is important." (Participant N9, Toronto hospital, health-care worker)

This speaks to the need for enhanced coalition building across the sectors in order to strengthen advocacy.

A final barrier to policy change identified by one participant is the lack of information required to make a case for these suggested changes, a point which is discussed in more detail below.
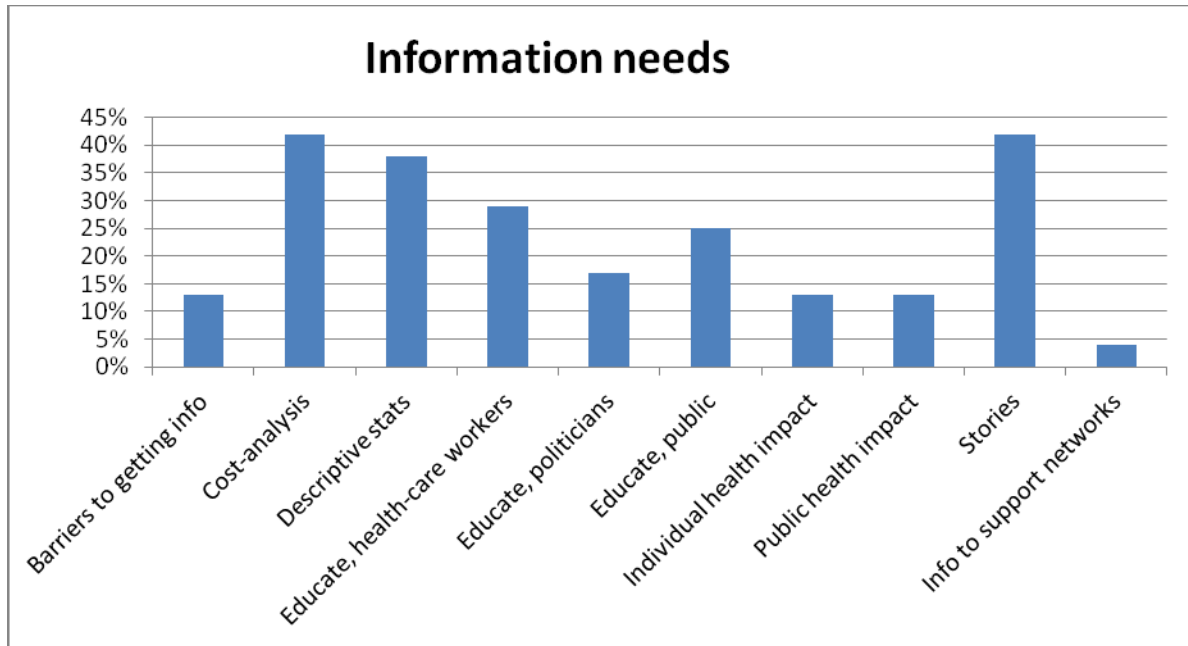
Information needs

Figure 5 Percentage of participants citing different information needs

Participants highlighted several areas that require additional information about the undocumented and uninsured population; required in relation to enacting policy change, and required more generally. The three most cited types of information required were cost-analyses, descriptive statistics and stories. Cost-analysis information regarding the health-care system costs associated with denying care, or the actual cost of removing the three-month wait period, were cited as potentially providing support for

policy change. Many participants said they expected to see an overall cost savings when providing the undocumented and uninsured with early treatment rather than waiting until their conditions were much more severe to provide care. Participants were also interested in cost-analysis information from other provinces who have removed the three-month wait period to use as a comparator. Descriptive statistics, mostly regarding how many individuals fall into the uninsured or undocumented category, were also identified as an important information requirement. Nine participants (38 per cent) noted that not enough is known regarding how many people fall into this category; a few participants had some suggestions regarding how this information could be gathered:

> *"So people are doing all this data collection on their own like in these little bits and pieces ... from all over the place and the governments like, no, that's not data ... So that's I think that's a pretty frustrating thing, so the government should actually collect data and should also have disaggregation within that data, like who is accessing."* (Participant N23, community-based (non-health) organization, lawyer)

> *"I think through the CHC network would be one place to start right because when people plug in there they don't need the health card so to look at ... maybe some of their intake data right... And you know service providers who are out there ... usually have a sense of ... what's happening ... the other place to look at actually would be ... maybe in schools because you know the children of some of these people do attend school right?"* (Participant N8, Toronto hospital, program director)

Individual stories were also identified as an information need which could be used as a means to raise awareness about the challenges facing this population, and also to help appeal to the public's and policy-makers' sense of human compassion. This was viewed as a way to deal with some of the discrimination and stigma that have acted as barriers to access and policy change.

Another information need identified by over half of participants (71 per cent) is the need for educating different groups about the health issues facing the uninsured and undocumented population. Politicians/policy makers (17 per cent), the public (25 per cent), and health-care providers (29 per cent) were the three groups identified as being in need of education on this topic. Educating health-care providers was mentioned the most frequently; participants found that health-care professionals sometimes lacked sensitivity to the situation because they were not aware of it.

> *"One thing that I believe could be helpful, I don't know how to do it, but if we could like educate the professionals, especially doctors and nurses ... try to make them understand how, you know, that when they ask for money or when they say no they are just making things worse for themselves in the future."* (Participant N3, community-based (non-health) organization, social worker)

> *"And I also think that the other group that needs more awareness are the health-care providers themselves. Um, who are on the front lines, and also the triage nurses in hospitals who might be those that are demanding uh, money up front before the person can seek care. It would be great to reach those people and to explain why sometimes demanding money for allowing someone to seek care can be very problematic."* (Participant N4, researcher)

Training and education for health-care professionals was considered by participants to be a key driver to improving access and reducing discrimination and stigma.

> *"And I think that there should be several ... training opportunities for people and front-line workers on how to actually, to be aware of the issues and the, and the situations that undocumented people face and to be able to be a bit more sensitive to those issues."* (Participant N21, Toronto CHC, case co-ordinator)

Participants also noted that education regarding which services were available to this population was also required for health-care professionals who sometimes turned patients away even when they had referrals from CHCs, or did not know how to deal with this population when they presented. Education for politicians and the public was also considered to be important to raise awareness, decrease stigma and discrimination, and potentially move policy change forward.

A few participants also noted the need for additional information regarding the individual health and public health impacts of being undocumented and uninsured. One participant noted that the intake process required for uninsured and undocumented individuals led to longer wait times in emergency rooms, demonstrating a potential broader health-system impact which could be studied further:

> *"But speaking ... with the manager of registration...* [he] *was saying that two of the biggest issues that flow down the registration process are: one – language, so somebody comes and they, they have difficulty speaking English or whatever so you have to run around, find an interpreter or get to the phone or whatever; and the other is ... payment issues. So it's not just the uninsured ... but you know self-pay generally and the uninsured will be part of that. So ... you have to send the person to patient accounts to set up the process and ... to begin the process for repayment and blah blah blah... it puts a kink in the system of ... the flow- through of patients."* (Participant N14, Toronto hospital, director)

Another participant identified the need for information regarding setting up informal networks and collaboratives to provide care to this population. A few participants also noted a need to identify the barriers to accessing information, such as a lack of funding for research of this nature, the inability to document these individuals because of their fear of institutions, and the inaccessibility of data gathered from research groups such as Statistics Canada.

Focus on women's health

While women's health issues did not figure prominently amongst discussions with network participants, given the strong focus on issues around providing care for pregnant women and policy change recommendations that speak specifically to the needs of pregnant women, women's health is clearly a central issue when talking about the uninsured and undocumented population. Other key concerns raised by participants included abuse and victimization affecting women. This suggests that a gendered analysis of the health issues facing the uninsured and undocumented population is warranted, and future work in this area should pay special attention to the health needs of women.

What's next

Gathering of additional information was considered to be an important factor in pushing for policy change. Further research and information sharing to support long-term policy changes while continuing to push for the "easier wins" in policy change such as removing the three-month wait period, are among the important future steps identified by participants. Some participants also noted the importance of keeping a broader goal in mind so that smaller policy changes can be enacted in the direction of larger, long-term goals. The identification of those long-term goals, and which smaller policy changes can help move in that direction, could be an effective next step.

Ensuring continued information gathering is another important factor for future work. The lack of needed information to make policy recommendations was a shared concern by most participants. In addition to gathering new data, there is also an opportunity to seek out and synthesize existing information and research to help push for policy change. With regard to data collection, some participants were concerned that some of the current practices that attempt to protect anonymity and provide a safe environment for the uninsured and undocumented (such as the "don't ask, don't tell" policy), may serve to perpetuate this lack of information, and so should be approached with caution. What is highlighted here is the need to strike a balance between ensuring the undocumented and uninsured are not fearful of accessing care, while not allowing the issue to be hidden from the public, health-care providers and policy-makers.

Finally, these interviews highlight some potential gaps in the discussion of the issues facing the undocumented and uninsured population. While many participants noted issues of discrimination broadly as a barrier to access and policy change, only a couple of participants specifically spoke to issues of racism and sexism acting as particular barriers. This intersection between discrimination and access to health-care services is likely a more prominent issue than was revealed in the interviews. This demonstrates some fragmentation and gaps in the discussion of the health problems faced by this population which could be dealt with through a continued sharing of information and a clear articulation of central concerns and common goals of the network and its partnered organizations.