Moving Asthma Issues Forward

Key Findings from the
National Asthma Patient Alliance Survey

Asthma Society of Canada
4950 Yonge Street, Suite 2306
Toronto, Ontario
M2N 6K1

(T) 416-787-4050
(F) 416-787-5807
(E) info@asthma.ca

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Section 1. Executive Summary

The Asthma Society of Canada and the National Asthma Patient Alliance (NAPA) conducted a survey, "Moving Asthma Issues Forward" in the summer of 2010 to determine the advocacy priorities of NAPA members.

After a rigorous process to identify the top asthma care and management priorities for Canadians, the NAPA Executive Committee settled on three major themes to ask about in the survey and determine the level of support from NAPA members and other Canadians affected by asthma nationwide. All three priorities were confirmed by the results of the survey. The priorities were:

- **Access to asthma medications and devices through public funding**
  - 94.4% or survey participants said this priority was "very important" or "important"
  - 88.9% believe the government has a role to play in providing full or partial public funding
  - Less than 20% have coverage for asthma devices (peak flow meters and chambers)
- **Access to medications at school for children**
  - 97.4% of parents say their children should be able to carry their medications at school
  - 96.9% of participants said this priority was "very important" or "important"
  - 95% believe capable students should be allowed to carry medication themselves
- **Access to asthma education and disease management programs**
  - 97.1% said this priority was "very important" or "important"
  - Less than half (49.2%) of our members are aware of an asthma clinic or asthma education centre in their area

Over 80% of our survey respondents have some form of financial coverage for their medications. About two-thirds of coverage is private, and more than half is partial coverage. 64% of our members use chambers to deliver their medication and 54% of our sample uses a peak flow meter.

Through comments, NAPA members report a worry about their medication coverage levels, especially among people who have lower incomes or are not in the workforce. Members also indicated how they cope with their inability to afford their medications, which include an increased reliance on medication samples, or frequent visits to emergency rooms for medication.

NAPA members also report that schools need to have consistent medication policies, and that there is a worry that teachers and administrators do not have enough training, or place enough emphasis on asthma. Respondents recount stories about children not being able to access their medication while on field trips or at recess, and how their children experience stress when they need to walk to the office or ask an adult for their medication.

NAPA members are most likely to receive asthma education from a family physician, but they indicate a need for more asthma training for their family doctors as well. Specialists are the most highly regarded source of information, as 74.4% of survey respondents regarded them as "essential" for education. Members highlighted a need for more asthma and disease management education in a variety of formats, and the need for more asthma awareness and education for the general public.

The Asthma Society of Canada (ASC) will be moving forward to implement and work on the identified priorities in the coming years.

Section 2: Survey Background and Collection Methods

2.1. About the National Asthma Patient Alliance (NAPA)

This survey was conducted by the Asthma Society of Canada, on behalf of the National Asthma Patient Alliance. [i]

The National Asthma Patient Alliance (NAPA) is a grassroots patient group of volunteers from across Canada, whose aim is to increase patient awareness about how to achieve optimal asthma control, address advocacy needs of this chronic disease, and build a network of patient volunteers dedicated to improving asthma care and education in Canada. NAPA was initiated in Hamilton, Ontario in 2007, and is governed by an Executive Committee of volunteer members who meet by teleconference.

2.2. Survey Objectives

In 2009, the NAPA Executive Committee undertook a rigorous process to identify three of the leading issues in asthma management for Canadians based on their beliefs and experiences. The outcome of this process was the identification of the following three issues, which are presented with priority order:

- Access to asthma medications and devices through public funding
- Access to asthma medications in school
- Access to asthma education and disease management programs

This survey was designed by the Asthma Society of Canada and approved by the NAPA Executive Committee. The purpose was to determine if these priorities were representative of the general NAPA membership, and to allow NAPA members to identify other topics of interest.

2.3. Timelines and Collection Methods

The survey was designed with questions surrounding the three identified priority issues, and was officially launched in May 2010. There were no prizes or incentives to complete this survey. All formats of the survey closed on September 17th, 2010. The various opening dates are outlined in detail below.

Data for this survey was collected using four formats as follows:

1. A long-form questionnaire was distributed to NAPA members via an e-mail alert (NAPAlert[ii]). This e-mail contained a password and a link to the survey, hosted by the website 'SurveyMonkey.net.' Only NAPA members were given access to this full survey, which was 44 questions in length, including demographic information. Questions were asked to obtain responses in both quantitative and qualitative formats. No questions on the survey were mandatory. This portion of the survey was opened on May 31, 2010.
   N=100 users filled out the survey in this manner.

2. The long-form questionnaire described above was printed and mailed to registered NAPA members upon request, and distributed at asthma clinics to individuals who signed up to be a NAPA member after speaking to their healthcare professional. This is the same 44 question survey as described above. When the copies of this survey were mailed back to the Asthma

Society of Canada, they were entered into the SurveyMonkey software as a new entry. This portion of the survey was mailed in August and September 2010.
N=6 users filled out the survey in this manner.
NOTE: formats 1 and 2 are not differentiated in any survey results

3. The NAPA website (www.asthma.ca/napa) contained a quickpoll of 5 questions to confirm the main priority issues. This website is not password-protected, and answers may have been entered by any visitor. The questions were asked sequentially, such that a user would have to answer question 1 before viewing question 2, and would have to answer question 2 before viewing question 3. The quickpolls were opened in early June, 2010.
   N=154 users filled out the survey in this manner.

4. The NAPA Advocacy Blog http://www.napa-blog.blogspot.com/ was specifically launched to comment on advocacy issues. This contained a quickpoll of 3 questions to confirm the main priorities. This website is not password-protected, and answers may have been entered by any visitor. The 3 questions were listed individually on a side-bar of the website, so users were able to answer any or all questions of their choosing. This portion of the survey was opened on August 17, 2010.
   N=20 users filled out the survey in this manner.

The total number of responses received from all sources was N=280, while the full survey was completed by 106 participants (N=106).

2.4. Analysis of Results

The results presented were compiled by staff of the Asthma Society of Canada upon accessing the responses provided through the various formats. Quantitative tabulations and connections were compiled by modifying filters to the SurveyMonkey software. Some questions had a section for qualitative comments, and an additional comment box was placed at the end of the survey. All comments were analyzed through manual coding performed by two independent reviewers, and the presented themes are based on this coding. As the sample was not controlled in any way, users of this data should exercise caution in the potential biases presented. The responses are considered representative of NAPA members, but may not be representative of broader populations.

2.5. Further Inquiries about this Survey

Additional questions about this report can be directed to:

Oxana Latycheva
Vice President, Programming
Asthma Society of Canada
4950 Yonge Street, Suite 2306
Toronto, Ontario
M2N 6K1
416-787-4050 x.108
oxana@asthma.ca

Rob Lanteigne
NAPA Coordinator
Asthma Society of Canada
4950 Yonge Street, Suite 2306
Toronto, Ontario
M2N 6K1
416-787-4050 x.100
rob@asthma.ca

Section 3: Participant Profile

3.1. Demographic Profile of Survey Respondents

This survey was given to NAPA members across the country, who participated voluntarily. The resulting sample is representative of the NAPA membership; however the NAPA membership is not necessairly a representative sample of Canadians with asthma, or the overall Canadian population. In particular, NAPA members tend to be more interested in receiving asthma information and getting their asthma under control with the help of the Asthma Society of Canada. Over 80% of the NAPA membership found the Asthma Society because of a proactive search online for asthma information, likely indicating that NAPA members are predisposed to seek the information and help they require.

The respondents were unbalanced with respect to gender (Section 6, Table 1). The majority, 88% of survey respondents were female, far outpacing the 59.2% of Canadian adults with asthma who are women[iii]. This also suggests that a larger number of mothers filled out the survey on behalf of a child with asthma, as compared to fathers.

The respondents varied slightly from the national numbers with respect to an urban/rural divide (Section 6, Table 2). Approximately 80% of the Canadian population is urban as defined by Statistics Canada criteria of living outside of a centre with a population of 1000 or more and outside of an area with a population density greater than 400 people per square kilometer.[iv] Respondents self-selected their urban (67.9%) or rural (32.1%) category, and may actually be representative of the population, but have different self-descriptions of those categories.

The level of provincial representation also differs slightly from the NAPA membership (Section 6, Table 3). British Columbia, Alberta, Saskatchewan and Newfoundland and Labrador have a higher response rate compared to their overall NAPA membership numbers, while Ontario, Nova Scotia and Manitoba have a lower response rate. The number of Quebec responses is particularly low compared to national population trends because NAPA is still developing a strategy to gain an increased presence in Quebec. It is positive to note that responses were received from all provinces, and one of the territories.

Income data was collected in broad categories of income ranges (Section 6, Table 4). The results appear to align directly with the national median household income ($68,860[v]); however the survey was not as accessible for the lowest socioeconomic households who might not use the Internet as a source of health information, or place a priority on receiving online health education.

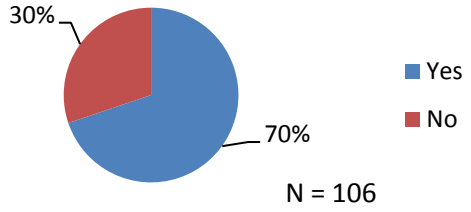
Survey respondents have higher educational attainment levels than the population at large (see the graph (Section 6, Figure 1) for details).

This survey was designed for adults, and thus this age sample contains no responses from children (Section 6, Figure 2). We note that adult parents answered this survey and have become NAPA members because of their children's asthma. The opinions presented are the opinions of adults and not necessarily their children. The profile contains a spike between the ages of 35-39, 45-49 and 60+. These ages are reflective of parents, grandparents, and people who are middle-aged or retirees and typically place greater emphasis on the health of themselves and their family.

3.2. Participant Connections to Asthma

Full survey participants were asked if they had asthma, and if they knew someone with asthma. The responses are presented below.

Figure 3. Do You Have Asthma?

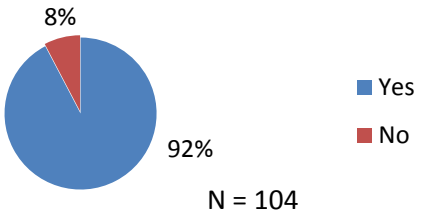


N = 106

Note: of the 32 people (30%) who did not have asthma, all of them know someone with asthma.

22 of these (21%) are parents of someone with asthma

Figure 4. Do You Know Someone With Asthma

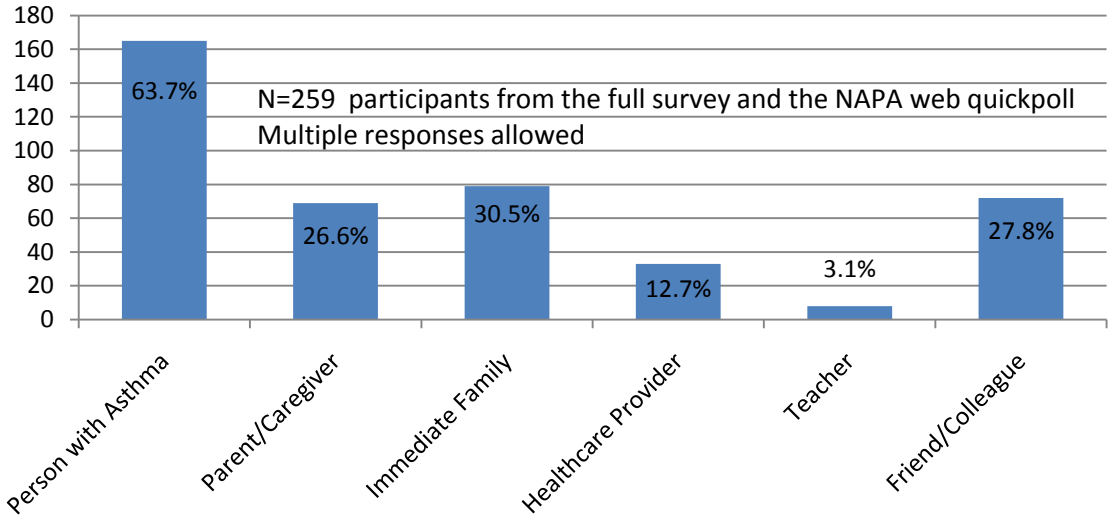


N = 104

Note: of the 8 people who did not know someone with asthma, all of them had asthma personally

All respondents from the full survey and website poll (excluding only users on the blog) were asked what their connection to asthma was (Figure 5). Over 63% had asthma personally, and over 30% have someone with asthma in their immediate family. Nearly 13% of the sample identified themselves as a healthcare provider to someone with asthma, and a small number were teachers of a child with asthma (3%). It should be noted that the NAPA-only survey identified above in Figure 3 showed that 70% of NAPA respondents had asthma. This suggests that our website quickpoll respondents were less likely to have asthma personally than NAPA members.

Figure 5. What is your relationship to asthma?



Section 4: Survey Results and Discussions

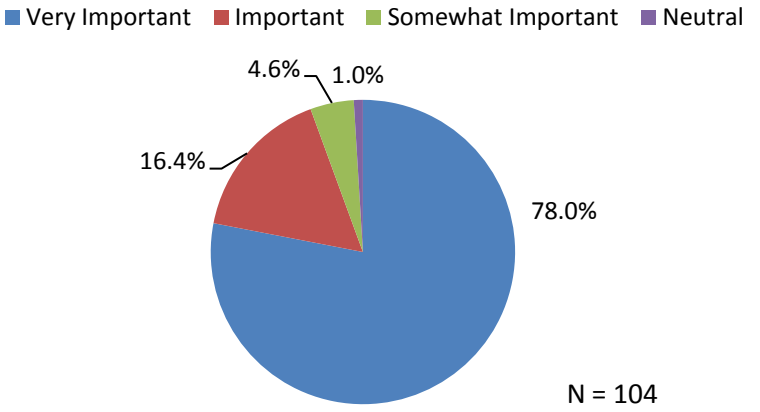
4.1. Access to Asthma Medications and Devices through Public Funding

The NAPA Executive Committee identified that this was the most pressing asthma issue in Canada, and asked a number of questions in the full survey surrounding medication and device coverage levels. It was anticipated that the results would show that some people with asthma do not have coverage, either public or private, for their medication and devices. This lack of coverage creates a barrier for some people who cannot afford to purchase medication and devices to properly manage their asthma as recommended by their health care professionals.

Perspectives towards public funding of asthma medications and devices

Participants of the full survey were asked their opinion about the importance of public funding of asthma medications and devices (Figure 6). Of 104 responses, only 1 was neutral, and none indicated "not important". The total of the respondents who chose "very important" or "important" was 94.4%. This result confirms that public funding is a matter of widespread importance among NAPA members.

Figure 6. How important is it to you that asthma medications and devices are accessible through public funding (i.e., provincial drug plan)? (full survey participants)

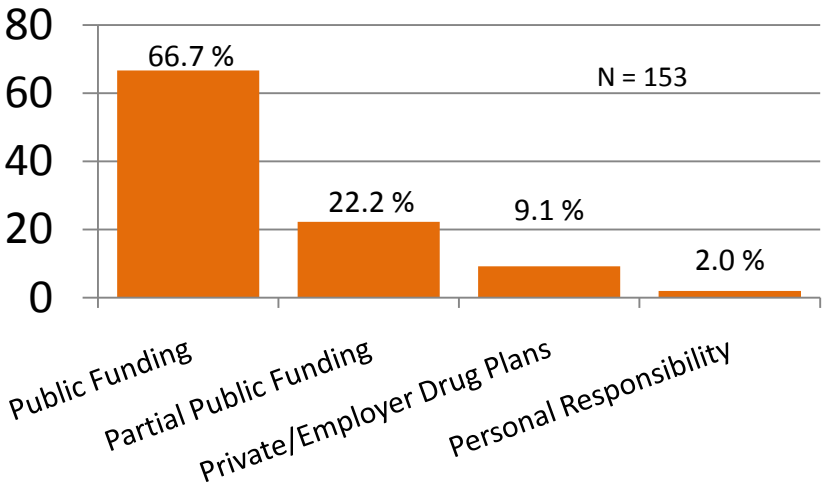


Total of "very important" and "important":

94.4%

Participants of both online quick polls (n=153) were asked how the cost of medications and devices should be covered, and provided four options (Figure 7). Two-thirds indicated that the costs should be fully covered through public funding, while a total of 88.9% indicated the government has a role to play through full or partial public funding. This result also helps confirm the importance of public funding among asthma.ca website visitors who are not NAPA members.

Figure 7. How should the cost of asthma medications and devices be covered? (online poll participants)



Total of "public funding" and "partial public funding":

88.9%

Personal medication coverage levels

Participants were asked if they had coverage for various types of treatments (Figure 8). The majority of respondents do have coverage of some form. 85.6% of people who use inhalers had some form of coverage, as did 83.3% of people who use pills as one of their treatment options. The number of participants who use injections is a smaller sample (n=16), and only half of them had some form of coverage.

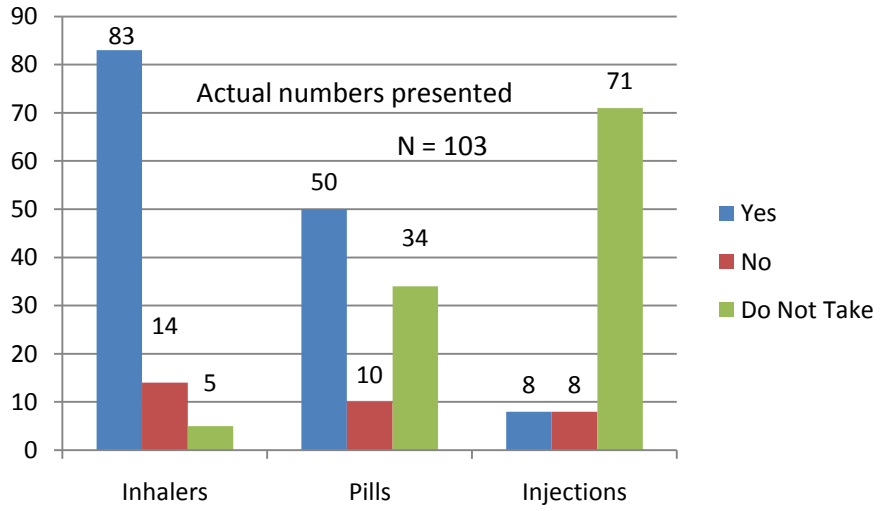
Of the 14 people who reported no coverage for their inhalers, 9 of them personally have asthma, and 5 of them are parents. None of them have coverage for their pills (N=9) or injections (N=5). None of these people reported use of chambers or peak flow meters, as asked in a subsequent question. The income breakdown of people reporting no medication coverage is shown in Table 5 below.

Of the 10 people who reported no coverage for pills, 7 of them have asthma, 2 are parents of someone with asthma, and 1 is an immediate family member. All of these people also use inhalers, and only 1 person has coverage for their inhaler. None of these people use chambers or peak flow meters, as asked in a subsequent question. Those who do not have coverage tend to have lower-incomes, and do not have coverage for any forms of asthma medication they are taking. The income breakdown of people reporting no medication coverage is shown in Table 5 below.

Table 5. Income breakdown of people reporting no medication coverage

Of the 14 people reporting no coverage for inhalers:	Of the 10 people reporting no coverage for pills
✓ 6 reported incomes less than $20,000 ✓ 1 reported income between $25,000 and $35,000 ✓ 2 reported income between $36,000 and $50,000 ✓ 2 reported income over $70,000 ✓ 3 declined to respond	✓ 5 reported incomes less than $20,000 ✓ 1 reported income between $25,000 and $35,000 ✓ 1 reported income between $36,000 and $50,000 ✓ 1 reported income over $70,000 ✓ 2 declined to respond

Figure 8. Do you have coverage for your and/or your child(ren)'s asthma medication (inhalers, pills and injections)?



85.6% (N=83) of people who take inhalers have coverage

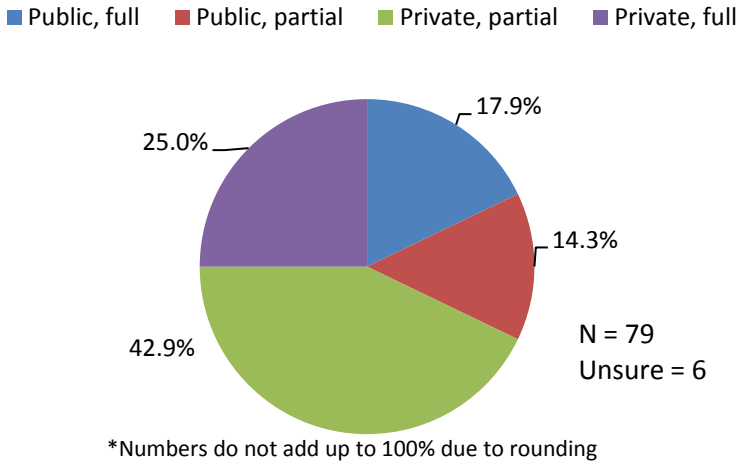
83.3% (N=50) of people who take pills have coverage

50% (N=8) of people who take injections have coverage

Types of medication coverage reported by survey participants

We asked participants in the full survey to tell us what type of medication coverage they have (Figure 9). The largest single category was private partial coverage, at 42.9%. Overall, more than two-thirds (67.9%) of respondents have private coverage (either full or partial). When comparing partial coverage to full coverage, partial (either private or public) has a narrower majority (57.2%).

Figure 9. What type of coverage do you have for your and/or your child(ren)'s asthma medication?



32.2% report public coverage (either full or partial)

67.9% report private coverage (either full or partial)

42.9% report full coverage (either private or public)

57.2% report partial coverage (either private or public)

We then cross-tabulated the answers to this question with some other questions asked in the survey, specifically income, province of residence, attitudes towards public funding, use of devices, and a question as to whether the cost of medications and devices is creating a barrier to asthma management (Table 6).

The results show that the lower income groups are relying on public coverage much more than higher income households. Among those who reported less than $20,000 in earnings and drug coverage of some kind, this group comprised 33% of the public full coverage category, 13% of the public partial coverage category, 3% of the private partial coverage, and 0% of the private full coverage categories. The highest income households show the reverse trend, comprising 48% of all private full coverage, 44% of private partial coverage, and just 17% of public partial coverage. Notably, 5 people in the highest income bracket reported full public coverage, accounting for 33% of people in that category. Overall, those with higher incomes report better coverage, although asthma device coverage remains low at all levels.

Overall, 22 people in the full survey (21%) reported that the cost of asthma medications and devices was a barrier to their ability to manage their asthma. Of these 22 people, 14 (64%) had coverage of some kind, while 8 (36%) reported no coverage. Interestingly, as reported below in Table 6, those people who reported full coverage were more likely to indicate that cost was a barrier compared to those who reported partial coverage.

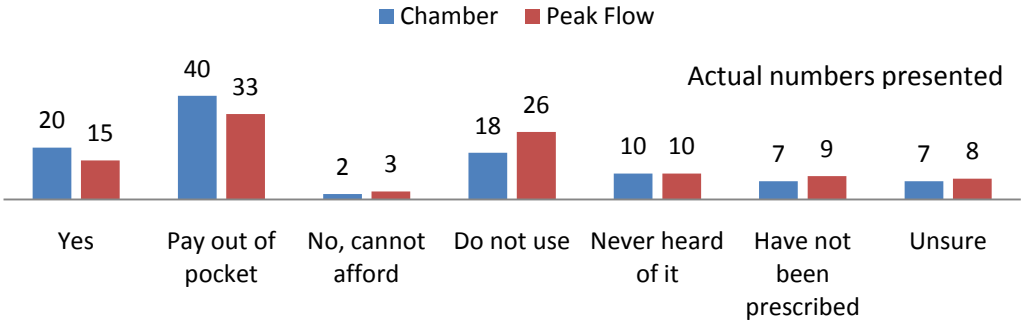
Table 6. Type of medication coverage presented with other factors

Public, Full N=15 5 incomes less than $20,000* 5 incomes over $70,000* 1 income unknown 6 Ontario, 5 British Columbia, 3 Alberta 15 labeled public funding as “very important” 3 have coverage for chambers; 6 pay out of pocket 2 have coverage for peak flow; 5 pay out of pocket 5 (33%) report the cost of medication or devices as a barrier to their ability to manage their asthma	**Public, Partial** N=12 2 incomes less than $20,000* 2 incomes over $70,000* 1 declined to respond 5 Ontario, 5 Alberta 11 labeled public funding as “very important” 3 have coverage for chambers; 4 pay out of pocket 3 have coverage for peak flow, 1 pay out of pocket 3 (25%) report the cost of medication or devices as a barrier to their ability to manage their asthma
Private, Full N=21 0 incomes less than $20,000* 10 incomes over $70,000* 3 decline to respond 13 labeled public funding as “very important” 7 labeled public funding as “important” 1 labeled public funding as “somewhat important” 7 have coverage for chambers, 9 pay out of pocket 5 have coverage for peak flow, 9 pay out of pocket 3 (14%) report the cost of medication or devices as a barrier to their ability to manage their asthma	**Private, Partial** N=36 1 income less than $20,000* 16 incomes over $70,000* 2 decline to respond 24 labeled public funding as “very important” 9 labeled public funding as “important” 2 labeled public funding as “somewhat important” 7 have coverage for chambers, 15 pay out of pocket 5 have coverage for peak flow, 10 pay out of pocket 3 (8%) report the cost of medication or devices as a barrier to their ability to manage their asthma
*only the highest and lowest income categories are presented for comparison	

Coverage for asthma devices reported by survey participants

Participants were asked if they have coverage for their asthma devices, and results are shown in Figure 10.

Figure 10.
Do you have coverage for your chambers?
Do you have coverage for your peak flow meters?
N=104



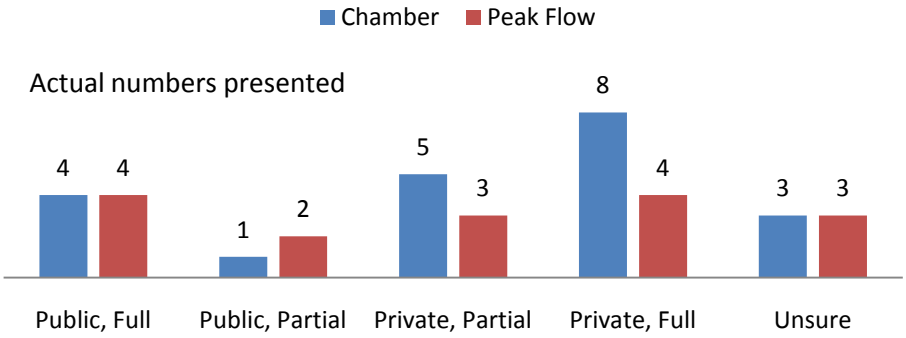
64% of participants do use a chamber, but only 19% have coverage for it, while 38% pay out of their own pocket, and 7% are unsure about their coverage level. 54% of participants use peak flow meters, but only 14% have coverage, 32% pay out of pocket, and 8% are unsure of their coverage level.

Over 90% of the sample reported knowledge of the devices, but most people who choose not to use one are doing so for reasons other than cost. Only a small number of people reported that they are not using a device due to concerns about affordability (Figure 10).

Types of coverage for asthma devices reported by survey participants

Participants who indicated that they did have coverage for their devices were asked which type of coverage they had (Figure 11). For both types of devices, there is a greater presence of private coverage than public coverage, and a greater presence of full coverage than partial coverage. The interpretation of these results is limited due to a small sample size

Figure 11. What type of coverage for asthma devices do you have?
N = 20 for chambers, N = 15 for peak flow meters



*One response indicated the user had both public full and private full coverage for each device

Asthma devices at the pharmacy

Participants were asked two questions about the use of asthma devices and where they should be located at their pharmacy. First, if there were a device available for about $30 that could be purchased to help monitor lung health before symptoms occurred, would they purchase it? This question refers to a peak flow meter, without naming the device. As shown in Figure 10 earlier, 57% of respondents would use a peak flow meter if affordability were not a concern, 54% of people are currently using a peak flow meter, and only 10% reported not knowing what the device was.

Yet despite those numbers, 87.4% of people indicated they would use the device to monitor their lung function if it were available at this price (see Table 7). This indicates that some people have not understood fully the information they have been given about a peak flow meter, and how using one could help them monitor their lung health.

Table 7. The number of participants who would like to have a device to monitor lung health

If there was a device available for purchase (for approximately $30) at the pharmacy that would help you monitor lung health before symptoms occurred, would you purchase such a device?	Number	%
Yes	90	87.4
No	13	12.6
Total	103	100

A large majority (78.6%) of people believe that asthma devices should be available in front of the counter at the pharmacy (Table 8). Although they were not asked about the reasons, it is presumed that a presence in front of the counter would provide a better shopping experience for the customer.

Table 8. Member preferences for where devices which help with the management of asthma should be located

Devices used to help with asthma are often located behind the pharmacy counter. Would you like to be able to have access to these products in front of the counter?	Number	%
Yes	81	78.6
No	22	21.4
Total	103	100

4.2. Additional Themes on Access to Medications and Devices Emerging from Participant Comments

Relying on emergency rooms

Some NAPA members are turning to emergency rooms as a source of medication when they cannot afford it from the pharmacy. This dependence on emergency rooms is troubling not only because these patients must wait until their situation is critical before their receive medications, but also because the cost to the healthcare system is much greater when someone walks into the emergency room because they cannot afford medication which would be able to help them manage their asthma at home.

> *"When a parent could not afford to purchase an inhaler critical for the child's asthma and so the child ended up in the hospital on a consistent basis"*
>
> *"No money so went to Outpatients to get a freebie as I could not afford one for my son"*
>
> *"When the monthly funds have run out, my son has to go without or we head to the emergency room to get a sample - only way to access it"*

Asthma medications are not affordable without insurance

> *"Although we have a good private drug plan, the expense of asthma medication is very daunting and I often wonder how people without a good health plan can pay for these meds"*
>
> "*We patients need support from the government or from insurance plans because the medication is to expensive"*
>
> **"***Without a health plan, cost of so many medications could be difficult to manage good care. Might have to cut out or cut back. Could mean the difference of working or not working"*
>
> *"I could not afford an inhaler, as a result I had an asthma attack"*

In addition to the many stories about people mentioning how they are not able to afford their medications, even people who do have coverage recognize how expensive the medications are. They worry about how they would be able to manage their asthma if they were not provided with coverage through their public or private source. Those without coverage report not being able to control their asthma properly because they were unable to afford the cost of medications.

Private insurance does not always provide adequate coverage

Despite the fact that most people rely on private drug plans, there are sometimes restrictions on the medication coverage provided.

> "*Right now I would like to get a digital peak flow meter, but it is not covered by my health plan at work"*
>
> *"Was covered for the drug but not the aerochamber which is the only way to actually get the drug in a child my sons age"*

Many people who are looking for help with the related devices for asthma management are finding that those devices are not being covered. Additionally, the cost of having anti-

allergy medications or asthma friendly products around the home to help control their asthma is not covered by many private health insurance programs.

> *"Insurance only allowed one at a time on health plan. Left it at home. If I had one at work I would have been ok. Didn't, then had a panic attack"*
>
> *"* (I don't have) *Access and medical coverage for HEPA air purifiers, bedding, dust mite covers, vacuums and other appliances and supporting devices certified by the Asthma Society"*

There are more issues for people who are not in the workforce

While many people who are working have the advantage of an employer-sponsored health plan, these benefits are not available to students or people who suddenly find themselves on Employment Insurance.

> *"When on a sick leave due to an asthma exacerbation and had no income coming in I did not have enough money to pay full price for my asthma meds and then wait a month for my refund. Because I had private insurance through work I was not eligible for government assistance since I was not able to work"*
>
> *"In between jobs, without an employer-provided drug plan and on Employment Insurance, I would not have been able to afford the medication I needed"*
>
> *"When I was a student some of my medications were too expensive for me to afford. ($70 / month)"*
>
> *"She has lost her job and is on EI. It will become increasingly difficult for her to pay for her medication"*
>
> *"If I should leave my job I would not have the excellent drug plan"*

In the first quote noted in the sidebar, that particular health plan required up-front payment and then reimbursement, and when asthma caused the need for a sick leave, our NAPA member was unable to afford the up-front payment required because no income was coming in. Any up-front payment requirements are a considerable barrier for anybody who is not earning an income for whatever reason.

The fear of no private insurance when leaving a job can be a disincentive for people looking to make a career change, or to leave the workplace for lifestyle reasons such as starting a family.

Appeal process can be lengthy and ineffective

When medications are not available through public coverage, there are additional processes in which a physician can try to help a patient receive coverage by filling out additional forms. Those processes are burdensome and often lengthy, and do not always result in the additional coverage despite the doctor deeming the medication necessary.

> "*Must go appeal process to have meds covered that is unnecessary with other meds and still get turned down"*

Public funding does not provide adequate coverage

For those who do have public coverage, the abrupt removal of medications from a formulary can suddenly make some medications unaffordable. If medications are available over the counter, they are often unavailable for public coverage even though they may be recommended for proper disease management. Additionally, asthma devices such as chambers and peak flow meters may not be covered under public funding, even though they are also considered necessary for proper asthma management.

"*Due to cuts to the provincial drug plan I have been denied Singulair, after several years of funding"*

"*After all there is other over the counter monthly expenses I have to pay, such as irrigation and nasal rinses, antihistamines. Also, for five years I had to pay for my immunotherapy injections. I am not complaining, but all of these treatments are necessary, but yet costly"*

"*Spacer devices should be covered under our drug benefit program"*

Samples are not an adequate and long term solution for a chronic condition

Many NAPA members are finding ways to obtain medication samples. However, as the comments indicate, these are not long-term solutions to manage the condition. Those with asthma are wondering if the samples are truly the best medications for them, or if they were given simply because that's what was there at the time. Even if samples are working for an individual, they cannot be transported as easily because they are not individually labeled, which would also likely cause issues when medication is stored at schools.

"Supplementing with samples/compassionate supplies, only works some of the time, and usually not long term. Not an acceptable solution to such a common chronic condition"

"Obtained meds from Respirologist...samples...always wonder if they were given because of what he had available or because they were meds fitting my condition"

"It was a sample, thus without my name on it, and it got confiscated at the airport security check"

There is a lack of coverage on native reserves

Provincial health plans are not the only areas that need improvement. There is still an identified need to provide additional coverage for those who are living on a reserve.

"*Live on native reserve, most meds not covered"*

4.3. Access to Medications at School

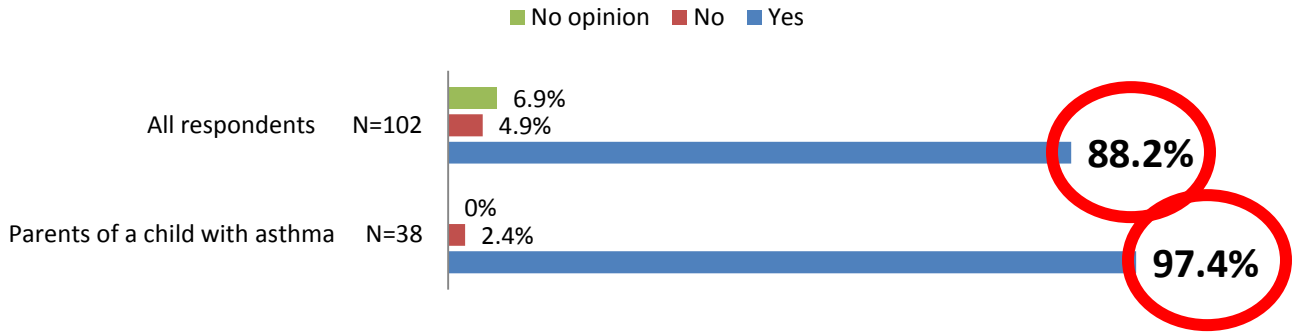
The NAPA Executive Committee identified this issue as the second highest priority. The basis for this priority was a perception of NAPA members that some children may be at risk due to school policies which do not allow children to carry their medication with them, especially when school board policies state medication must be locked in the office. It has also been noted that policies can vary significantly across different jurisdictions, and schools do not always adhere the policies outlined by their boards.

Children being able to carry medications while at school

The participants of the full survey were asked about whether children should be able to carry their medication with them at school. A subsequent question asked whether they were parents of a child with asthma, and answers of parents were filtered within this question (see Figure 12).

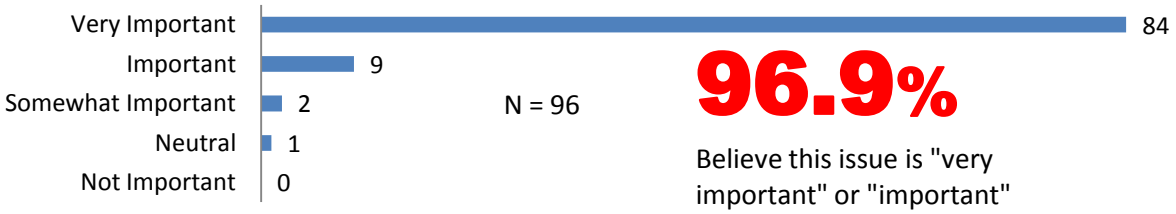
An overwhelming majority of NAPA members indicated that children should have the ability to carry medication with them at school, and this number was surpassed by the number of parents who felt the same way. Only one parent indicated 'no', that their child should not be able to carry medication with them. In a qualitative response box to that question, that parent indicated that their child was "*too young to understand that it was not a toy, and the child would empty it through play leaving it useless when he really needed it*." Based on this response, it is assumed the only dissenting parent is not opposed to the principle of students carrying their own medications, but expressed an opinion that the policy should be based on factors relating to the individual child.

Figure 12. Do you feel that children with asthma should have immediate access to their asthma medications at school (ie. be able to carry it on themselves)



NAPA members were also asked about the importance of immediate access to medications at school. Nearly 97% of responses indicated either "very important" or "important", indicating that members would prefer access to medications to be immediate, even if children are not carrying the medication themselves (Figure 13).

Figure 13. How important is it to you that children be able to have immediate access to their asthma medications at school? (full survey)



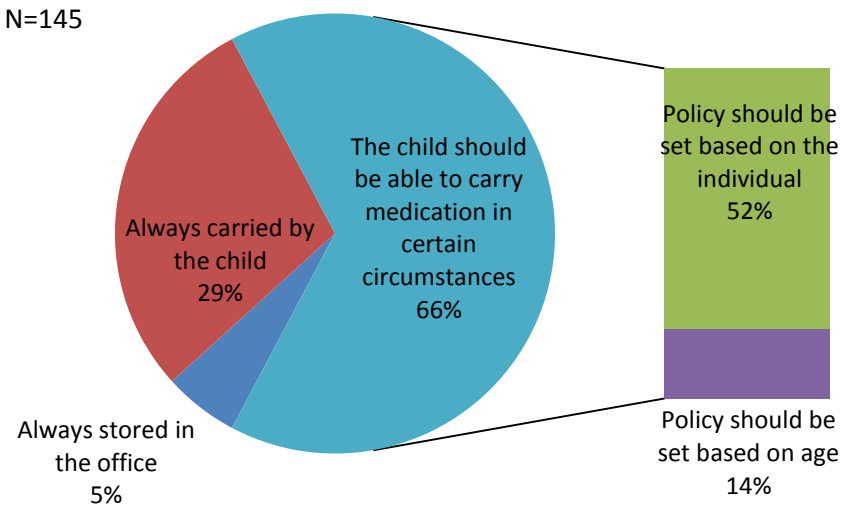
Both of these questions confirm that NAPA members believe access to medications at school is an issue of significance for our members.

Storage of asthma medications for a child while at school

The participants of the online quick polls were asked where a child's medication should be stored while they are at school (Figure 14). 5% indicated that it should always be stored in the school office, and 29% said that it should always be carried by the child. The majority, (66%) said that the child should be able to carry their own medication in certain circumstances, with 52% saying it should be based on the individual child, and 14% told us it should be based on their age or grade level.

Overall, 95% of responses indicate that there are times and circumstances in which it is right for children to carry their asthma medication themselves while at school. Based on this and the Asthma Society of Canada's knowledge of current policies, our website responses also confirm that this issue has significant support among people with asthma in Canada.

Figure 14. Which policy do you think is most appropriate regarding asthma medication in schools? (online polls)



95%
of respondents believe a capable child should have the right to carry their medication while at school

4.4. Additional Themes on Access to Medications at School Emerging from Participant Comments

We asked NAPA members if their children or others they know were not able to receive appropriate care at school. A few important themes emerged from this open-ended question:

Teacher Training

Based on the comments received, teachers need to be provided with asthma education and training to ensure they are able to keep children safe, especially children who are too young to understand what their symptoms might mean or how to ask for help.

> *"Until she is old enough it* [medication] *should be in the classroom with the teacher who should have some training on basic signs and symptoms of asthma and use of asthma medications"*
>
> *"Schools and Teachers need to be aware of how to identify children who are showing symptoms so they can alert the parents"*

Students Experience Stress when Asking for Help

> *"Teacher has always allowed my son to self administer but principal has now stopped him, he also suffers from anxiety which prevents him from asking for help and allows himself to get quite short of breath or covered in hives, then they call me to school. Has spent a night in hospital as a result."*
>
> *"My daughter does not want to go to the office to get her medication (she finds it stressful to go to the office and look for the vice principal). Also - it is hard to remember to pick up her medication at school at the end of each year. In many cases the school just throws it out."*

We know that stress in itself can be an asthma trigger for many people. Some answers from parents indicate that the fear or stress children feel from walking into a central office location for medication, or asking for a certain person can contribute to the exacerbation of asthma symptoms and quickly make a situation worse. If children were allowed to keep their medications with them, they would not have this additional worry placed on them.

Outside the Classroom

NAPA members pointed out that there are a number of situations where students are in the care of a school, but they are not necessarily in the classroom. These could include lunch, recess, field trips, and extra-curricular activities. When medication policies are not flexible enough to provide immediate care during these situations, asthma symptoms which would otherwise be treated quickly with reliever medication have the potential to become a larger problem.

> *"Having asthma flareup on the playground – ventolin locked up and no teachers available in school to provide puffer."*
>
> *"x-country running and ski practises or races students forgot them several times"*

Schools Need to Have Emergency Medications and Devices

"My son forgot his blue inhaler at home and the school did not have an emergency kit at that time. Now I make sure the school has both an extra inhaler and aerochamber just in case"

"If you have a child at school or daycare they should have a chamber to keep there. It does not make sense to carry back and forth since schools won't allow students to carry on them and the chambers need to be left with the medicine."

Asthma is such a common condition that it is quite likely there are multiple children in each school who might require the same reliever medication. Some members expressed the desire for schools to keep emergency medications and devices on hand for children in emergency situations, or because of the burden of carrying them back and forth each day.

Inconsistent Policies

Based on the comments, some schools do not have policies on access to medications which our members would perceive as good for their school or their child. In many of the situations that members would rate as poor, medication must be stored somewhere out of the classroom that does not allow for immediate access. Additional research into this topic has shown that there is a wide variation in Canada, and even within provinces, about where medication should or must be stored while at school. In many of the unfavourable cases, it is locked in a central office. In better situations, children are allowed to carry medication themselves, and it will be stored in an unlocked location within the classroom for children who are incapable of handling their own medication. When a child changes schools or teachers, inconsistency often causes confusion and could lead to the decreased availability of emergency assistance when symptoms appear.

"Our schools have always allowed the children to carry their asthma medication, Benadryl and epi-pens. If they didn't my children would not attend school. The teachers are not allowed to keep medication in their rooms for the children, however."

"Too many [asthma incidents] *to count…no deaths, but some very scary situations that were unnecessary."*

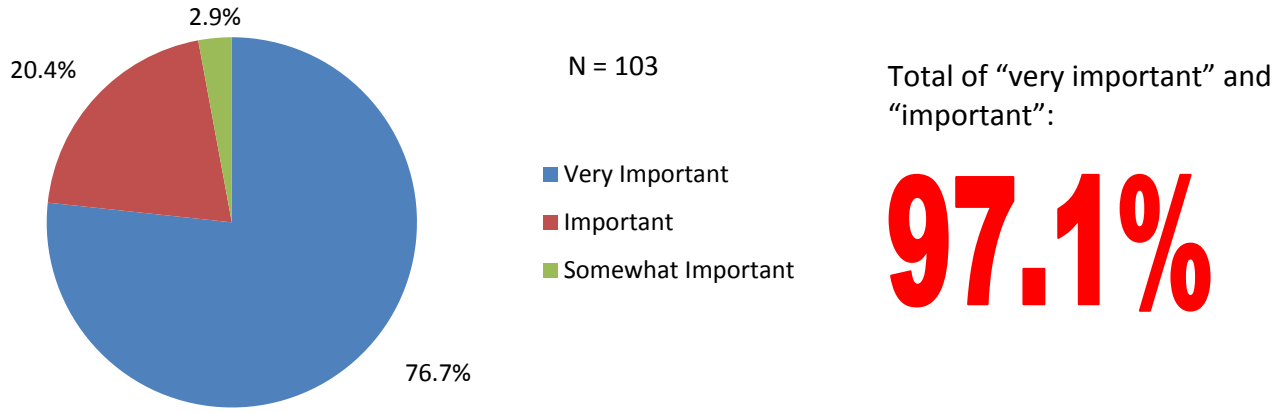
4.5. Access to Asthma Education and Disease Management Programs

The NAPA Executive Committee identified access to asthma education and disease management programs as the third priority issue. The expectation behind this issue is that many Canadians are looking for more asthma education and disease management information from health care professionals, but are either unaware of what their options are, or unable to access programs in their area.

The importance of asthma education

NAPA members were asked about the importance of asthma education and disease management programs being readily available in their area (Figure 15). Not a single person chose "neutral" or "not important", and 97.1% indicated support for "very important" or "important" on this topic. This result is a significant confirmation of the importance of this issue to NAPA members.

Figure 15. How important is it to have asthma education programs, including disease management, readily available in your area?



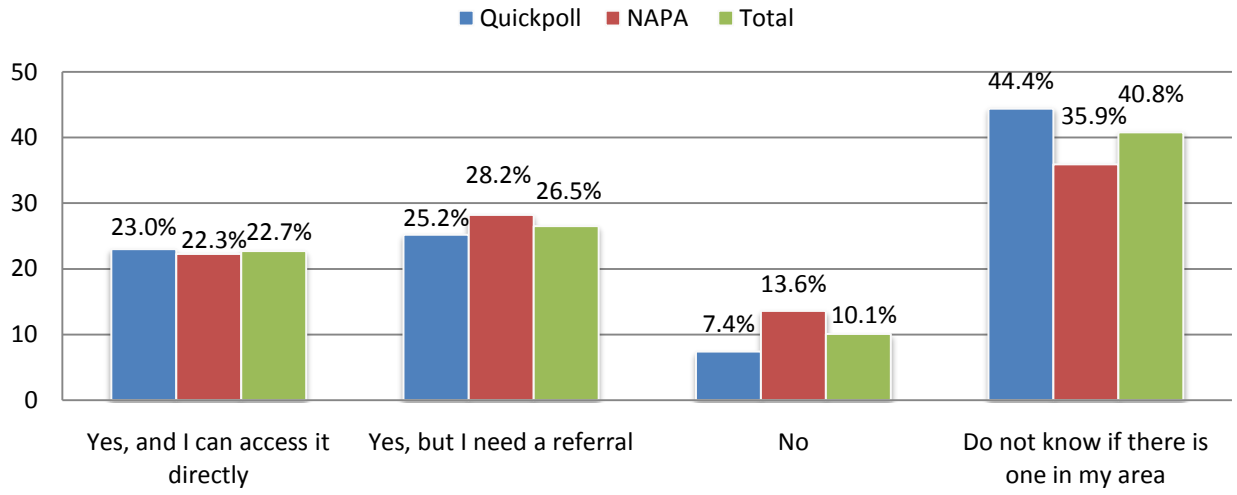
Asthma education centres in your area

All survey and quickpoll respondents were asked if they had access to an asthma clinic or asthma education centre in their area (Figure 16). Just under half (49.2%) were aware of a clinic in their area, and those were roughly split between clinics that could be accessed directly, and clinics that required a referral. A further 10% were confident that there was no clinic in their area. Over 40% of people were unaware if there was one in their area, which is a very high number, based on the level of importance the same respondents placed on asthma clinics.

The differences between NAPA members and quickpoll responses is found in the answers of "Do not know" about asthma clinic locations, and "No" there is not one in the area. NAPA members are more likely to report knowing that there is definitely not a clinic in the area, while quickpoll answers indicate a greater level of uncertainty. This indicates that our NAPA members are slightly more knowledgeable about the level of resources in their area than are quickpoll participants. In both cases, however, it is still a concern that only about half of the sample is aware of an asthma clinic or education centre in their area.

Figure 16. Do you have access to an asthma clinic or asthma education centre in your area?

Quickpoll N=135 NAPA N=103 Total N=238



*Numbers may not add to 100% due to rounding

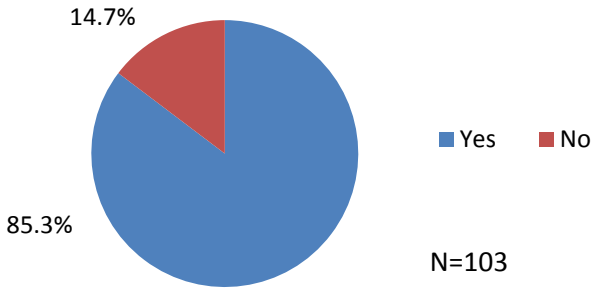
Access to primary care providers

We asked NAPA members if they have timely access to a family doctor (Figure 17), and a large majority, 85.3% of them, do. This is similar to the national average, where 84.9% of people have access to a regular medical doctor.[vi]

Of 15 respondents who don't have a doctor, 11 are parents of a child with asthma, indicating a higher risk factor may be present in their care due to a lack of regular access. However, of the 15 responses, almost half (40%, N=6) reported having access to an asthma clinic.

Survey results indicate a level of care among survey participants that is similar to the population at large, although there are still people with asthma, including children, who do not have access to either a family doctor or an asthma clinic.

Figure 17. Do you have timely access to a Family Doctor in your area?



Access to asthma information

NAPA members were asked if they have ever received information or education about asthma from at least once source (Table 9). 82.5% said they have received information, while 17.5% have not. No examples of potential sources were provided for this question, and thus some results in Figure 18 and subsequent questions may have been sources that respondents did not consider when answering this question.

100% of the people who answered 'No' indicated interest in receiving asthma education and materials, showing that those who have not yet received information have a desire to receive asthma education in some way.

Among those who answered 'Yes', the majority (78.6%, N=66) were satisfied with the information they received. 21.4% (N=18) were not satisfied, and N=1 declined to respond. This indicates that there are some unsatisfactory sources of information; even those who have received some information may be looking for the information which better suits their needs.

Table 9. The number of participants indicating they have received asthma education

Have you ever received information/education regarding asthma?	Number	%
Yes	85	82.5
No	18	17.5
Total	103	100

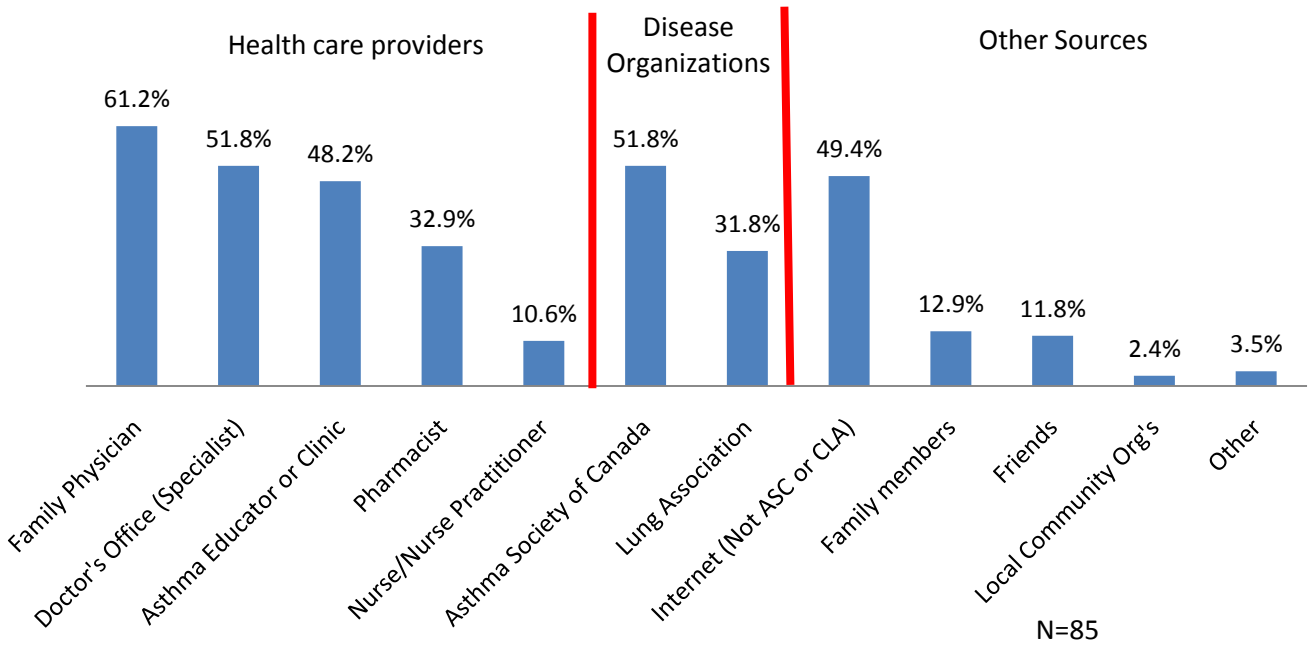
We asked NAPA members what sources they have used to receive asthma information. 12 choices were presented, beginning with five healthcare providers, two disease organizations, and five alternate sources. Multiple responses were allowed. Though they were not explicitly divided into categories when the question was asked, we have divided the categories to present the results in Figure 18, with each category's top responses shown in descending order.

The largest sources of information identified are: family physicians (61.2%) followed by specialists and the Asthma Society of Canada (51.8% each); and the Internet at large (49.4%).

One person reported receiving asthma information only from the last category. Four people reported receiving information only from the Asthma Society or the Lung Association. Of the participants who answered this question, a total of 8 people (9.4%) have received some information without receiving the advice from any of the health care providers listed on the left side of the graph.

The results indicate that overall, primary care physicians are playing the largest role in providing asthma education and information, though disease organizations are often playing a significant role as well. The Internet, as well as family and friends are still important information sources which do play some role in helping NAPA members manage their asthma.

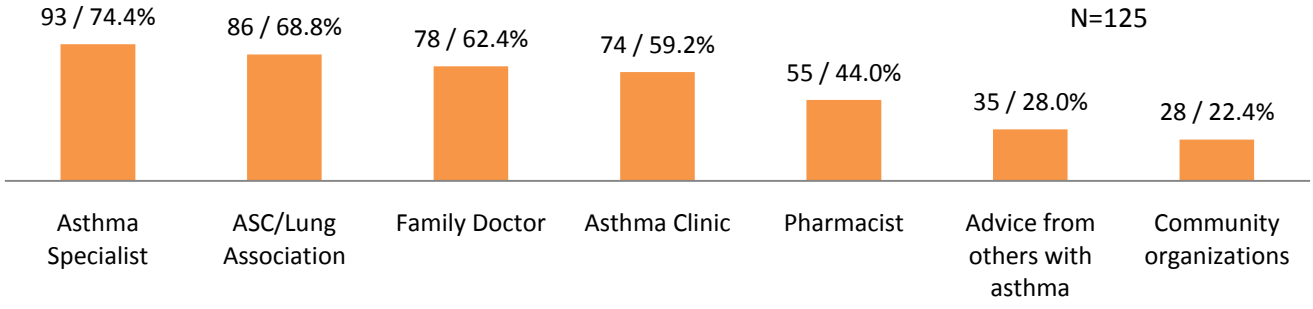
Figure 18. Where did you receive your asthma information?



In the website quickpoll, we asked users to indicate which sources of information were essential for people with asthma to receive, and multiple responses were allowed (Figure 19). The most popular source of essential information was an asthma specialist, followed by the Asthma Society or the Lung Association, a family doctor, and an asthma clinic. A pharmacist received less than 50% of responses, as did advice from others, and community organizations.

14 people chose all 7 sources of education as essential, while 9 people chose almost all (6) of the options. 33 people chose only one source as essential. These results show that most people believe it is essential to receive asthma education from more than one source, and asthma specialists have the trust and respect from the most number of participants. While second-last on the chart, advice from others with asthma garnered 28% support as an essential information source, which indicates the need for peer to peer support groups such as the Asthma Ambassadors program[vii] which was recently launched by the Asthma Society of Canada.

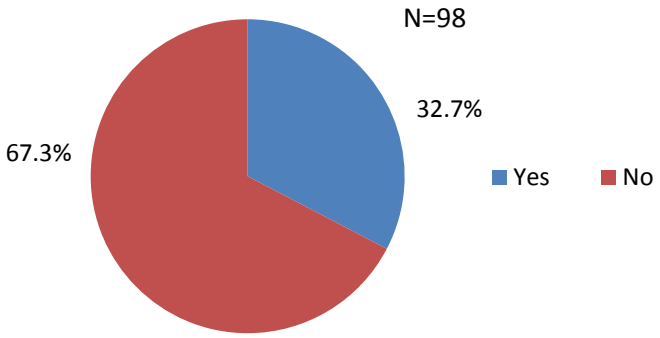
Figure 19. What sources of asthma education are <u>essential</u> for people with asthma to receive?



Pharmacy-based asthma education

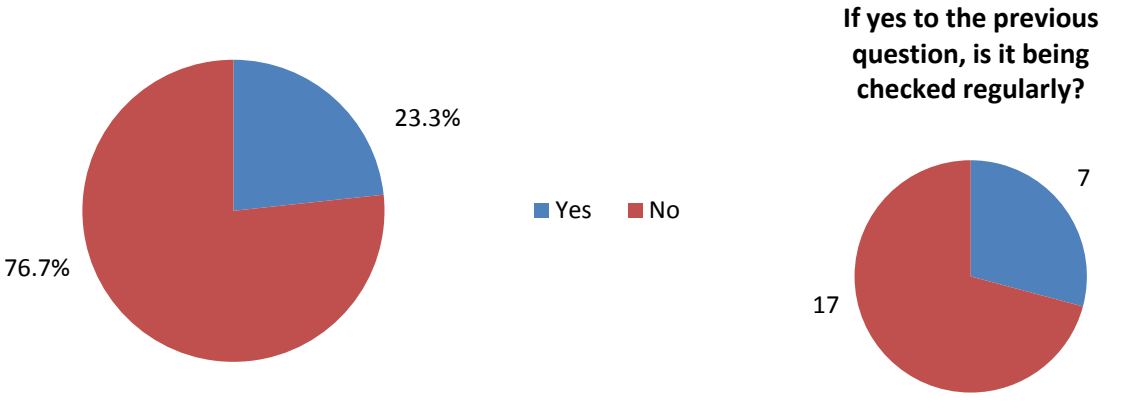
We asked NAPA members if their pharmacist has ever recommended the use of a chamber (Figure 20). 67.3% (N=66) reported that they have not had this discussion with their pharmacist. Of the 32.7% (N=32) people who did report that their pharmacist recommended the use of a chamber, 25 of them (78%) do use one, suggesting that a significant number of people are following the advice and making the purchase if they have been given a recommendation. Also among the 32 people who did receive a recommendation, 20 of them are parents of a child with asthma, representing 53% of all parents completing the survey. This suggests that pharmacists are recommending chambers for children about half the time, while providing recommendations for adults at a much lower rate.

Figure 20. When filling your prescription at the pharmacy, has your pharmacist ever recommended the use of a chamber?



We asked NAPA members if their pharmacist has ever checked their inhaler technique (Figure 21). Only 23.3% (N=24) reported that their technique has ever been checked, and only 6.8% (N=7) report that their technique is checked on a regular basis. This indicates that, according to NAPA member experiences, most pharmacists are simply dispensing the medication without ensuring that the patients understand the proper ways to use their medication.

Figure 21. Has your pharmacist ever checked your inhaler technique?



N= 103

N=24
Actual numbers presented

4.6. Additional Themes on Access to Asthma Education and Disease Management Programs Emerging from Participant Comments

Proper asthma management is critical and can be gained through asthma education

NAPA members have commented that they find substantial value in asthma education, or that they should be finding a significant benefit from the sources available to them. However, there are barriers preventing the fulfillment of a desired level of information, which include geography, the methods used to deliver education, and the source (including healthcare professionals who could be delivering more). Members commented that education during childhood is critical, and that pharmacies should play an extended role in teaching proper medication technique. A large number of comments indicated that people were eventually able to access information later in life after coming across education packaged in the proper format for them, but they wish that education and disease management programs would have been available to them earlier.

> *"I see many patients who have never received any education and are unaware of how best to manage their condition"*
>
> *"Asthma educators was best thing when I had my first serious bout with asthma"*
>
> *"Rural areas are at a real disadvantage for regular asthma education...our nearest is 1.5 hours away so many people i know go once and don't follow up"*
>
> *"There should however be more Educators and better training. Not a criticism of the Educator but of the process. She was excellent and I am eternally grateful. Most of my asthma-friend contacts had not heard of or used the services of an educator. ....wow!*
>
> *"Pharmacists should teach and observe patients inhaler technique with every prescription filled."*
>
> *"Much that I learned after 35 could have helped me have a better childhood/teenage"*

People are looking for alternative formats to the traditional education sources

> *"...my child with asthma could use more education specific to adolescents... but not from a parent!"*
>
> *"There are so many reliable online resources these days that most information can be obtained directly from the home."*
>
> *"It's very stressful to have a child who suffers with asthma. A support/education group for asthma, like LaLeche League for breastfeeding would be fantastic. It's helpful to talk to other parents who are experiencing similar events."*

While it is recognized that education is available from "traditional" sources such as doctors, pharmacists, specialists and clinics, NAPA members have indicated a need for additional education sources. Alternate formats (i.e., support groups) could be available for those who are unable to see a healthcare professional, or for those who are seeking support from others who are experiencing similar issues.

More support and knowledge towards asthma management is required from family physicians

Based on the comments we received, there is a considerable opinion that family physicians are not taking responsibility for the proper education and care of their patients with asthma. Even when patients have been proactive to find help in alternate formats such as an asthma action plan or a clinic, their doctors do not use the resources or follow-up with the patients as much as desired.

NAPA members also report feeling that family doctors do not have enough basic education about asthma to provide their patients with proper information. None suggested that their doctors provided the wrong information, but that the depth of knowledge was lacking for initial diagnosis and ongoing follow-ups. According to the feedback received, family physicians require more education about asthma to help treat patients before and after they are referred for specialist care.

"When I was diagnosed a couple of years ago, I felt my doctor was not giving me the time and attention required to educate me on my asthma. I suffered as a result."

"*None of this* (asthma education) *was done by my doctor. When I told my doctor that I went to the clinic and how much better I was feeling, and how much more confident I was feeling to partake in physical activities, my doctor was less than enthusiastic."*

"I wanted an asthma action plan because I felt my asthma was not controlled and I photocopied a template from the asthma.ca website and my doctor brushed it off and just told me to take more Symbicort if I felt it wasn't controlled."

"Although I was given a peak flow monitor when I first got asthma a few years ago by someone, I have never been asked about it or asked to show a chart by my doctor or nurse who I see regularly"

"I wish the asthma care was taken more seriously by family physicians. Sometimes it feels like there is too much trial and error in asthma treatment I receive and I don't feel I have a good personal management technique."

"*My former family doctor was not sufficiently equipped to give the proper education. I did research on my own"*

Support on asthma-related lifestyle issues is needed

"*I can learn the basics of asthma, but I do not hear much about improving or coping with asthma problems: i.e. finding housing without pets; finding a gym that TRULY bans scented products; flying on a plane (thank you Air Canada!), etc."*

"(More information is required) *on how important it is to exercise with asthma and have it controlled so you can especially for kids (lifestyle and participation)"*

"*Government should fund HEPA systems"*

NAPA members are finding it hard to access proper information about some of the lifestyle issues which are related to asthma, or about avoiding triggers. Even when information exists, it may not be practical, possible, or affordable to find a businesses or housing which accommodates the needs of someone with asthma. More specialty information about asthma-friendly locations and activities is necessary, such as information about travel and fitness programs.

Lack of asthma awareness in the general public

According to our membership, the regular population does not perceive asthma as a chronic disease which can be life threatening for some people. Based on the comments provided, these public misconceptions translate into influential citizens thinking that people with asthma may be pretending, or attempting to use excuses about asthma as a way out of tasks, and can result in disadvantages in the workplace and other settings.

"There is a lack of information regarding asthma for management regarding asthma. My boss doesn't seem to understand that I can be fine one day and be having severe asthma related reactions the next day."

"I wish that there was some way to make all people take asthma more seriously. I personally know people living with asthma who do not take it seriously and do not take their medication regularly. I also know people who do not have asthma who think that it is no big deal and do not understand me when I say that this is a life threatening disease"

Educating the public needs to be a priority

"The general public needs more information about asthmatics. People have all the wrong information and they often think that asthmatics are overreacting when they are having an attack."

"Many people who don't have asthma do not understand how dangerous it is. For instance when people smoke in or by the bus stop."

"Have more posters/ads throughout schools, medical offices, workplaces, and government buildings"

"Have more TV commercials showing the severity and amount of time someone can develop asthma or how fast someone can be affected by an asthma attack"

A number of NAPA members indicated that education for the general public is very important. Information could be produced which could help others understand the needs and the dangers relating to asthma, and reduce some of the stigmas and misconceptions associated with having this condition. This in turn would help the general public make daily decisions which could benefit those who do suffer from asthma.

4.7. Smoking-Related Questions

This survey included a short section of questions about smoking habits and second-hand smoke exposure (Table 10).

Table 10. Findings relating to smoking and second-hand smoke[viii]

Are you currently a:	Number	%
Smoker	3	2.9
Ex-smoker	25	24.5
Non-smoker	74	72.5
Total	102	100

The numbers in the first table do not add up to 100% due to rounding.

Are you aware of smoking cessation programs in your community? (asked only to smokers, ex-smokers, or people who skipped the first question)	Number	%
Yes	18	60.0
No	12	40.0
Total	30	100

A much lower proportion of this sample is a current smoker as compared to the general population (about 20%), however there a fair number of ex-smokers. Two of the current smokers report having asthma themselves.

Have you accessed smoking cessation programs in your community? (asked only to smokers, ex-smokers, or people who skipped the first question)	Number	%
Yes	3	10.3
No	26	89.7
Total	29	100

Of the current and former smokers, the majority (60%) indicate knowledge of smoking cessation programs, but very few have utilized them (10.3%). 23 smokers were able to quit without reportedly using the services of a smoking cessation program.

Are you exposed to second-hand smoke?	Number	%
Yes	20	20.2
No	79	79.8
Total	99	100

Is a child(ren) in your care exposed to second-hand smoke?	Number	%
Yes	4	5.9
No	63	92.6
Not Sure	1	1.5
Total	68	100

Most of our participants believe they are not subject to second-hand smoke exposure, but a fair number do still encounter second-hand smoke. Those with children are far more diligent about keeping their children away from second-hand smoke exposures, with only 4 parents reporting their children have been exposed to second-hand smoke.

4.8. Other Identified Issues

NAPA members were given a section at the end of the survey to identify any additional priority issues, and expand on any comments previously given. Comments which relate to survey topics were placed in the appropriate analysis sections, while additional topics are presented below.

More needs to be done about scent policies

Exposure to scents is a large concern for many people with asthma. While a growing number of locations are creating scent-free policies, very few of them are being enforced. Increasing numbers of consumer products are scented, which creates dangers in a number of environments for people with asthma.

> *"Greater usage of scent free environments by employers"*
>
> *"Why does there have to be so much scent added to products?"*
>
> *"Scent-free schools"*

Asthma testing should be more widely available

> *"Testing needs to be available to all patients with asthma in more locations"*

The issue of adequate testing for asthma is crucial for diagnosis and ongoing management. Although this survey did not ask members if they had been tested for their asthma, or monitored it on a regular basis, it is believed that a significant number of people with asthma have not had spirometry or lung function testing to help them analyze and understand if their condition is managed properly over time.

People who have asthma need legal protection

People with asthma are concerned about their rights, even if they have taken the proactive steps to let others know about their condition and what could cause exacerbations. In some cases, there are no legal protections for people who willingly or deliberately expose people with asthma and allergies to their triggers, and these exposures can have significant repercussions for people with asthma.

> *"We need legal protection for asthmatics who are exposed to allergens by people who know of their asthma and allergies"*

4.9. Findings on Low Income and Affordability

The sample of those people who reported a very low income is a small one, but the results are quite compelling (data is described below). All of them believe public funding of asthma medications is a high priority issue, and the majority of them consider public funding of asthma medications and devices to be an issue of personal concern. Only one third of these individuals receive full public funding for their medications. 40% of this low income sample who use inhalers, 55% of those who take pills, and all of those who require injections do not have any public funding for their medications.

Over half are reporting that the cost of their medications and devices are creating a barrier to their asthma management, which translates into an increased reliance on other, more expensive sources of asthma treatment such as emergency room visits and hospital admissions.

The comments received from our lowest income responses suggest greater affordability problems, including the reliance on emergency rooms, free samples, or going without medications. Related costs to asthma management such as nebules are necessary for some people, but supplies can sometimes be wasted due to short expiry periods, which is an incredibly inefficient use of money for someone who is already struggling to pay for the other necessities of life.

Household income under $20,000 N=15

- "How important is it to you that asthma medications and devices are accessible through public funding?"

  Very Important: 14 Important: 1 Other Responses: 0

- "Is this a personal issue for you?"

  Yes: 11 No: 3 Skipped Question: 1

- "Do you have coverage for your and/or your child's medication (inhalers and pills)?

  Inhalers: Yes: 9 No: 6
  Pills: Yes: 4 No: 5
  Injections: Yes: 0 No: 3

  Public, Full Coverage: 5 Public, Partial Coverage: 2

- "Is the cost of asthma medication or devices creating a barrier in being able to efficiently manage asthma for yourself, your child(ren), or another family member?"

  Yes: 8 No: 3 Do not know: 3 Skipped Question: 1

- "Do you have timely access to a Family Doctor in your area?"

  Yes: 11 No: 3 Skipped Question: 1

Sample comments:

"Under the AISH program the government decides what meds you can have not the doctor. If you disagree you have to appeal which could take months. Meanwhile, while you try and live without your meds you pay from your pension" (**Alberta**)

"Due to cuts to the provincial drug plan, I have been denied Singulair, after several years of funding" (**Ontario**)

"My family doctor has given me pharmaceutical samples for the times when I was unable to pay the Trillium deductible due to other expenses. My income is the CPP-D Pension." (**Ontario**)

"I now have to pay for nebules for my nebulizer. They are necessary because the nearest hospital is 17km away, I don't have a vehicle, and there is no public transit at night. The nebules only come in boxes of 20, and I don't always use all of the nebules before the expiry date. Being on disability, I can't afford to throw away money, but because of the reasons above, I can't be without reliable fresh nebules" (**British Columbia**)

"When the monthly funds have run out, my son has to go without or we head to the emergency room to get a freebie – only way to access it." (**Prince Edward Island**)

[Paraphrased from 2 comments] *My reliever medication expired and I didn't have money to buy one when I needed it* (**both from Ontario**)

"The doctor wanted to see me and I had run out of money. I couldn't get there without the use of medication. So I had nothing and ended up going to emergency." (**Saskatchewan**)

Section 5: Conclusions

The Asthma Society of Canada and the National Asthma Patient Alliance were able to gain very important insights into the collective perspective of the NAPA membership on a number of important issues related to asthma care in Canada. The sample included more than 100 NAPA member responses of the full survey, and a total of over 250 responses to questions about advocacy priorities posted on the NAPA website.

After the NAPA Executive Committee went through a process to identify three priority issues for people with asthma in Canada, those three priorities were confirmed by the membership through the results of this survey.

- On the topic of public funding for asthma medications and devices, 94.4% believed this issue was "very important" or "important", and 88.9% indicated that the government has a role to play in covering the cost of asthma medications and devices
- On the topic of access to medications in schools, 88.2% of respondents and 97.4% of parents said that children should be able to carry their asthma medication with them at school. The vast majority, 96.9% said that it was "very important" or "important" that children have immediate access to their medications at school, and 95% believed that school policies should allow a capable child to carry their medication with them.
- On the topic of access to asthma education and disease management, 97.1% believed that having access to programs in their area was "very important" or "important"

It is very indicative that the responses which highlighted a lack of coverage for medication and devices tend to come from the lower end of the economic spectrum. If someone does have coverage, it tends to cover all asthma medication they are taking, and may cover devices. If someone does not have coverage for one type of asthma medication, it is unlikely that they have coverage for any other asthma medications, and they will not have device coverage. None of the lowest income people without coverage are using asthma devices to help manage their condition.

The number of respondents reporting private coverage doubles the number reporting public coverage, and the number who have partial slightly outweighs those who have full coverage. Interestingly, those who report full coverage of their medications are still more likely to consider affordability as a barrier to the management of their asthma. This is a discrepancy that may need more understanding and is worth pursuing with future research.

The results also indicate that there is a knowledge gap concerning the benefits of peak flow meters, but when asked, respondents are interested in finding out more, and having access to these devices at the pharmacy counter. NAPA members are not receiving asthma education from their pharmacist, despite a pharmacist being the healthcare provider who they would typically interact with regularly. There is a need for programs, advice and recommendations at the pharmacy level; however it appears from these results that pharmacists may be recommending asthma devices predominantly for families where there are children with asthma, while adults are not receiving the education they need and/or desire. It is presumed that if more patients had pharmacy-based education interactions, more patients would begin ranking a pharmacist as an "essential" source of information.

NAPA members also introduced some very interesting observations related to the affordability and funding of medications. Of particular note is the reliance of many people on medication samples, and visiting emergency rooms to obtain their medication. For individuals who lack the ability to afford some asthma medications, this has led to increased emergency room visits and hospitalizations. It is astonishing to learn that some NAPA members have become reliant on trips to the emergency room for care and medication. While it would take great resources, more follow-up is necessary to study the unnecessary costs borne by hospitals treating patients who have the education and desire to manage their asthma properly at home, but are unable to do so purely because of their ability to afford asthma medications.

The comments received surrounding medications at schools confirm the belief that education and more consistency in policies is necessary in school settings. School policies can vary greatly surrounding access to asthma medication, and some schools have policies which forbid children from carrying their own medication, or keeping it in the classroom. In areas where a centralized storage location is necessary, this causes unnecessary problems when children are outside their regular classroom, either at recess, in activities, or on field trips. Parents, in particular, would like their child's teacher to have additional asthma training, and would like schools to have backup medications and devices on hand. The Asthma Society will be working over the next year to compile more information about this issue for parents, teachers and school administrators, and to identify some of the best practices relating to school medication policies in the country. It is our belief that provinces must legislate the right to medication access at schools across their province, which will help ease confusions and differences for parents and children. While we continue work surrounding school board policies, it is recommended that parents, voters, and school boards place more emphasis on ensuring that local practices reflect the needs of their students with asthma.

Survey results indicate that more needs to be done to inform people with asthma about asthma clinics or education centers in Canada. NAPA members are among the most engaged patients with asthma in the country, and if over 40% of our members "do not know" if there are education opportunities in their local area, this shows significant progress needs to be made. In all facets of asthma education, the number of people receiving help from their health professionals remains less than expected. Approximately 20% of participants have a family doctor but has not received any asthma education from their physician. A number of the comments received also indicate that the level of knowledge and care from their regular physician is substandard, and that there is little or no attention paid to the templates and knowledge provided by the Asthma Society of Canada and other disease organizations through education initiatives. These issues should be examined to determine what more can be done at the family physician level, and how physicians can appropriately inform people of local sources of additional care (i.e., asthma clinics) to ensure proper asthma management.

The participants identified a much greater need for education on asthma aimed at the general public. NAPA members still perceive a social stigma associated with asthma, or encounter those who are not willing to accommodate or modify behaviours based on the needs of someone with asthma. Even in places which purport to be asthma friendly, such as those which indicate a scent-free policy, those policies tend not to be enforced, and complaints are dismissed. In order to create a truly asthma-friendly world, there needs to be greater public education about asthma geared to the general population, and increased understanding of the challenges that many people with asthma face in their everyday lives.

Section 6: Tables and Figures

Table 1. Gender of Survey Participants

What is your Gender?	Number	%	Adult Canadian Population with Asthma%[ix]
Male	18	17.0	40.8
Female	88	83.0	59.2
Total	106	100	100

Table 2. Urban/Rural Split of Survey Participants

Where Do You Live?	Number	%
Urban	72	67.9
Rural	34	32.1
Total	106	100

Table 3. Provincial Breakdown of NAPA Survey Participants and NAPA Members

Please Specify your Province or Territory	Number	%	NAPA %*
British Columbia	16	15.1	14.5
Alberta	19	17.9	11.1
Saskatchewan	7	6.6	3.5
Manitoba	2	1.9	4.4
Ontario	48	43.5	52.1
Quebec	3	2.8	3.8
New Brunswick	3	2.8	3.1
Nova Scotia	2	1.9	5.3
Prince Edward Island	1	0.9	0.6
Newfoundland and Labrador	4	3.8	1.3
Yukon, NWT, Nunavut Territory	1	0.9	0.3
Total	106	100	100

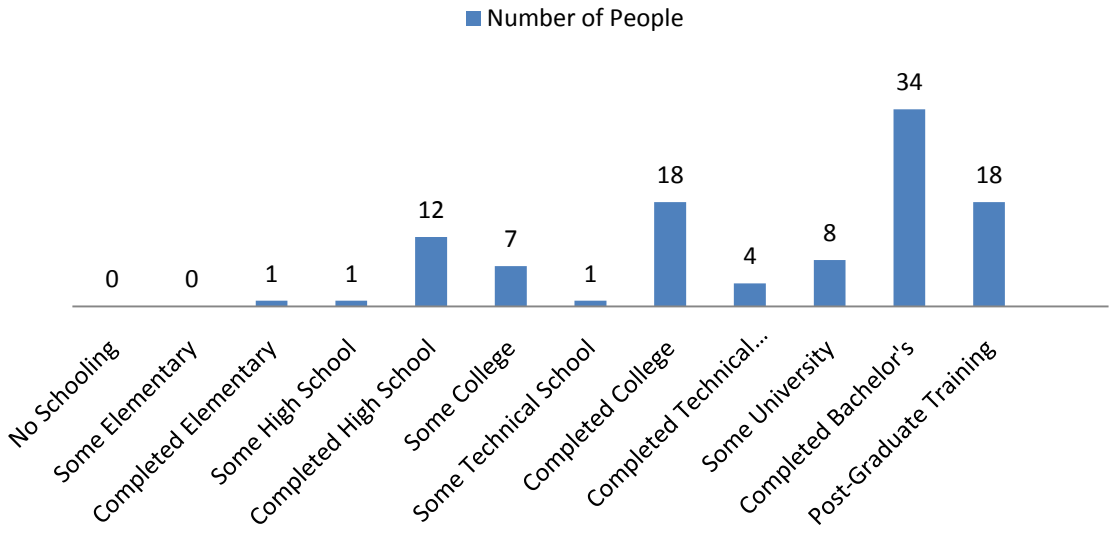
* Only NAPA members who have provided a Canadian mailing address form the population for this column. The percentages were compiled in late fall, 2010.

Table 4. Income Levels of Survey Participants

Self-reported Annual Household Income	Number	%
Less than $20,000	15	17.4
$20,000 - $35,000	11	12.8
$36,000 - $50,000	12	14.0
$51,000 - $70,000	11	12.8
Over $70,000	37	43.0
Total Responses	86	100
Do Not Know	3	
Declined to Respond	17	

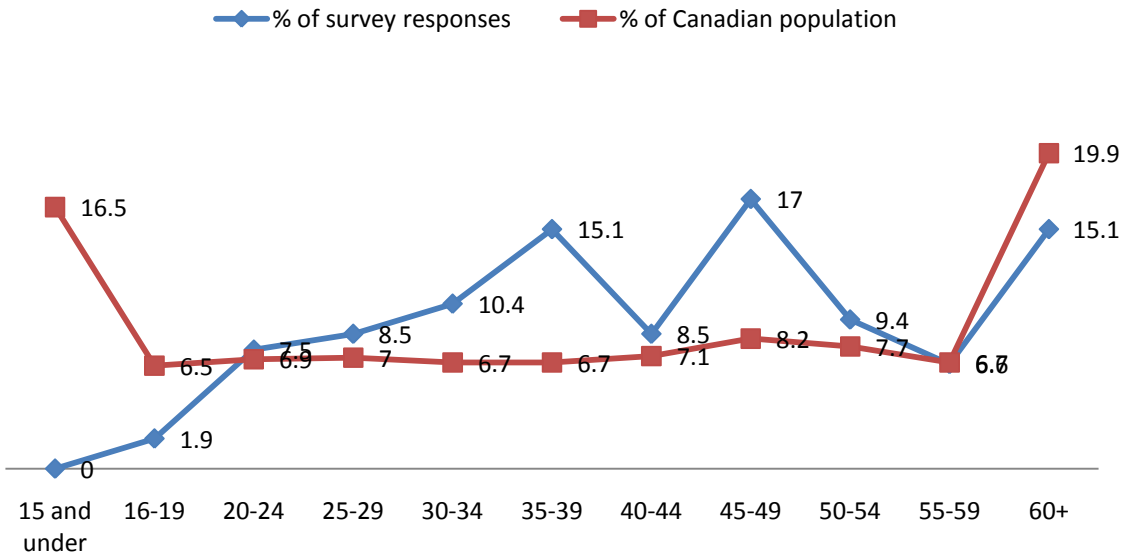
Canadian family median income: $68,860[x]

Figure 1. Self-reported Highest Level of Education Completed



N=104 answered this question
Median = Some University/Bachelor's Degree
Canadian Median = Apprenticeship or Trades Certificate or Diploma[xi]

Figure 2. Age of Survey Respondents



N=106 answered this question
National statistics from Statistics Canada[xii]

Section 7: References

[i] For more information about the National Asthma Patient Alliance, or to sign up as one of our members, please visit www.asthma.ca/napa.

[ii] A NAPAlert is an e-mail broadcast message sent out only to NAPA members, which relates to patient-based advocacy activities, breaking news alerts, and feedback requests from people with a connection to asthma.

[iii] Statistics Canada. Asthma, by sex, provinces and territories, as of July 1, 2010. Population aged 12+ http://www40.statcan.gc.ca/l01/cst01/health50a-eng.htm.

[iv] Statistics Canada. Population urban and rural, by province and territory. http://www40.statcan.gc.ca/l01/cst01/demo62a-eng.htm?sdi=rural.

[v] Statistics Canada. Median total income (all census families). http://www40.statcan.gc.ca/l01/cst01/famil108a-eng.htm?sdi=income.

[vi] Statistics Canada. Having a regular medical doctor, 2009. http://www.statcan.gc.ca/pub/82-625-x/2010002/article/11260-eng.htm.

[vii] Asthma Ambassadors is a peer-to-peer support and education program, where some NAPA members are provided with asthma education and physical materials. When they interact with anyone in their everyday life who would like some asthma information, they are ideally suited to providing materials as a follow-up. For more information on this program, please visit www.asthma.ca/ambassadors.

[viii] National figures on current smoking rates can be could through Statistics Canada at the following link: http://www12.statcan.gc.ca/health-sante/82-213/Op1.cfm?Lang=ENG&TABID=0&PROFILE_ID=0&PRCODE=01&IND=ASR&SX=TOTAL&change=no. About 20% of Canadians are current smokers.

[ix] Statistics Canada. Asthma, by sex, provinces and territories, as of July 1, 2010. Population aged 12+ http://www40.statcan.gc.ca/l01/cst01/health50a-eng.htm.

[x] Statistics Canada. Median total income (all census families). http://www40.statcan.gc.ca/l01/cst01/famil108a-eng.htm?sdi=income.

[xi] Statistics Canada. 2006 Census Educational Attainment. http://www12.statcan.ca/census-recensement/2006/dp-pd/hlt/97-560/pages/page.cfm?Lang=E&Geo=PR&Code=01&Table=1&Data=Count&Sex=1&StartRec=1&Sort=2&Display=Page.

[xii] Statistics Canada. Population by sex and age group, as of July 1, 2010. http://www40.statcan.gc.ca/l01/cst01/demo10a-eng.htm.