



IMPROVING THE JOURNEY FOR PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) IN ELGIN COUNTY

USING HUMAN-CENTRED DESIGN TO BUILD EMPATHY &
UNDERSTANDING

Description

Emerging Opportunities from Interviews, Journey Mapping and
other Experience Based Design Activities

BIG EYE
INNOVATION

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INTRODUCTION

Thank you for allowing Big Eye Innovation to be part of helping Elgin County’s Ontario Health Team (OHT) better understand the needs of community members who are living with Chronic Obstructive Pulmonary Disease (COPD). Having the time to speak one-on-one with people living with COPD, their caregivers, and various members of the health care system who support them was an interesting, enjoyable experience and I am grateful to all who participated for their open-minded approach and willingness to share their perspectives on the COPD journey—the positives, opportunities for improvement, insights and ideas. One thing that permeated every discussion I had was people’s commitment to using their own experiences to help build a better, more responsive, and effective health system for ALL of the people living in Elgin County.

A Note on Design Thinking

Big Eye Innovation uses the design thinking process **to** understand, create and deliver solutions to challenges faced by organizations and as a way to uncover opportunities for new ideas to flourish. Our vision is to be *a partner in transformation and purpose-driven innovation* and our mission is to try to *simplify complexities and create meaningful results through experience-based design*.

Fundamentally there is a strong overlap between **person/caregiver-centred design** and the steps within design thinking. Both begin by developing deep empathy for the people involved (and served) to gain greater clarity of challenges and opportunities. This understanding lays the foundation for **insights and opportunities we hope will inform changes and improvements Elgin OHT is committed to making to positively impact people in the community living with COPD, and the health of the community more broadly.**

The Design Thinking Process



The contents of this report focus on the first three steps of the design thinking process. The emphasis of this report is to highlight:

- What is most important to people in the community living with COPD.
- What they perceive to be working well and where there is room for positive change.
- How the current system and health care organizations/providers support them (and where there are gaps).
- The successes, struggles and insights health care providers see as supporting people with COPD and where they see “friction,” problems and gaps.
- Pivotal steps in the health care journey of people diagnosed with COPD and those moments identified as mattering most to them.
- Opportunities to better support people with COPD and priorities identified by “heat-mapping” (i.e. voting).
- Deeper thinking on two priority areas: COPD self-management and emotional support.

Roadmap Activities:

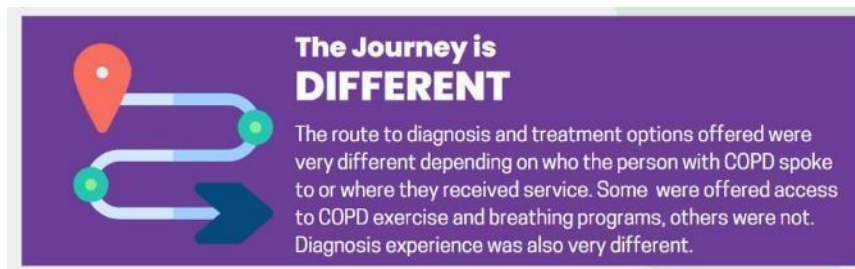
Below are the roadmap activities set forth as part of Elgin OHT’s engagement strategy. These activities, though separate, are meant to inform and validate the ongoing population health work being conducted at the subcommittee level.



KEY THEMES THAT EMERGED FROM INTERVIEWS:

Over the span of several weeks, **nine people living with COPD, one caregiver and six health care providers were interviewed** in depth about their experiences in relation to COPD. Though we created a menu of approximately 20 questions (including follow-ups) to provide some consistency, participants “steered” the conversation in any direction they saw fit-- to discuss observations, experiences and feelings that were most important to them. The results were quite varied in content, length and level of detail.

Despite the diversity of thought, perspective and experience, however, several key themes did emerge. We’ve done our best to summarize more than 70 pages of interview notes below but note--it’s by no means a complete list!



The Journey is a Personal (and Lonely) One:

From symptom presentation to approach (family doctor to Emergency Department physician) to treatment options presented, the journey of a person diagnosed is a highly personal one with many different variables.

Some interviewees did not present with “typical” symptoms. For example, Susan discussed her poor sleep and fatigue with her doctor for several years. This was written off as, “you’re getting older”, until a sleep study identified extremely low blood oxygen levels.

Other signs that prompted medical care included:

- A chronic cough that was hard to get control of (Cherie).
- Early signs of chronic bronchitis, prescribed Ventolin, but breathing got progressively worse (Paul).
- Trip to the emergency department with breathing difficulties (Claire, Karen).
- Feeling like something was stuck in the throat, had trouble breathing, went to emergency (Jacob).
- Coughing and shortness of breath resulted in family physician ordering pulmonary function test and x-rays (Ellinor).
- Feeling of being congested for several weeks—went to family doctor and had a breathing test with Nurse Practitioner (NP) (Mark).
- Visited family doctor and showed picture of “red stuff” he was coughing up (John). X-ray showed fungal mass.

Asthma as a Complicating Factor:

In three instances, people had been diagnosed with asthma earlier in life. This diagnosis seems to have interfered with a faster diagnosis of COPD. Another interviewee, not included in full in this summary, was diagnosed with COPD, only to have the diagnosis changed recently to asthma by a respirologist.

“I had gone to my doctor but was written off as a smoker with asthma. He noted that I had COPD but said it was essentially the ‘same thing.’”

--Karen

Jacob noted that at his first visit to the emergency department the friend he brought to translate for him (Jacob is part of the Low German-speaking community) was not allowed in. Because of this, he struggled to communicate with the doctor in broken English. When the doctor asked if he had “asthma” he replied “yes” but didn’t have the language capabilities to explain how the symptoms were different. From this the doctor concluded Jacob’s troubles were perhaps asthma-related, ‘gave him a needle’ (for what is still unclear) and sent him on his way without a proper diagnosis.

Other Co-Morbidities:

There were a number of other conditions identified (by interviewees with COPD and health care providers) as “typical.” These included:

- Heart issues and congestive heart failure
- Stroke
- Diabetes
- Anxiety
- Sleep apnea
- Peripheral vascular disease
- Malignancies (cancer)
- Liver disease
- Kidney disease
- Dementia
- Falls (not a health condition but noted as a problem in later stage COPD)

The Emotional Toll of COPD

Any chronic, progressive disease diagnosis can be challenging to accept. With COPD, though, we heard there is also an element of guilt, shame and denial that people with other conditions don’t necessarily experience. For both people with COPD and the health care providers that care for them, it’s a complicated journey; according to the [Canadian Lung Association](#), 80-90 per cent of COPD cases are caused by smoking. At the same time, we also know that cigarettes and nicotine are highly addictive: **“Inhaled smoke delivers nicotine to the brain within 20 seconds, which makes it very addictive—comparable to opioids, alcohol and cocaine”** notes the [Canadian Association for Mental Health \(CAMH\)](#).

“I have a hard time dealing with the fact that I have COPD. I should have known better, I watched my dad die from basically the same thing. I blame myself, it’s my fault.”

--Ellinor

It’s a difficult dance of where the more people feel “blamed and shamed,” anecdotally at least, the less they’re willing to speak with a medical professional about what’s happening to them. And while the medical community is aware of the fact that smoking is highly addictive, empathy is sometimes a challenge:

“I think those are the people (fearful of blame and shame) that they tend to avoid me or avoid coming in unless they're actually quite sick because they're embarrassed about the fact they continue to smoke. They're worried I'm going to scold them, which sometimes I do. I mean, I'm not. I'm not perfect. And so, there is that.”

--Family physician

Though it didn’t come through the interviews quite as strongly, conversations **around loneliness, an emotional heaviness and the stress of the unpredictable journey ahead**, were all discussed during the journey mapping activity and the online brainstorming session.

One Nurse Practitioner (though dealing mostly with palliative care) noted she was non-judgemental and more pragmatic in her advice to individuals, telling them that the more they smoke, the more likely they would be to have shortness of breath and exacerbations that might land them in hospital again.



Connections to Supports, Education and Exercise:

Recommendations for supports, access to programs and an understanding of what was available once diagnosed with COPD varied greatly from person to person. It’s difficult to assess how much timing of diagnosis (during the height of the pandemic or prior) influenced program offers. Some reported being left “totally on my own” (Paul); while others touted the physical and social benefits of being connected to other people with COPD—noting that this was a great way to learn more about the condition, how to safely gain strength and ability and how to better manage breathing during moments of exertion (e.g., climbing of the stairs).

“The COPD Clinic saved my life.”

--Susan

COPD “bootcamp” and other exercise programs on offer received rave reviews from all interviewees who joined, but there was also a sense of loss when the program(s) ended and support for their COPD felt “cut off.”

“They provided medical transportation or gave me money to go back and forth to the program. But when that was done you were all on your own—you didn’t have an exercise program. You didn’t have a card anymore and you didn’t have transportation. They won’t pay for you to go to the Y (MCA) because they don’t see it as a health thing.”

--Cherie

There was a quite a lot of inconsistency, however, about program offerings, awareness and availability that was also identified by health care providers as well.

“I can’t say that information (re: COPD programming) is communicated at all to physicians in the hospital...I think there’s an education gap there.”

--Emergency department physician

Several people noted that outside the offer of smoking cessation program referrals, they had never been offered the opportunity to be part of COPD programming.

Smoking cessation criteria, cost and availability were also not well understood and referrals to such programs were a question mark for some health care providers. One health care provider noted that they had referred someone to a smoking cessation program, but they weren’t accepted—the worker was unsure whether it was due to certain restrictions or just because there wasn’t room.

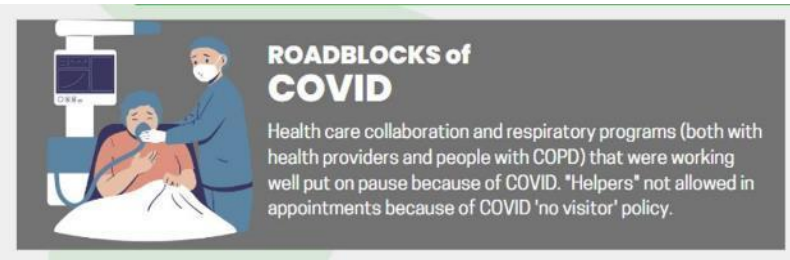
“...you basically hand people some information and you know you really should quit smoking and I’ll see you later—frankly I don’t think that comes close to being enough to really helping people.”

--Family physician

The cycle and frustrations around start-and-stop programming was also mentioned by more than one health care provider. In other words, the work is put in to develop a program, it gains traction and, by all accounts, works, only to end because there isn’t consistent and continued funding to keep it going. One example of this was a program that emerged out of a coroner’s inquest over an avoidable asthma death. The asthma care program was started up at St. Joseph’s Hospital in London and would visit St. Thomas’ Community Health Centre bi-weekly. The program evolved into a respiratory disease program.

“And then, like most programs, funding dries up after five years or whatever and we no longer have that (program).”

--Family physician



Covid Roadblocks:

And the Undoing of Effective Collaboration and Programming

Throughout the interviews there was a blurring of lines between successful programs that ended at a specific point in time due to funding, and other work that seemed to dissolve because of the pandemic's grip on the healthcare system. The Emergency Department physician interviewed spoke very highly of the [PREVENT Program](#) which was often applied to people admitted for COPD exacerbations.

"...a day or two prior to discharge (we would) create a patient-centered discharge plan ...We'd have a... teleconference essentially with the family doctor there'd be outreach community nurse through the homecare lens and if the patient was on oxygen, we'd have the home respiratory therapist involved as well, doing follow-ups...But the pandemic kind of put PREVENT on complete hold... because you couldn't have multiple people in the same room anymore." –ED Physician

A number of people with COPD also discussed not knowing what the current status of the programs they attended were. Of those who had never attended an exercise program, one felt an online version would suit her better—especially in the winter—because of travel and COVID concerns. Another interviewee talked about her avoidance of the hospital and other medical spaces because she has a mask exemption (too difficult to breathe with the mask on) and is not vaccinated.

Support Limited Due to Hospital Measures

Hospital restrictions meant caregivers and other support people couldn't enter the hospital with a person seeking care. For Jacob, a member of the low-German speaking community with limited English ability, this meant his friend who brought him to the hospital emergency department to translate, was turned away. This resulted in confusion, anxiety, frustration and ultimately left Jacob untreated for COPD because he wasn't able to communicate effectively with the physician he saw.

"I couldn't explain exactly what it was that bothered me and I couldn't understand exactly what she (physician) was telling me. It was very annoying to me since we both (Jacob's friend) had our vaccines which I thought was good enough to let someone in with me to help."

--Jacob

While other interviewees did not talk about this kind of experience, it's likely they're all fluent in English. And we can assume there are many other members of the Low German population, and

other people with language limitations, who experienced severe challenges because they were denied the support they needed to clearly express the details of their health problem(s).

The Ups and Downs of Virtual Care and Technology:

Though several providers lamented the technical challenges of trying to provide virtual care, a few people with COPD (and one caregiver) were pleasantly surprised by the phone calls (no one spoke directly of video care) they had with their family doctors. Virtual care seemed to increase people's access to their family doctor—92-year-old caregiver Eric noted he could send a message through a messaging system (Pompeo)—and get a response much more quickly than in the past. Of those who participated in virtual care, most felt it was an efficient and helpful supplement to in-person care. According to Ellinor, doctor's appointments by phone were much easier than travelling an hour for an in-person appointment. For Karen, virtual (phone) care was her biggest surprise:

"I didn't think I would like it but I'm really pleased with that (virtual visits). If I have a problem I can call. It's more timely, more convenient. This is better."

--Karen

Most health providers, however, suggested there were few options for individuals and caregivers to access their own information or to connect digitally with health care providers. One provider complained about the ease of access to information—even amongst other providers.

"To be honest, I couldn't even tell you what HPG is, but apparently, it's something they send our notes through. But the nurses have to physically look for them...and each one (nursing agency) has their own ways to connect with them."

--Nurse practitioner

When systems are broken or seen to be too complex/difficult, it's not surprising that workers find what they see to be simpler workarounds—including texting health care team members about the person receiving care without any identifying information contained in the message. People also ask to message with certain providers—e.g. Nurse Practitioners—and without another viable, simple options for communication, prefer texting to speaking over the phone, even if it means the conversation isn't "private" from a health care perspective ([PHIPA](#)).

"I won't talk to patients by text, but for many patients, especially with COPD, if we're speaking on the phone it is difficult because of their shortness of breath.

And so, there are times where they want to communicate with me by text and I say, 'you can text me but two things: when I'm not available, you're not going to get an answer, and you won't know whether I'm available and two; it's not private. And so, if you send me a message, it's like you're saying it to me in the middle of the Tim Horton's. And if you do that, I will, I will respond. And I'm taking it that you initiated that conversation. That's your consent for me to reply.' And I'm careful about what I reply...anybody can hear what you're saying to me. And, and most people... they're like, 'I don't care.'"

--Nurse practitioner



Timely Access to Non-Emergency Care

Surprisingly, every person with COPD we interviewed had a regular family physician. Oversight by a family doctor, however, didn't necessarily guarantee access when someone was experiencing an urgent health matter.

“I could never get in to see her (the family doctor) when I was sick...she was always overbooked. By the time I would be better right?...You don't need to see a doctor in three weeks or in a month, so I had to go to a walk-in clinic.”

--Cherie

Several of the service providers worried about people without regular family doctors . According to the emergency department physician, these individuals are caught in the urgent discharge clinic until they have a family doctor, so if they've visited the emergency department, there is a tie to follow-up care made.

There is still the concern though, that there are many people being missed because they're not being regularly followed by family physicians, and that these people typically end up in the emergency department.

Palliative Care—An Earlier Opportunity?

Full disclosure: because several of the health professionals were involved in providing palliative care to people with COPD, it's important to note they are looking at care through a very specific lens.

Though the general population often think of palliative care as “end of life” care, the definition of palliative care is much broader. [Health Canada defines palliative care](#) as “*a holistic approach that treats a person with a serious illness of any age, and in any setting. It involves a range of care providers and includes the person's unpaid caregivers.*”

Several health care providers noted that the more holistic approach to symptom management and follow-up would benefit individuals with COPD s earlier on in their journey, but that currently the stigma around palliative support means many people would resist the idea. Several conversations included thoughts about a “pre-palliative” program (without using the word palliative) that could rely on the same palliative team (currently not being used as fully as possible) to provide people in early stages of COPD with help, monitoring and advice for self-care.

A Healthy, Supportive Community:

Despite Covid 19's huge strain on the health care system, both people with COPD and service providers were overwhelmingly positive about the care they received in Elgin County, and care

received at St. Thomas Elgin General Hospital—even though we keep hearing reports of [community hospitals struggling to keep up](#) and having to close elsewhere.

The health care providers interviewed were undoubtedly passionate, caring, and committed to delivering better care and supporting people on their COPD journey. They were open about the challenges they face—in terms of resources, capabilities and personally—to achieve this.

Feeling Heard:

Health workers are human, however, most people seeking care—while noting many positive moments along their COPD journey—expressed opportunities for better collaboration and situations where they received less-than-ideal care.

Whether it was repeatedly going to the doctor about fatigue (Susan) and feeling written off; trying to communicate the complexity of symptoms in broken English without the support of a translator (Jacob); or lamenting to a family physician (Cherie) that the newly prescribed puffer isn't as effective only to be told by the physician that "it is," several people with COPD talked about frustrating situations. They felt unheard by health care providers even when they did their best to advocate for themselves.

“Over time you feel beaten up by the system...Some friends don't see doctors because they don't know how to speak up for themselves.”

People with COPD interviewed also found that constantly repeating their story to every health care provider along the way, wasn't just annoying, but exhausting.

Culture and Historical Legacies:

Two of the people with COPD interviewed are part of the Indigenous community. At a few key points in care, through the interview and journey mapping process, it was noted that though the care and relationships with health providers were positive overall on a personal level, **there continues to be an underlying mistrust of the system and motivations** behind health care provider suggestions.

Cherie's discussion with her respirologist—who decided to put her on the list to get a lung transplant—illustrates this. As Cherie describes it, she was taken aback by the suggestion (especially since the doctor had noted no change in her lung capacity), and the only explanation she was given for a transplant was that she was, “a good candidate.” Cherie also noted that the doctor never **asked her** if she was actually interested in a lung transplant or adequately explained to Cherie why she may want to consider the procedure.

“What do you mean? I'm a good candidate. Why? Because I said. I'm not dying till I'm 99, you know, like who the ** is a good candidate? I think that this is **** ...I said, you're going to have to find yourself a new candidate. I didn't say, you know all the cursing, all the cussing. I just told them I said, 'you're going to have to find a new candidate because I you know, that's the way I came into this world and that's the way I'm going out of this world. The Creator don't make no mistakes,' I said.**

...A lot of times I feel like the Guinea pig. They know it will be paid for and you know they can practice--just another Indian.”

Awareness, acknowledgement and a keener interest in the beliefs, practices and environment of individuals who are Indigenous may help to bridge this gap.

As part of the journey mapping activity, it was also noted that providers don't consider Indigenous holistic practices in relation to COPD practices and how they could be modified (e.g., boiling sage vapours instead of burning sage for smudging practices). The group talked about how this cultural responsiveness would help to build trust and confidence with providers. As noted in the discussion, there is still room for providers to have more meaningful dialogue with Indigenous people with COPD (and other ailments) to ensure a treatment plan that works for them. Along with that, there could be more education and resources given to providers to develop a deeper understanding of Indigenous perspectives, culture and needs.

Language:

As noted earlier, providing interpretation support so that people with COPD whose first language is not English can help greatly improve communication and understanding between health provider and the person with COPD and help to reduce confusion and anxiety.



Education and Tools for Self-Management

As both health care providers and people living with COPD noted, there are many tools and resources available to effectively manage COPD. There is a sense, however, that opportunities are being missed to educate and inform people diagnosed with COPD. Aside from being told to quit smoking and being referred to a smoking cessation program, several people weren't made aware of resources available to them to manage their COPD. As one health care provider noted,

“People leaving the hospital do not have a lot of understanding about what it means to them personally (to be diagnosed with COPD) what their life is going to look like, what can stay the same and what needs to change.”

--Rapid Response Nurse

Without guidance and support, some people with COPD took matters into their own hands, searching the internet for more detailed information and tools to support breathing. Karen, for example, has never been offered any COPD programming (beyond smoking cessation) by her doctor, so she invested in a breathing tool from Amazon which she finds helpful in “clearing out her lungs” every morning.

While a number of people spoke of COPD Bootcamp (run out of [London’s St. Joseph’s Hospital](#)), not a single health care provider or person with COPD mentioned resources available through the [Canadian Lung Association or other free self-management supports](#). This suggests that the challenge to better self-management isn’t a lack of resources, but rather a lack of awareness of many of the tools, programs and information that are available if you know where to look.

IN-PERSON JOURNEY MAPPING ACTIVITY

Journey mapping is a process that involves creating a visual “journey” of the experiences and interactions that an individual has with the health care system.

As an activity, it helps healthcare organizations and providers understand the needs of the people they serve, and find opportunities to improve the experience of the person navigating the system. The goal is to identify the “moments that matter” most to the person with COPD, uncover challenging interactions (i.e., “pain points”) that need improvement, and look for successes to amplify and/or find a way to make these consistent for every person. This can ultimately lead to better health outcomes and increased individual and health provider satisfaction.

We began drafting a journey map for a recipient of care after conducting 16 interviews—9 were with people diagnosed with COPD. This information—and the key themes that emerged—were used to name the different activities, thoughts and feelings of their COPD journey, including things like scanning the internet, talking to friends, scheduling appointments, receiving test results, and interacting with healthcare professionals.

For this activity, the journey stage headings we used were:

- Something is wrong
- Seeking support
- Diagnosis
- Life changes
- Living with COPD

We then created three personas—or fictional profiles based on real information collected during the interview process—of people diagnosed with COPD. The personas included:

- Cherie, an Indigenous woman and mother of two who lives on a Reserve
- Jacob, a member of the Low-German-speaking Mennonite community
- Susan, a Caucasian grandmother who lives in Elgin County

For full personas, please [see Appendix](#).

A journey map sheet was created for each persona and participant groups were assigned one persona each to work through. To give participants an easy starting point, and to help guide them through the exercise, prompts were included as examples in the first two sections of “Something is Wrong” and “Seeking Support”.

On March 28, 2023, a group of [11 people](#) came together to work on “filling in” the details of three different journey maps for people seeking care.

Group Makeup

Because we wanted people to feel more comfortable engaging in the activity and speaking openly with other participants, the 11 members were divided into three groups. Most participants with COPD were seated at a table where the persona profile most closely resembled their own journey—though this was not true for all. Health care providers were dispersed amongst the groups and included: a physician, a pharmacist, a Personal Support Worker (PSW) and a respirologist.



Goals and Objectives of Journey Mapping

While greater understanding of the journey for individuals with COPD was the over-arching goal—mapping various events, activities thoughts and feelings along the way—there were other benefits of organizing this kind of in-person activity we felt were important, including:

- **Bringing diverse perspectives together in one room.** Including individuals with COPD, caregivers and members of the health care community together provides a unique and important chance to build connections, empathy, understanding and trust among all participants of the health care system in Elgin.
- **Helping people to see, feel and understand the COPD journey a little differently** by assigning people “roles” they may not be used to. For example, a physician took on the role of “journalist,” spending a majority of the activity asking questions to the “lived experience expert,” (i.e., person with COPD), delving more deeply into what that person thinks, feels, does, and wants/needs at every step. These roles help to disrupt more traditional dynamics that can sometimes be present in a health care setting. Having the group assign roles also brought more structure to an activity that can sometimes feel a little ambiguous.
- **Reinforcing a person-centred approach to care.** The complexity of the health care system (and pressures to improve efficiencies, outcomes and other metrics) can send health care providers and administrators down a rabbit hole of frameworks, systems and management approaches that can distract from the fact **that a living, breathing, caring and feeling human is at the centre of everything we’re working to improve.** Meeting with people in a non-clinical setting helps break down professional barriers and **re-focuses health care providers and administrators squarely on the people they’re all working so hard to help and support.**
- **Identifying opportunities to enhance the journey of the person navigating the COPD journey.** Because we didn’t want people to feel pressured to find solutions to every

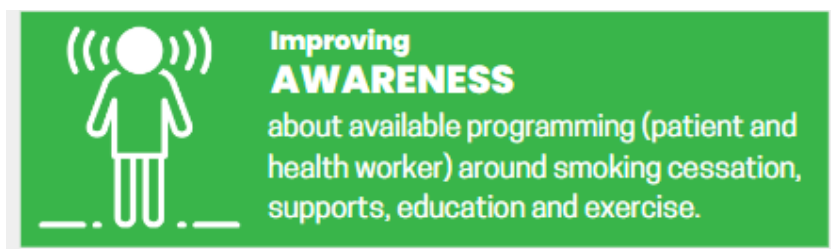
identified issue along the journey, the notion of an opportunity was left quite broad to include:

- Questions: *What if? Is there anything out there?* etc. questions spark curiosity and help frame the problem in a way that leaves the door open to potential solutions.
- Needs: Highlighting some of the unmet needs deemed important on the journey.
- Ideas: Allowing people (without pressuring them to do so) to jot down any ideas they felt could improve the journey.



Key Opportunities to Emerge from the Journey Mapping Exercise:

Below is a description of opportunities identified through the journey mapping process where the theme recurred in more than one persona group.



Both people with COPD and health care providers lamented the fact that they “don’t know what they don’t know.” A few members discussed programming they’d attended in London, while others knew little about available supports. One person with COPD noted that there needs to be a digital resource with legitimate “approved” information (the Canadian Lung Association would likely fit this bill yet is still woefully under-promoted).



People with COPD and health care providers both discussed the need for greater knowledge around managing their COPD and what to expect on the journey ahead. Better self-management could hold the key to fewer hospital admissions. As one rapid response nurse noted, “We do not invest in prevention and treatment at home,” and added, “it’s not sexy.”

Throughout journey mapping and interviews, several opportunities emerged to help people self-manage their condition better. Some of these suggestions included:

- The possibility of finding a way to allow people to leave the hospital earlier by providing them with short-term oxygen—something currently not available because there’s no funding to support it.
- Self-referral to smoking cessation and other COPD programming (right now, much of the programming requires a health care provider to refer).
- Providing education and review on effective puffer use—one NP talked about discovering people who were using puffers (for over a decade) were using them incorrectly.

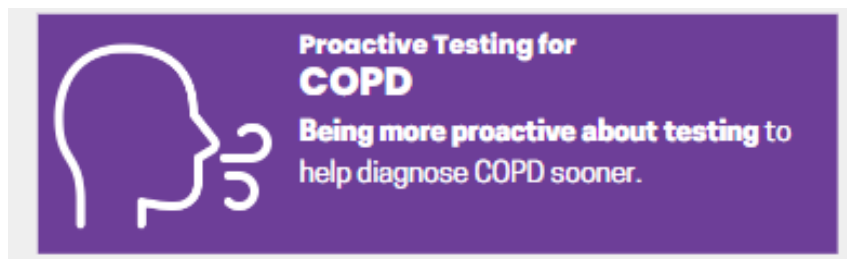
Though health care improvements often focus on streamlining processes and increasing efficiencies, it should be noted that education and knowledge transfer for individuals receiving care are areas where **repetition, clarification and reinforcement**—regardless of the health care provider delivering the messaging—are vital to successful self-management. In marketing, experts often refer to the “rule of seven,” or that, people need to hear a message seven times to fully process it and take action. Reinforcing key messages around self-management, puffer use, and breathing techniques throughout the journey is one area where repetition and over-messaging, though more time-consuming, may be more efficient and effective in the long run.

People with COPD—both in interview and in the journey mapping exercise—expressed a desire to learn more about better managing and dealing with their condition. As one participant noted, “information tends to come in drips,” and it’s really the “thousand little things” that can make a difference.



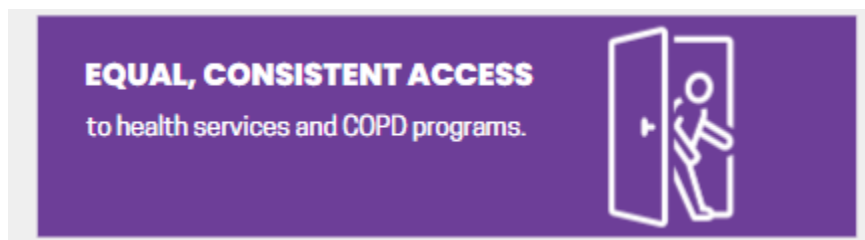
If a person doesn't have prescription medication benefits, the COPD journey can be an expensive one. As one physician noted, COPD can be a real challenge for the working poor: those that don't have benefits, don't receive funds from the Ontario Disability Support Program (ODSP), or aren't yet eligible for senior's medication coverage. They're sometimes forced to make the difficult decision between putting food on the table and spending several hundreds of dollars on puffers.

As one participant with COPD noted, the financial burden of expensive puffers puts added stress on him. In these situations, doctors noted they sometimes don't prescribe the most effective puffer, they prescribe the most cost-effective one. Smoking cessation program medications and patches can also be costly, though many people noted there are free products to be had for those in need (though awareness about these offerings wasn't consistent).



It seems that people deemed "high-risk" to develop COPD rarely do a spirometry test until they present with breathing issues. This seems to be a missed opportunity for both people with COPD and some health care providers to catch emerging breathing problems early.

As a member of the Best Care team noted, "If you have a history of smoking, you should probably have a breathing test." She also said that fears of shame, judgement and concerns about having to quit smoking often get in the way of earlier testing. "They're not going to tell the doctor they are having shortness of breath because they do not want to be judged and will not quit smoking. They are looking for more understanding and are shut down immediately."



Conversations around equity and consistency arose at all journey mapping tables—likely because the level of support, information provided and follow-up spans the spectrum from "you have COPD, here's a puffer," to regular, ongoing support and programming. The need for better supports for Indigenous populations and those whose first language is not English were also highlighted. Though the journey for each individual is highly personal, a standard path of care, follow-up, resources and program opportunities should be consistently offered.

Emotional SUPPORT

Peer and/or professional support to help cope, feel less lonely and encourage smoking cessation.



Both in the journey mapping activity discussions, and in interviews, a number of people noted the “loneliness” of diagnosis, often accompanied by fear, anxiety and a sense of shame/guilt due to smoking. Emotional support—be it from a mental health professional or a peer with COPD who understands the journey, to a “smoking quit buddy,” were all seen as important possibilities in helping people living with COPD cope.

Maintaining

CONNECTION TO SUPPORTS

when you don't have a family doctor, or maybe even a home.



How many people who aren't being followed by a family physician or clinic, or don't have a permanent home address are falling through the cracks? As an Emergency Department doctor noted, anyone considered an “orphan patient” is referred to an urgent discharge clinic, but waiting for people to get to a crisis situation is less than ideal. The fact that everyone who was interviewed has a family doctor is (likely) an unfortunate reflection that there's a group of people who are “disconnected” from the system and are harder to reach and support.



Reduce culture, language & gender BARRIERS

so that health teams build more trust and connection with people who have COPD.

Awareness around systemic barriers—be they cultural, social, language or related to gender—has increased significantly over the last decade. And while awareness is a positive step, it's just the first one. Addressing these roadblocks requires deep empathy, greater education around implicit bias and, as an article in the [New England Journal of Medicine notes](#):

“...examples of actions that clinicians can take immediately to manage the effects of implicit bias include practicing conscious, positive formal and informal role modeling; taking active-bystander training to learn how to address or interrupt microaggressions and other

harmful incidents; and undergoing training aimed at eliminating negative patient descriptions and stigmatizing words in chart notes and direct patient communications.”

Where Should Energy and Resources be Focused?

Not surprisingly, findings from interviews and journey mapping align well with the themes and focus of the population-based health managementwork. Though these began as two distinct streams of work, the commonalities suggests that collectively Elgin Ontario Health Team priorities are focused on what’s most important to the people it serves and the organizations that are there to support them.

Without doubt, ALL of the opportunities identified are important and need to be explored. But given time, resources and Elgin OHT’s desire to make strides early and often with people in Elgin who have COPD, we asked participants of both the in-person journey mapping and another virtual brainstorm to select what they deemed as the most important themes to begin with. The top two determined via survey were:

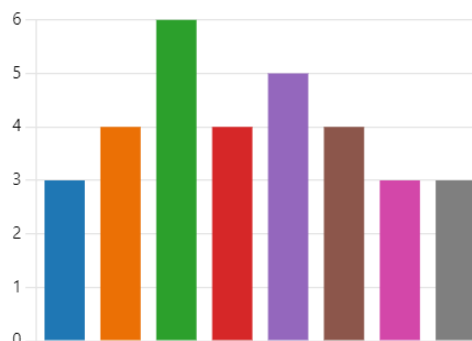
- **Empower people to manage their COPD better** on their own day-to-day through knowledge and support.
- **Improving awareness about available programming** (person seeking care and health worker) around smoking cessation, supports, education and exercise.

These priority themes are, in fact, quite interdependent and cursory research would suggest resources already exist that could support people to effectively manage their COPD day-to-day. The more challenging task is likely to find ways to help people learn about these resources upon diagnosis in a way that is **consistent, clear, addresses any barriers** and is effective in matching people with COPD with the kind of information, support and format they prefer.

1. Of the following themes, which ones do you feel are most important to start with in our work to improve the journey for people living with COPD?

[More Details](#)

- Being more proactive about t... 3
- Emotional support: Peer and/o... 4
- Empowering people to manag... 6
- Equal, consistent access to hea... 4
- Improving awareness about av... 5
- Maintaining connection to su... 4
- Reduce culture, language and ... 3
- Social supports (e.g., financial... 3



ONLINE BRAINSTORMING ACTIVITY: 10X10 LIBERATING STRUCTURE

A 10x10 liberating structure is a group process that facilitates collaboration, creativity, and insights, using a series of prompts to help generate new ideas, solving complex problems, and foster meaningful conversations among participants. While there was some conversation included in the activity, time limitations (90 minutes) meant that the discussion around results was not as fulsome as we would have liked. Still, the activity generated quite a bit of food for thought around the themes of **empowering people to manage their COPD** and providing them with **more opportunities for emotional support**. After completing the prompts, people were asked to vote on the top two to three answers they felt were most important or relevant. Below are some observations about the themes that emerged.

Providing More Opportunities for Emotional Supports:

When asked to fill in the prompt: ***Something a person with COPD might actually need is...*** the highest ranked response was “information about the trajectory of the illness.” Almost all other responses focused on the need for greater peer support from someone who had been there.

Something a person with COPD might NOT actually want is... “to feel judged” emerged as the highest ranked response, highlighting the theme of shame and judgement that permeated interviews as well. The next most voted on was “to be under-estimated” suggesting people with COPD don’t want to feel dismissed and are motivated to be partners in managing their condition. Finally, it’s worth noting the third-ranked item was “to be given only one option for support.” People want choice in the type, mode and kinds of help they receive and to feel empowered in finding what works best for them.

An uncertainty we must consider is... “lack of knowledge or understanding” ranked highest, suggesting there is a strong awareness of knowledge gaps for people living with COPD. “Availability of supports” was unsurprisingly second giving the fragile nature of the health care system at (hopefully) the tail end of the pandemic and the identified lack of awareness of services that do exist.

Before Elgin OHT makes its next move, it cannot neglect to... “talk more to community care providers” and “know all available resources to help support patients” ranked highest emphasizing the importance of community collaboration and deeper awareness of existing resources.

A big opportunity I see for Elgin OHT is... “Be timely in providing service when people need it instead of waiting for acute care to be activated” ranked highest followed by, “including mental health services in the care pathway.”

A courageous conversation we are NOT having is... “Goals of care conversation! COPD is a life limiting condition,” ranked highest, suggesting that both providers and people with COPD are aware of the “elephant in the room” (and perhaps want to have a frank discussion about it?). Second in rank was, “there are some people who might avoid this kind of support because of

stigma or "that's not for me, I don't need it," acknowledging that there are still social barriers to mental health/emotional support regardless of how potentially helpful it could be.

A bold idea I have been thinking about is... "Mental health/addictions services for all clients," ranked highest followed by a tie between, "Ambulatory (i.e., care outside the hospital) palliative care clinic for earlier intervention" and "peer outreach immediately after diagnosis."

A question that is emerging for me is... "Is there peer support that already exists that we currently aren't connecting people to?" ranked highest suggesting this is still an unknown followed in second by, "how might we change relationships between health professional and patients?" perhaps speaking to the desire for greater partnership and collaboration.

When all is said and done, I want the journey for someone living with COPD to be... "Empowering for the person" was most voted on, follow by a tie between, "Explained and supported on their terms," and "Feeling like health care providers know and honour who I am." While the statements are slightly different, they all speak to person-centred care that addresses the specific needs and preferences of the individual.

Empowering People to Manage Their COPD

The summary below relates to the liberating structure questions specifically around self-management and empowerment.

Something a person with COPD might actually need is... "To know what is available and how to access it" ranked highest, reinforcing the key theme of awareness as integral to improving the COPD journey. "Access to information and technology," placed second.

Something a person with COPD might NOT actually want is... "To think they're on their own" generated an overwhelming response voted on by all participants reinforcing the notion that "self-managed" should not ever leave anyone feeling alone and unsupported.

An uncertainty we must consider is... "Limitations of resources available (certain languages, certain times, certain access restrictions, no people to offer the services, financial barriers)" came out on top, highlighting the awareness of systemic challenges while, "how to get help when needed," ranked second, suggesting people with COPD need a clear understanding and path to supports.

Before Elgin OHT makes its next move, it cannot neglect to... "Reach out to health providers and offer information on services available within the community," ranked highest, again stressing the importance of awareness both for health providers and those receiving services. "Coordinate with South West Chronic disease management programs already in place," ranked second highlighting the desire to maximize the reach of existing programs through effective outreach and coordination versus 're-inventing the wheel.'

A big opportunity I see for Elgin OHT is... “Tapping into great expertise that exists in the community, both individuals with COPD and providers,” was voted highest, while “helping people get out of hospital earlier during an event with the right supports,” suggests an interest in examining opportunities to help people admitted to hospital get home safely, sooner.

A courageous conversation we are not having is... We need to “reach out and offer information regarding self-management, financial management for medications” ranked highest highlighting an appetite for a “point-person” to follow the person with COPD along their journey.

Something that needs to be researched is... “What has been successful/exists elsewhere that we can build on/adapt to Elgin,” was most voted on, suggesting that the focus be on small “i” innovations and process improvements customized to the unique needs of Elgin’s COPD population.

A bold idea(s) I have been thinking about is(are)...

“That as soon as someone is diagnosed, they are assigned a “care coach” to help them learn to self-manage,” ranked highest but, with only three options to choose from “Courses with team teaching e.g., nurse and peer” and “the opportunity to share successful stories and inspire hope,” were not far behind.

A question that is emerging for me is... “Will we adequately provide the information needed, often enough for people to self-manage well enough?” ranked highest, suggesting there is an awareness that self-managed care requires steady support and oversight to minimize risk and produce better outcomes.

When all is said and done, I want the journey for someone living with COPD to be...

“Empowered and feeling like they've managed their COPD better because of the knowledge they have,” was most agreed upon, summing up the overarching goal of this theme. Similar in sentiment and a close second were, “having a sense of control over their own journey,” and “well supported in the community on their terms.”

SUMMARY OF IDEAS TO EMERGE

Though the focus of this report is to gain deeper understanding of the challenges and successes of the COPD journey and the high-level opportunities identified from this work, many specific ideas did emerge from interviews and the activities people living with COPD, caregivers, and health care providers participated in.

What follows is a summary of these ideas we’d suggest a diverse, core team map out on an IMPACT/EFFORT matrix to help focus on starting point activities that offer the biggest impact, with a lower amount of effort. Narrowing in on these smaller, easier activities will help build

trust in the process, enthusiasm about the changes and ultimately momentum that will help drive larger journey improvement projects.

Ideas



NEXT STEPS:

This is a lot of information to take in—and there are still some ideas within this wealth of data that have yet to fully considered and evaluated. While to date, these activities have remained separate from other OHT work, sharing this report, and bringing more partners into the conversation about the research, considerations and opportunities to get moving on (knowing that some of this work is already underway) is a vital next step. Other potential activities to work on include:

- Creating an “ideal state” journey map for each persona profile that emphasizes “moments that matter”—especially as they relate to key priorities—using the information collected and identified priorities as a guide.
- Working a core team to map out ideas brought forth throughout this whole process on an [IMPACT/EFFORT matrix](#) to help decide on “quick win” activities (i.e. those with the highest impact and lowest effort) to help build moment and enthusiasm around changes within Elgin County. Despite being labelled as “quick wins,” any changes within a complex medical environment, will take a certain amount of thought, effort, discipline and buy-in to succeed.
- Combining the information uncovered here, with the work of other OHT stakeholders (including health care providers, people with COPD, community partners and caregivers) to create an action plan, beginning with the priorities of **building greater awareness**

around existing COPD programming for both health providers and people with COPD as well as providing support to help empower people to better manage their COPD.

- Designing small-scale tests of change, collecting feedback and adjusting/adapting/scrapping or scaling depending on results.

CONCLUSION:

From the conversations, research and activities that took place over the last month and a half what really shone through brightly was the optimistic and positive attitude of all involved.

A community isn't just made up of buildings and roads, but of people who care: who provide their time and energy to make the lives of others in the community better. Whether it's through sharing their own lived experiences or caring for and supporting residents living with chronic illnesses such as COPD, the members of Elgin County are clearly committed to making a difference by creating supports driven by the wants, needs and preferences of the people for whom they're designed.

Appendix A:

Persona: Susan Carter, Age 63



“I thought it was just insomnia that was making me tired. It turns out it was COPD.”

Susan was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) a year ago after complaining (for several years) about having trouble sleeping and general fatigue. Her low blood oxygen level was only flagged when she went for a sleep study. A spirometry test helped to confirm diagnosis of COPD.

Goals and Motivations:

- Being able to help my daughter with the grandkids.
- Continuing to work at my administrative job—I still have a few good years left, I enjoy it and am not ready to retire yet.
- To quit smoking for good.

Fears:

- I won't ever be able to quit smoking and that will make my lung function go down faster.
- My COPD will get worse and I'll need to go on oxygen.
- I'll run out of puffer medication, there will be a delay, and I won't be able to breathe.

Frustrations:

- I have to tell my story to EVERY new doctor or health care worker I see.
- Having my puffer prescriptions/renewals questioned by the pharmacist.
- I wasn't connected to COPD programs by my original family doctor—I lost important time!
- Getting in to see my family doctor can sometimes be hard.
- Information sometimes comes in “drips”. For example, I learned small things about how to use my puffer properly after the Nurse Practitioner showed me the problem of a titled inhaler which becomes useless/empty very quickly.
- Some of the information about COPD and managing it came through my own research online. For example, I found out about a breathing trainer tool on Amazon myself. That tool has been really helpful in exercising my lungs.

Tasks and Tactics:

- Even through Covid I have tried to exercise.
- Trying to quit smoking for good (I have cut way back).
- I stay on top of issues with breathing and connect with my family doctor if I get a chest cold I'm worried will become pneumonia.

Needs:

- Better co-ordination between my family doctor and the pharmacist.
- More information about what is available for people with COPD more quickly.
- Sharing of information between health workers so that I don't have to repeat my story every time I see someone new.
- To have complaints taken more seriously when I go to the doctor about changes to my health instead of being told, “you're getting older.”



Persona: Cherie Longman, Age 50

“Being diagnosed with COPD changed my life—it got me to quit smoking.”

Cherie, a mother of two, lives on reserve and was diagnosed with COPD a year ago after going to a walk-in clinic with a cough that wouldn't go away. Spirometer testing showed Cherie was at the mid stage of COPD. She was slowly able to wean herself off cigarettes and has been smoke-free for 6 months.

Goals and Motivations:

- Stay smoke-free for good.
- I want to stay as healthy as I can for as long as I can because I just became a grandmother.

Fears:

- My COPD will get worse, and my health will deteriorate.
- I saw my grandfather at the end stages of COPD and I'm worried that will be me someday.

Frustrations:

- I have to tell my story to EVERY new doctor or health care worker I see.
- Even though I have a family doctor, getting in to see that doctor takes weeks.
- The doctors make it seem like there is nothing to be done to heal from COPD, but I believe there are things you can do to keep a good quality of life.
- My positive attitude about COPD seems to encourage my lung doctor to “treat my like a guinea pig” and consider all kinds of things without much explanation and without asking me if I'm actually interested. The attitude feels like an institutionalized mindset—like I'm “just another Indian” to experiment on.
- One of my puffers seemed to work best for me, but then the doctor changed the prescription. I told my family doctor it's effective, but she ignores me and says, “it is” and won't change me back.

Tasks and Tactics:

- I quit smoking all on my own by slowly cutting back.
- I am familiar with using puffers as I've had asthma since I was a kid.
- I spent a lot of money to get the mold out of house to create a clean environment (without any support from the Band).

Needs:

- More Indigenous spaces—a healing centre with a stovetop to boil traditional healing medicines.
- More information about what is available for people with COPD more quickly.
- Sharing of information between health workers so that I don't have to repeat my story every time I see someone new.
- Funded programs to help me manage my COPD and stay fit ongoing—no one has given me any information about these....

Persona: Joseph Werner, Age 59



“I was tired and had a very dry throat. I felt like my throat was swollen and had a hard time getting air, and I started coughing.”

Joseph, a member of the Low-German Mennonite Community, was diagnosed about a year ago after initially seeking help from hospital emergency and then being referred back to a clinic. He has trouble communicating in English and relies on help from friends and Low-German-speaking health care workers.

Goals and Motivations:

- To cut back on my smoking because I sleep and feel better.
- I want to travel to Mexico to see some of my family there.

Fears:

- My COPD will get worse, and my health will deteriorate.
- That I won't be able to bring someone with me (because of COVID restrictions) to interpret when I need medical help.
- That I won't have enough money to pay for the things I need.

Frustrations:

- Because of the communication difficulties at the hospital, the first time I went they gave me a shot (I think for pain) but did not do a breathing test to diagnose me with COPD.
- Even though my support friend and I have been vaccinated for COVID-19, I am not able to bring that person with me to hospital visits consistently to help translate.
- Communicating in English is very difficult for me, the doctors and I don't fully understand each other.
- I don't have a regular family doctor to follow my care.
- Driving to St. Thomas is difficult to do. I don't drive so have to rely on a friend.
- Earlier testing would have meant an earlier diagnosis and less struggle for me with sleep and breathing.

Tasks and Tactics:

- I have cut back on my smoking and use the prescribed puffers—but I can't seem to quit.
- Someone at the CCHC gave me nicotine gums and patches to help me quit smoking—I learned about these services from a friend.
- I go to the CCHC which is much easier (they speak Low-German) and closer/more convenient.

Needs:

- Support to pay for medications—right now my family takes turns buying puffers.
- Low-German-speaking help to communicate better with the health community.
- Support on how to use puffers—I am not sure I am using them right.

Appendix B



Joseph Werner, Age 59

"I was tired and had a very dry throat. I had a hard time getting air, and I started

Scenario

Joseph, a member of the Low-German Mennonite Community, was diagnosed with Chronic Obstructive Pulmonary Disease (COPD).



Susan Carter, Age 63

"For years, I thought it was just insomnia that was making me tired. It turns out it was COPD."

Scenario

Susan was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) after several years of having trouble sleeping. Her oxygen level was only flagged when she went for a sleep study to confirm diagnosis of COPD.

