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Opportunities to improve asthma and COPD prevention and care: insights from the patient journey obtained through focus groups

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ABSTRACT

Background The healthcare experiences of patients hold valuable insights for improving the quality of services related to their well-being. We therefore invited and explored the perspectives of patients living with asthma and chronic obstructive pulmonary disease (COPD) on their interaction with the systems supporting health, in order to identify opportunities to improve services to prevent, treat and manage these conditions.

Methods Two virtual focus groups were held in August 2021, one for adult asthma and one for COPD, to learn of patients' experiences receiving care for these conditions in the Vancouver Coastal Health (VCH) region of British Columbia. Participants were recruited through online postings or their clinician. We discussed the care pathway for each condition and invited participants to share their experiences of the past 5 years, specifically their reflections on the process, including feelings, points of praise and frustration, and opportunities for improvement in this context. Composite patient journey maps were developed for each condition to reflect the experiences shared. Audio recordings of the focus groups were transcribed and used in qualitative data analysis.

Results Thematic analysis revealed the following as possible areas for improvement: low public awareness of asthma and COPD and associated risk factors, non-standardised diagnosis pathways that delay diagnosis, and inconsistency in delivering valued aspects of care such as supports for self-management, trust-inspiring acute care, empowering patient communication and timely access to care.

Conclusion We successfully used focus groups to generate composite journey maps of the experiences of patients living with asthma (n=8) and COPD (n=9) to identify features that these patients consider important for improving the healthcare system for asthma and COPD in VCH. Health professionals, decision makers and patient advocates in VCH and beyond can consider these insights when evaluating, and planning changes to, current practices and policies in service delivery.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The patient experience is a pillar of healthcare quality and should inform care improvement.

WHAT THIS STUDY ADDS

⇒ We share features of healthcare that patients with asthma and chronic obstructive pulmonary disease identify as important and describe a method to efficiently obtain such insights simultaneously from multiple patients.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Health professionals, decision makers, researchers and patient advocates can reflect on these features in their health settings and explore practices and policies to address them.

INTRODUCTION

Asthma and chronic obstructive pulmonary disease (COPD) are the two most common chronic respiratory conditions globally. Together they affect approximately 600 million people worldwide[1 2] including 5.6 million Canadians.[3] Uncontrolled asthma and COPD significantly reduce quality of life,[4] cause preventable deaths and create massive economic burdens for affected individuals, their families and the healthcare system.[4–7]

In British Columbia (BC), about one million people are living with asthma and COPD[8 9] and risk factors or triggers for these conditions are common.[10–12] Vancouver Coastal Health (VCH) is a publicly funded regional health authority that provides health services to about 25% of the BC population. Legacy for Airway Health (LAH) is embedded within the Vancouver Coastal Health Research Institute and has a mandate to generate and mobilise knowledge to prevent airway diseases and improve care for people living with these conditions within VCH and across BC.[13]

Health services are necessary to prevent and manage asthma and COPD. Patients are end users of health services and evidence shows that their involvement in decision making can increase the relevance, acceptability and effectiveness of health services.[14] Indeed, patient experience is a domain of health service quality.[15] Health service improvements can be achieved through co-design that is informed by patient experiences as well as requirements for performance, and safety and governance.[16]

Journey mapping is a user-centred design technique that originated in the business sector to understand customer experiences and needs, so as to design services of greater value.[17] Journey mapping is increasingly applied to elicit the patient experience when interacting with the health system[18] and reveal opportunities to improve health services.[19–23] Patient journey mapping is commonly done using individual interviews, making data collection overwhelming if multiple perspectives are desired.

We aimed to identify opportunities for improving the current system of prevention and care of asthma and COPD from the patient perspective. Our specific objectives were to: (1) Elicit and document, in an accessible format, patients' experiences of asthma and COPD care in VCH and (2) Analyse these experiences to generate insights for improving asthma and COPD prevention and care.

METHODS

Patient involvement

We used integrated knowledge translation to ensure relevant and implementable findings.[24 25] Our project team had a combination of knowledge users (patient partners, respirologists, decision makers, respiratory therapists (RTs), and patient engagement specialists) to provide multiple perspectives. Patient partners were members of the LAH Community Stakeholder Committee (CSC)[26] and were compensated according to the LAH policy on patient engagement for their contribution to the project. Patient partners contributed to the development of the project objectives, project design, participant recruitment, validation of the journey maps and dissemination. We report patient participation and the project using the Guidance for Reporting Involvement of Patients and the Public 2[27] and the Standards for Reporting Qualitative Research[28] checklists, respectively.

Study design

To design the project, researcher AC-F engaged patient partners in a group discussion about patient journey mapping, its applications and methodological approaches. Following this, patient partners were sent an email with a stepwise outline of the journey mapping methodology with guiding questions eliciting their input for decision on each step. Patient partner inputs were de-identified, collated and divergent ideas for each step included in the draft protocol outline as options for decision making. This draft was emailed to all project team members for input. A virtual meeting was held to reconcile and confirm, through discussion, the project objectives and design. Our interpretivist approach to learning of patient experiences used focus groups[29] for data collection to efficiently gain recent experiences (within the previous 5 years) across the care pathway, focusing on VCH which was the health region of interest. Our methodology had four stages: recruitment, prediscussion survey, focus group discussion with live graphic recording and validation.

Recruitment

Participant inclusion and exclusion criteria were designed to obtain patient experiences across the pathway of care and from individuals with different severity of conditions. The inclusion criteria were: being older than 18 years, residing in the VCH region, being diagnosed with COPD and/or asthma, and being able to complete a prefocus reflection. Exclusion criteria were: only having asthma care experiences, below age 18 years, moving to the VCH region within the past 5 years, inability to write or converse in English, and inability to participate in the virtual focus group. Our recruitment strategies included online posts via the Patient Voices Network[30] and the BC Lung Foundation Better Breathers[31] Facebook group, contacting LAH CSC members[26] and through clinicians within the LAH scientific team.[32] Researcher KR followed up with interested study participants by phone or email to assess eligibility and confirm availability. All focus group participants were offered a $75 gift card to acknowledge their time and input.

Prefocus group reflection and survey

Each participant was asked to complete an online patient reflection survey (University of British Columbia Qualtrics platform) 1 week prior to the focus group sessions. The survey, developed within the project team, encouraged participants to recall and reflect on relevant experiences in preparation for the focus groups. Survey responses were not intended for, nor used in, qualitative analyses.

Focus group discussion

We conducted the focus groups[29] virtually through Zoom due to COVID-19 pandemic protocols. We held separate focus groups to create distinct patient journey maps for asthma and COPD to capture disease-specific, care-specific and population-specific differences. Patients diagnosed with asthma-COPD overlap syndrome were invited to self-select between the two groups. One patient partner participated in a focus group. The 2-hour focus group discussions were held in August 2021.

The focus groups discussed care experiences across progressive stages of the care pathway: prediagnosis, diagnosis, management and exacerbation/severe illness[23] (table 1). We also captured patient perspectives on changes in care during the COVID-19 pandemic. Discussions were limited to care experiences within the past 5 years in order to reflect experiences relevant to current health services. KR moderated the focus groups with co-facilitation by the graphic recorder. A facilitator's guide (online supplemental table 1) based on the matrix

Table 1 Care pathway-patient experience matrix used to guide patient journey discussions

	Pre-diagnosis	Diagnosis	Chronic disease management	Exacerbation and severe illness	COVID-19
Process					
Feelings					
Praise points					
Pain points					
Opportunities					

framed the semistructured discussion which followed guiding questions for each stage such as: 'What was your overall experience with care during this stage?' or 'what worked well for you at this stage?'. Journey maps were created in real time during the focus group discussions to document experiences shared and were visible to all participants via Zoom screen share. The facilitator invited participants to review the graphic map and provide feedback midway and at the end of each focus group.

KR held one-on-one telephone discussions with three participants who were unable to participate in the Zoom session. Notes from these sessions were added to the composite journey maps by the graphic recorder.

After the focus group sessions, the graphic facilitator produced the two draft composite patient journey maps. The project team provided feedback for revision of the journey maps.

Validation of journey maps

The draft journey maps were shared with the participants for member checking and further revision. Participants had the opportunity to clarify or add information. The final draft of the patient journey maps included additional icons to indicate positive or negative experiences and improvement ideas. A summary report of the process and final journey maps were shared with participants, the LAH CSC and the BC Lung Foundation. The journey maps were presented as one data source at the LAH COPD and Asthma Care Summit, which enabled collaborative development of priorities to improve asthma and COPD care in VCH.[33]

Thematic qualitative data analysis

Audio recordings of the two focus groups were transcribed by a professional transcriptionist and used in explicit thematic analyses[22 29 34 35] of the asthma and COPD journeys to identify common patterns in patient experiences that highlight opportunities for improvement. Two researchers, AC-F and KR, independently conducted deductive level 1 coding of each transcript to identify challenges, assets and improvement ideas that patients described at each stage of health service. Extraneous experiences or information were excluded. The researchers cross-checked and reconciled codes through discussion to ensure consistency in coding of experiences or ideas. For each focus group, these level 1 codes were consolidated to level 2 codes reflecting similar or related ideas, renamed and reconciled between researchers. Researchers collaborated to inductively identify emerging themes from the level 2 codes of both focus groups, and iteratively refined them. Final themes were synthesised into a narrative description.

Ethics consideration

Research ethics approval was not required because this project was done to inform healthcare improvement. We completed the A pRoject Ethics Community Consensus Initiative screening tool[36] because of the potential of discussing sensitive personal, or health information. Participants received privacy guidelines and provided informed consent prior to the focus group sessions. We did not capture any video recording. No healthcare provider participated in the focus group discussions and LAH funders had no role in the project.

RESULTS

Description of participants

The asthma focus group had eight patients (three male and five female) who lived in the cities of Vancouver and North Vancouver. Their ages ranged from 37 years to 74 years and they self-rated their asthma as mild (n=3) or moderate (n=4).

The COPD focus group had nine patients (five male and four female) who lived in the cities of Vancouver and Richmond. Their ages ranged from 50 years to 77 years and they self-rated their condition as mild (n=1), moderate (n=4) or severe (n=4). Our recruitment was unsuccessful in rural communities.

Experiences along the asthma and COPD care pathway

Overview

Composite journey maps were generated to reflect patients' descriptions of their recent experiences with health services for asthma (figure 1) and COPD (figure 2) in urban areas of VCH. These patient experience journey maps depict perceptions, emotions, and needs of multiple patients as they interacted with a range of services and health service providers. Services accessed include: spirometry-confirmed diagnosis, referrals to respirologists and RTs from a family physician, pharmacotherapy, and maintenance services such as preventative education, allergy testing, pulmonary rehabilitation and emergency care.

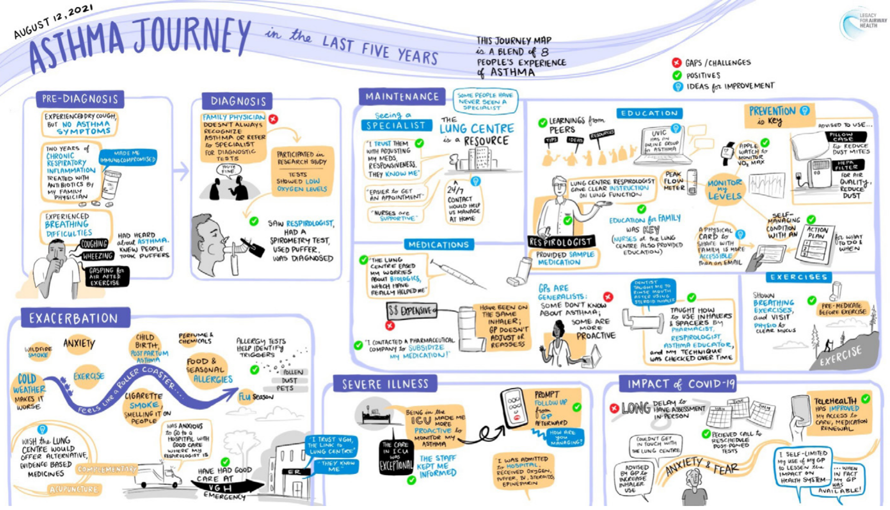

Figure 1 Composite journey map of the experiences of patients receiving care for asthma in urban communities of the Vancouver Coastal Health (VCH) region of British Columbia.

Prediagnosis

One patient with asthma experienced this stage in the last 5 years. They reported knowing little about asthma outside of the need for puffers and had no recognised risk for asthma. Three patients with COPD contributed experiences in this stage. Their knowledge of COPD varied from never having heard of the condition to knowing of it due to a personal contact being affected or genetic risk factor being identified in the family. COPD risk factors were identified retrospectively but were unknown prior to diagnosis and include: long-term smoking, secondhand smoke exposure, recurrent lung infections and occupational exposure to silica. Inadequate awareness of asthma and COPD is the main theme in prediagnosis.

> I've never heard about the word COPD before…and I was smoking cigarettes for 50 years.

Diagnosis

Diagnosis was described by the same patients who reported their prediagnosis experience. Non-standardised pathways that delay diagnosis and prolong distress emerged as the main theme. Diagnosis for COPD seemed to be a circuitous process occurring after multiple healthcare encounters to treat respiratory conditions such as recurrent lung infection, persistent coughing and difficulty breathing. These patients were referred to a respirologist after persistence of their illness, or sometimes a health crisis, and obtained spirometry testing that confirmed their asthma or COPD diagnosis.

> now I can see that when I got sick, I got really sick, so there was probably something,— had I not got that [pneumonia diagnosis], I don't know that I would have found out right away. Who knows what would have happened

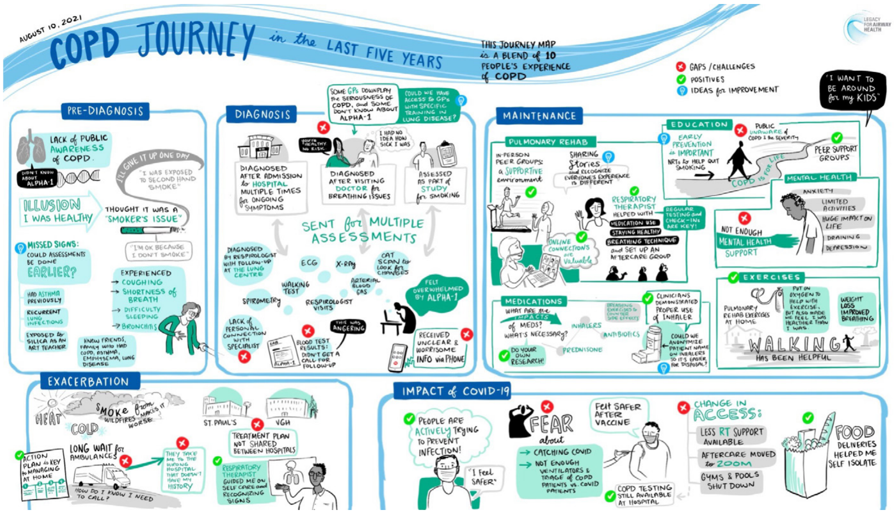

Figure 2 Composite journey map of the experiences of patients receiving care for COPD in urban communities of the Vancouver Coastal Health (VCH) region of British Columbia.

Patients had the perception that family physicians are unable to adequately recognise or diagnose asthma and COPD, suggesting that this is due in part to the belief that COPD is a 'smoker's issue' and limited awareness of the role of alpha-1 antitrypsin deficiency (a rare genetic disorder that increases susceptibility to COPD,[37] which was reported by two participants).

Chronic disease management

All participants shared their experience receiving chronic disease management. Discussions highlighted the variety of supports used for maintenance, and many aspects of care that patients valued but these were not universally received, indicating inconsistent quality or scope of care.

Primary care

There were descriptions of proactive family physicians who coordinated care, for example, with specialists, RTs and after discharge from hospital, as well as reports of others that did not.

> …my experience with some family doctors prior to the one that I have right now has not been great. I currently have an amazing family doctor and she is very well educated about many things, and more so my health. You know, so she's really gotten to know me, and I appreciate that. However, she's following a regimen that I received from a respirologist, which is working, and so she will keep me on track with that, and so I don't have to see the respirologist right now, who's actually quite busy, but my family doc is very much on top of my health right now, and she keeps things, up and going. She always asks me about my breathing, and she actually calls me on the phone, and if I sound like I'm losing breath for any reasons, so she will make comments about it and inquire.

Multiple participants expressed low trust in family physicians to amend their medication regimen, preferring that respirologists do this.

> …the only people that I allow to adjust my medications is the [specialist] because my GP and even the emergency department screwed them up so badly that I just have no trust in them, so I always go to the [specialist].

Specialty care

Participants expressed appreciation of integrated lung health centres where respirologists and respiratory educators (nurses, RTs) collaborate in their care. Participants were appreciative of preventative education provided by specialty care staff such as RTs and respirologists including inhaler education (also provided by pharmacists), use of action plans, identification of triggers, exercise advice and receiving allergy testing on referral by their respirologists.

> …when I finally got to see a respirologist, he gave me instructions on how to maintain myself. And prior to that, I had never received instructions. I really just received inhalers, and when this happens, take this inhaler, so it was really reactionary as opposed to preventative maintenance. And so having some instructions from a respirologist really helped me move forward.

Peer groups

Peer support groups were highly valued—descriptions of their benefits included providing a supportive environment that motivates exercise, improving mental health and increased knowledge for living with asthma and COPD.

> I joined a COPD group…we COPD patients learn tonnes of stuff off each other…whatever they've gone through, we pass on the information…it's been very, very enlightening.

Mental healthcare

The heavy mental and emotional toll of living with COPD was described and current mental health support for COPD was viewed as insufficient.

> (On living with COPD)…it drains you and it depresses you
>
> (On whether adequate mental health support is provided for COPD) No, I don't think so

Health and medication literacy

Participants desired more resources (information and tools) to improve self-management. They described applying the guidance that they received from public health advisories, including using[1] high efficiency particulate air filters during wildfire smoke and[2] self-management knowledge they learnt from clinicians including exercising, avoiding allergens confirmed by allergy testing and referring to their action plans to manage exacerbations before they require medical attention. One patient stated the desire to 'be around' for their kids as a motivating factor for self-managing and other patients endorsed this.

Participants described wanting to know how a medication works, its benefits and the side effects prior to taking it. Multiple participants described seeking information online to improve their understanding of medication effects and learning about unpleasant medication side effects from peer support groups.

> I try to stay on top of all my medications. When they give me something new, I ask what it is, I ask what it's going to contraindicate with because I'm on so many different medications.

Exacerbations and severe illness

All patients with asthma and three patients with COPD shared their experiences with exacerbations. Collectively, participants identified well-known triggers including allergies, chemicals, wildfire smoke, cigarette smoke and viruses as agents that worsened their condition.

Multiple participants shared that hospitals differ in the quality of care provided and the availability of resources. This was a source of anxiety during exacerbations as they were uncertain of which hospital they would be taken to by paramedics. Participants preferred receiving care for exacerbations at hospitals where they had prior care relationships (eg, specialist care) due to the availability of their treatment plan to healthcare providers at those hospitals (but not to healthcare providers at other hospitals). Additionally one hospital was identified in both focus groups to provide excellent care for exacerbations. Three experiences of emergency care for severe exacerbation at this hospital described prompt triage and presentation to a doctor, receiving a familiar treatment process that is effective, and having improvements in their condition monitored and communicated, as additional reasons for identifying that hospital as providing excellent care. The availability of acute care services that patients trust was the main emergent theme.

> I fought with the paramedics to take me to [desired hospital] because I knew that's where my respirologist was and that's where I'd been receiving the proper care, and I was paranoid about the hospital that they were taking me to because [it], doesn't have the services that [desired hospital] has, and I was skeptical, which added to my anxiety and my stress.

Recurrent themes

For both asthma and COPD discussions, patients described experiences where they appreciated the communication they received from their healthcare provider or desired communication that more adequately addressed their need to understand their condition or treatment. Empowering patient-centred communication recurred in discussion of services throughout the care pathway.

> (On why the care at a specific hospital was exceptional) Well, I had one-to-one nursing, but they were actually communicating to me and saying, 'Yeah, we're doing okay, the Ventolin's working. You're coming out of the hole.' That kind of reinforcement was actually very important to me, and knowing that I was going in the right direction.

Participants described having timely access to services or the desire to have had more timely access to services across the care continuum to relieve their distress.

> …what's nice about the [specialist], except [during] COVID, is if I have a problem, like, I can usually access somebody rather quickly there, you know, within at least three or four days, and that's been really important.

The main emerging themes (box 1) reflect opportunities for health system improvement and are common to both focus groups except for the need for mental health support which was strongly described in the COPD but not the asthma focus group.

Box 1 Summary of major themes emerging from journey mapping focus groups among patients with asthma and chronic obstructive pulmonary disease (COPD) in the Vancouver Coastal Health region of British Columbia. Themes indicate opportunities for improving the system of health services for these conditions.

Prediagnosis
Low public awareness of asthma and COPD and their risk factors hinders prevention and symptom investigation.
Diagnosis
Unstandardised diagnosis pathway (attributed to inadequate knowledge of asthma and COPD in primary care) delays diagnosis and prolongs distress.
Chronic disease management
Inconsistent supports create challenges for self-management. Valued but inconsistent supports were:
⇒ Proactive coordinated care
⇒ Preventative specialty care
⇒ Mental healthcare
⇒ Accessible peer support
⇒ High health and medication literacy.
Exacerbation and severe illness
Trust-inspiring acute care reduces anxiety and stress.
Recurrent themes
Patient-centred communication empowers patients.
Timely access to services minimises distress.

DISCUSSION

Our journey mapping exercise generated insights from patient experiences with health services in the pathway of care in urban VCH communities for improving asthma and COPD care. The experiences validate that patients view features such as awareness of asthma and COPD risk factors, defined care pathways (for diagnosis in this case), proactive coordinated care, mental healthcare, peer support groups, patient-centred communication, and timely access to services as important. These align with professional expertise on features of quality of care within[38] and outside BC.[15] These patient-identified features should be considered alongside performance (eg, clinical effectiveness, care guidelines) and safety requirements[16] to improve healthcare quality. Patient experiences are context-specific but opportunities for improvement that are identified in VCH urban areas can be assessed elsewhere to confirm patient needs in other geographical and chronic disease contexts. The patient-identified areas for improvement could inform health professionals who serve different roles on possible areas to target to achieve better care delivery and strengthen patient advocates in their work for improved quality of care.

The opportunities for improvement identified from these patient experiences are consistent with standards for asthma and COPD prevention and care.[39 40] They align with professional expertise and reiterate issues that challenge care for these conditions outside of BC. Worldwide, there is a need to increase awareness of asthma and COPD as priority chronic respiratory diseases,[41–43] increase prevention through mitigation of risk factors, address challenges with asthma and

COPD diagnosis,[44 45] and better leverage integrated care for effective maintenance.[39 40] The features that patients affirmed as valuable could be replicated across VCH for more consistent delivery of quality care and promote equitable health outcomes. Knowledge exchange and closer collaboration across sites and levels of care could support sharing of existing expertise available within the system to address key issues.

- Specialty care could help develop primary care capacity to recognise patients who should be tested for asthma and COPD, and increase awareness of COPD risk factors other than smoking.[37 46 47]
- Streamlined diagnostic pathways could incorporate routine screening for earlier identification of patients who need spirometry confirmation,[48] strengthen coordination among the multiple healthcare professionals who patients encounter prediagnosis, link candidates to guideline-recommended diagnostic testing, and provide more support for patients and their families at diagnosis.
- Primary care networks, which are being implemented in BC to transform primary care and improve system capacity to care for complex chronic conditions, could include specialised team members such as respiratory educators to provide integrated care and address challenges across the care pathway including consistent provision of self-management support which is vital to chronic disease management.

Recognising the small number of focus groups conducted, we shared the composite journey maps with a larger group of patients with asthma and COPD from the LAH CSC.[26] They confirmed that the maps are engaging and reinforced the salience of issues and themes discussed. These journey maps could similarly be used to promote dialogue with patients outside of VCH urban areas to determine whether similar patient needs exist. Patient journey maps are reported to enhance healthcare professionals' ability to empathise with patient challenges[22] and could motivate behavioural changes among providers.

The focus groups had a positive group dynamic and participants shared openly. Our methodology provided efficiency in capturing and analysing patient experiences while promoting participant interaction to enrich dialogue about the range of experiences. This is an advantage of the focus group methodology.[29] This focus group-based composite journey mapping approach is promising for use in enabling patient involvement in healthcare decision making.

Patient partners contributed to the appropriateness of the study design and procedures used. For example, they confirmed that experiences obtained in the last 5 years would likely reflect the current system of care, shared focus-group flyers in their networks and led discussion of the final journey maps with CSC members for knowledge translation.

Limitations

We generated composite journey maps rather than maps from a singular experience across the care pathway to enable consolidation of multiple experiences for each stage of care. This composite approach precluded us from identifying specific equity determinants that are associated with the divergent experiences. Various biases could impact these findings including participation bias considering our exclusion criteria. Recall bias could have impacted the details shared about experiences occurring from up to 5 years prior. Hindsight bias could introduce differences in patients' current perception of the care they experienced and their perception of care at the time. Inherent to focus groups is the influence of dominant voices and the group steering the focus of the discussion. These might determine which experiences participants share or the intensity of the impact of experiences described. Our insights were obtained from a small proportion of patients with asthma and COPD in VCH. They are a reference for obtaining further patient perspectives on improvement opportunities throughout VCH since the region is diverse in terms of patient demographics and resources available in urban and rural communities, and patient needs may vary based on health equity determinants, comorbidities and life stages.

CONCLUSION

The patient experiences we obtained using group-based composite journey mapping highlight multiple challenges along the pathway of care for asthma and COPD in VCH, including inconsistent provision of supports for self-management which is vital to the management of chronic diseases like COPD. These insights can inform evaluation of current practices and policies and help formulate changes to deliver better quality healthcare.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants. Research ethics approval was not required because this project was done to inform healthcare improvement. We completed the A pRoject Ethics Community Consensus Initiative (ARECCI) screening tool (36) because of the potential of discussing sensitive personal or health

information. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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