20 SENSE

THE 20SENSE REPORT

Spotlight on the Canadian Specialty Pharmaceutical Market

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Issue 25

Health Equity *In* Specialty Medicine

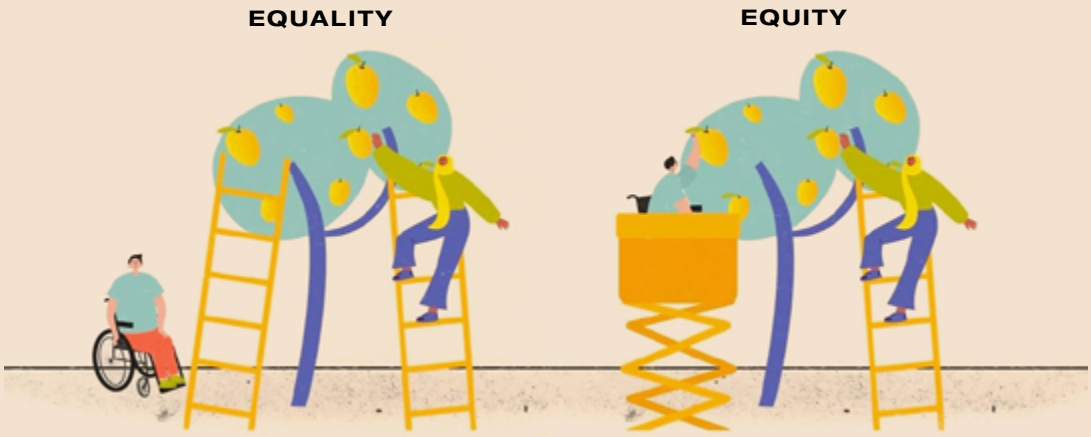
Facts and figures bring health equity into focus

Levelling the access playing field for specialty medications

ACE's Cheryl Koehn and Kelly Lendvoy on equity and access

By the *Numbers*

Scientific breakthroughs are fuelling life-changing new treatments, but without health equity we can't call it a true victory. Before we get to the facts and figures, here are some definitions to bring the big picture concepts into focus.



Health equity

Health equity occurs when each individual has the opportunity to reach their fullest health potential.[1] In practice, this means reducing unnecessary, unjust, and avoidable differences in access to healthcare.

Health inequity

The flip side of health equity, health inequity refers to systemic differences in the health status and distribution of resources among different populations.[2] Arising from the social conditions in which people are born and live, these inequities can be reduced with equity-oriented policies and initiatives from governments, academia and industry. Health inequities may also play out across diseases – for example, when certain diseases receive disproportionately low funding.[3]

Equity vs. equality

Equity means fairness, which does not mean giving everyone the same thing – but rather giving individuals and groups what they need to level the playing field.[4] Translated to the healthcare realm, it means removing systemic differences in access so that no population group experiences extra barriers to health.

By the Numbers

ON THE WORLD STAGE AND IN CANADA

79.7%

Proportion of Caucasian enrollees in US clinical trials reporting ethnic distribution over the 2000-2020 time span,[5] exceeding the estimated percentage of Caucasians (72.4%) in the US population.

86%

Proportion of Caucasian enrollees in combined US/ Canadian clinical trials for cancer drugs between 2010 and 2016,[6] once again exceeding the 72.4% population benchmark.

> 450

Ethnic or cultural origins reported in the 2021 Canadian census.[7]

22%

Percentage of Canada's population reported to be born abroad in the 2016 Canadian census.[8] As of 2010, Canada had the highest proportion of immigrants among G8 countries, ahead of Germany (13%) and the US (12.9%).[8]

INEQUITIES IN HEALTH

100+

The number of public prescription drug plans in Canada, along with the country's 100,000+ private plans.[9] This means that a resident in one province may not have access to the same medications as someone living in the province next door – or may face higher copays or bureaucratic hurdles to gain access[4]

20%

Proportion of Canadians living in rural communities.[10] For Indigenous peoples, the figure rises to 50%.[11] This requires people to travel long distances for care – which takes time and money – and can have a detrimental affect on health and quality of life.[12]

80%

Proportion of Indigenous Peoples in Canada who will develop type 2 diabetes in their lifetime.[13] The condition has reached epidemic levels in some communities, with socioeconomic disadvantages such as inadequate housing, food insecurity, unsanitary water, and unequitable healthcare access amplifying the inequity.

EVERY 22 MINUTES

That's how often a woman dies of a heart attack in Canada, and most of those deaths are preventable.[14] In relation to men, women have smaller hearts and different heart attack symptoms – but their treatment doesn't always account for these differences.

46.3% TO 64.2%

Proportion of Black participants in a Canadian survey reporting racial discrimination in various contexts including health services.[15]

36%

Proportion of Canadians with rare diseases who report they are unable to access prescribed medicines for their condition.[16]

CLOSING THE GAP

$198B

Government of Canada investment in healthcare announced in February 2023, with "access to high-quality family health services [for everyone] when they need them" as one of 4 goals.[17]

$1.5B

$1.5 billion over 3 years pledged by the Government of Canada to implement the Rare Disease Drug Strategy endorsed in 2019.[18]

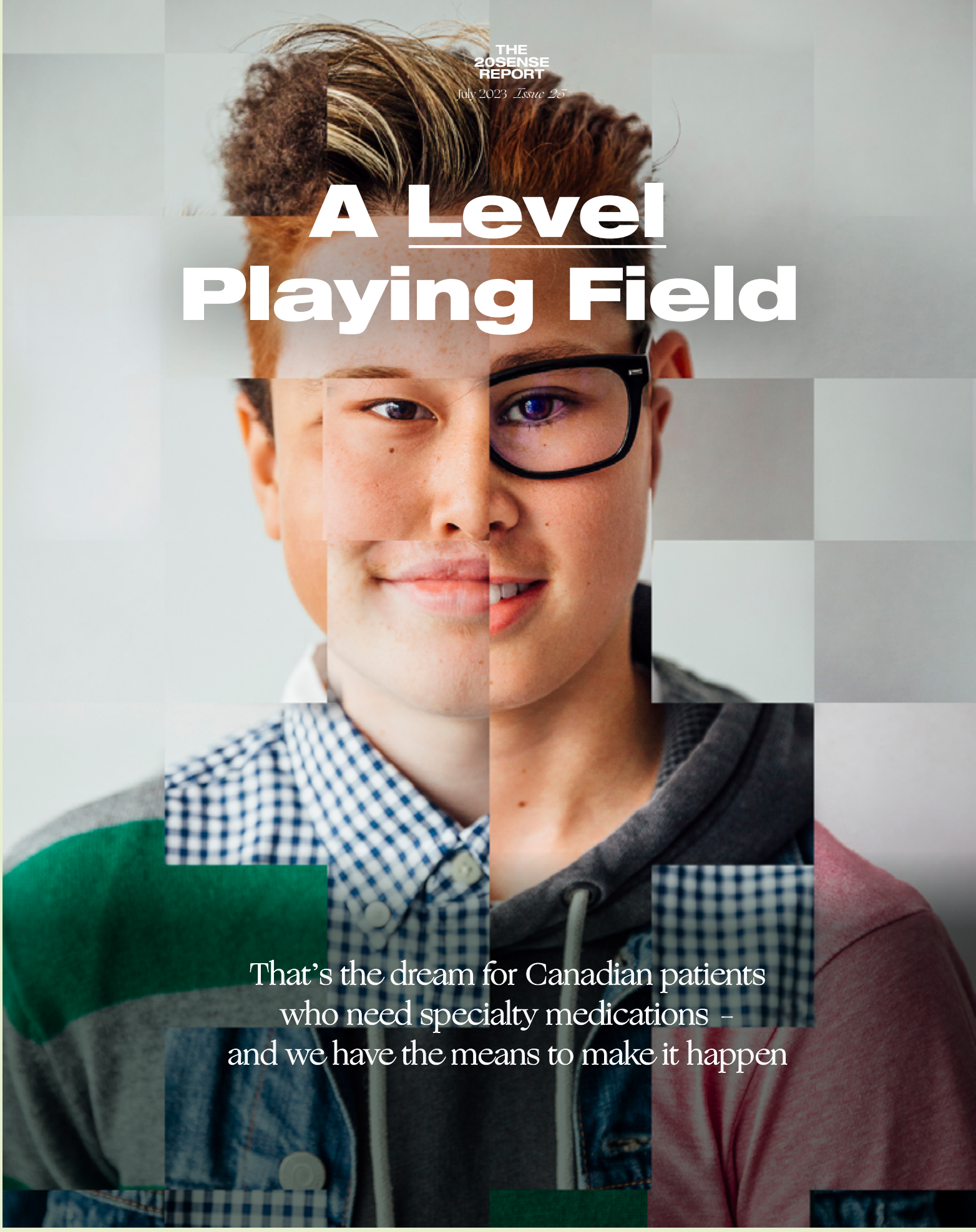
2022

Year that Health Canada made a formal commitment, in alignment with the federal government's Sex- and Gender-Based Analysis Plus Action Plan, to improve the capacity to collect the disaggregated data needed to assess, monitor and report on the diversity within clinical trial populations.[19]

6

Number of health equity research grants recently awarded by the Canadian Cancer Society across 6 provinces.[20] With grant figures totalling $1.6M, this funding program supports projects that seek to advance cancer-related health equity, such as addressing inequities in prostate cancer care for Black patient and cancer outcomes for Métis communities in rural Manitoba.

A Level Playing Field



That's the dream for Canadian patients who need specialty medications – and we have the means to make it happen

Ask someone what the word "Canadian" makes them think of, and chances are the list will include politeness, hockey, and universal healthcare.

While not without challenges, our publicly funded healthcare system elicits pride in over 90% of Canadians, reflecting our shared belief in equality and solidarity.[21] We also take pride in our diversity, as evidenced by our immigration policies and practices. Over 450 ethnic and cultural groups call Canada home,[7] and about 22% of the population was born abroad as of the 2016 census.[8]

These shared values bode well for health equity – the opportunity for everyone to reach their optimal state of health.[1] At the same time, medical research has not always put equity front and centre, creating a drag on the quest for health equity. Traditionally, the "reference man" used to develop drugs is a Caucasian male, aged 20 to 30 years old and weighing 70 kg.[22] This legacy may help explain why, in a recent analysis of clinical trials used to support FDA approval of cancer drugs, only 27% of the trials fairly represented older adults and only 11% included an adequate number of subjects from minority racial and ethnic groups.[23]

Fortunately, awareness of such systemic inequities has pierced through the status quo – and stakeholders are doing something about it. In the US, the FDA will soon require late-stage clinical trials to include a plan for ensuring representative diversity among subjects.[23] Along similar lines, Health Canada will institute a formal process to verify whether clinical evidence for new drug submissions includes fair representation of age, sex, and race.[19] Canada's Sex- and Gender-Based Analysis Plus Action Plan, launched in 2009 and updated in 2021 to emphasize intersectional identities such as age, ethnicity, geographical location, and education, has made a commitment to "identify and characterize different risks between populations."[24]

But how? "Real-world data can help us understand which patient populations are affected by a disease and set recruitment goals that reflect this mix," says Nina Lathia, a pharmacist and health economist based in Toronto.[25] We saw a similar process play out during the COVID-19 pandemic, when real-world data revealed excess cases and deaths in socioeconomically disadvantaged communities.[26] Governments responded with equity-oriented policies, such as prioritizing elderly and Indigenous populations in vaccine distribution.[27] We have the opportunity to increase equity with specialty medications as we did for the Covid-19 vaccines.

What factors drive the prevailing inequities in the specialty pharmaceutical space? Which populations are underserved? What are stakeholders doing – and what could they be doing – to close equity gaps in Canada?

Let's explore together.

Disclaimer: While we don't have the space to report on all health inequities, we hope to shine a light on some pain points to help move the equity agenda forward.

THE ROOTS OF HEALTH INEQUITY

Health depends not only on individual genetics and lifestyle, but on what the World Health Organization (WHO) defines as social determinants – the wider social forces that shape people's daily lives.[28] Not surprisingly, inequalities in the social arena may lead to disparities in health outcomes.[29] When we have the ability to prevent or mitigate these disparities through policy and action, they are considered unjust, or inequitable.[29] Within specialty medicine, inequity may arise from geographical and financial disparities as well as discrimination due to ethnicity, gender and religion, among other factors.

Location, location

In a country as geographically diverse as Canada, we don't have to look hard to find inequities based on where people live. For people living in remote locations, time, distance, and money often stand in the way of specialty treatments. Inequities may also arise from policy differences between provinces/territories. Often substantial, these differences in funding, copays, and coverage criteria work against the Canadian vision of healthcare access based on need. When one province funds a drug and another does not, a patient's access to that drug may depend more on their bank balance and postal code than on their need.

We as a country cannot possibly accept healthcare based on age and postal code. *Patients' lives all have equal value.*

Susi Vander Wyk, Executive Director, Cure SMA Canada

Consider the example, described in a report from the Government of Canada on the potential for National Pharmacare, of a 58-old mechanic with an income of $50,000. After a recent diagnosis of advanced lung cancer, he takes an oral drug that costs $100,000 per year. Depending on where he lives, his public plan may completely cover the drug – or leave him with out-of-pocket expenses ranging from $250 to $8,000.[30] An even larger equity gap exists for Spinraza (nusinersen), a life-changing medication for spinal muscular atrophy (SMA). In 2022, CADTH's recommendation against reimbursing the drug for adult indications left Canada's SMA community in "stunned disbelief."[31] At present, Quebec is the only province to fund the medication to all SMA patients, irrespective of age or disease type, a policy followed by more than 25 countries worldwide. "We as a country cannot possibly accept healthcare based on age and postal code," says Susi Vander Wyk, Executive Director of Cure SMA Canada. "[Patients'] lives all have equal value."[31]

> We have one of the best health-care systems in the world, and we're not serving women. *We have to do better.*
>
> Dr. Paula Harvey, cardiologist, Women's College Hospital, Toronto

Ethnicity and gender

At present, neither ethnicity nor language are routinely coded in administrative health data in Canada,[32] thus opening the door to inequities based on ethnicity. It is no secret, for example, that Indigenous peoples face systemic disadvantages that result in worse health. When it comes to cancer care, a scoping study determined that these populations face inequitable access across the care continuum, from screening to treatment, with individual, health-system, and societal factors feeding into the imbalance.[33]

In Black communities, systemic discrimination continues to create barriers that threaten access to advanced cancer care, an especially troubling scenario in light of the disproportionate burden of breast, colorectal and prostate cancer among Black Canadians.[34] Inadequate access to such technologies as molecular diagnostics results in substandard care, while accessing costly personalized treatments through private coverage or out-of-pocket payments places heavy financial burdens on Black patients.[34]

Historically, clinical trials have not equitably represented females, resulting in medications developed primarily for male physiology.[35] A case in point: while females account for 51% of cancer patients, one analysis found that only 41% of subjects in cancer trials were female.[36] Research also finds women up to 50% less likely than men to attend a cardiac rehabilitation program, with barriers ranging from lack of referral to a tendency to minimize personal needs.[14] As noted by Dr. Paula Harvey, a cardiologist and department head at Women's College Hospital in Toronto: "We have one of the best healthcare systems in the world, and we're not serving women. We have to do better."[14]

GENETIC INEQUITY: A CASE STUDY

Cystic fibrosis (CF) is associated with thousands of different genetic mutations, and recently about 90% of Canadian CF patients who have at least one copy of the most common CF mutation have become eligible to access the drug Trikafta (elexacaftor/tezacaftor/ivacaftor).[55] Among the remaining 10% of the Canadian CF population, about 4-5% of people who have rare CF mutations could benefit from Trikafta – if they could access it.

Two years ago, the FDA approved laboratory evidence to expand the use of Trikafta to cover some of the rarer mutations associated with CF – including a very rare mutation found among Hutterites. Predominantly located in the Western Canadian provinces, the Hutterite community has a high rate of cystic fibrosis (CF), and the condition is often more severe in this group.[37]

France, Israel, and England have also accepted laboratory evidence to enable an expanded Trikafta indication and patient access, but to date Canada has not. "We have a group that Trikafta can treat, but who won't get treated because Canada is not accepting evidence that will allow people with rare and ultra-rare mutations to get access to medicines," says Kim Steele, Director of Government and Community Relations at Cystic Fibrosis Canada. In effect, "these patients face layers of inequities – being born with a rare mutation, insufficient numbers for clinical trials, and Canada's unwillingness to review laboratory evidence."

But there's hope: "We are calling on Health Canada to accept laboratory evidence, and the drug manufacturer has studied 18 of the 177 rare and ultra-rare mutations that cause CF, including mutations often found in the Hutterite community. Depending on the results, we hope to see some expansion of the approved indication, and ultimately access for patients."

In support of this view, a recent report from the Heart and Stroke Foundation of Canada uncovered significant inequities in women's heart and brain healthcare, particularly in women belonging to racialized, Indigenous, LGBTQ2S+ communities.[35] The report's troubling conclusion: these gaps in research and care are putting lives at risk.[35]

Economic barriers

Financial constraints can impede access to healthcare, especially among people with multiple chronic conditions, and thus worsen health outcomes. If an Ontario study is any indication, the inequity gap appears to be widening: between 1993 and 2014, while overall avoidable mortality (AM) decreased in Ontario neighbourhoods, the AM gap between the poorest and wealthiest neighbourhoods increased more than twofold.[38] With inconsistent public coverage of prescription drugs across the country, many people rely on employee benefits to make up the shortfall – an option available to 75% of Ontarians overall, but only 58% of the poorest people in the province.[39]

This leaves far too many people shouldering the financial burden of their care. Take diabetes, for example, a progressive condition that requires not just prescription medications but devices and supplies. In certain parts of the country, annual out-of-pocket costs can top $10,000 for people with type 2 diabetes and $18,000 for people with type 1.[40] "While many people my age are saving $10,000 for a down payment on a house, as a Manitoba resident who has never been eligible for publicly funded diabetes programs, I have been saving for a safe pregnancy, which includes a [continuous glucose monitoring device] and insulin pump," say advocate Nikki Webb, who lives with type 1 diabetes.[40]

You don't have to be poor to feel the pinch: with diseases such as cystic fibrosis now treated with advanced and expensive medications, the middle class also struggles to carry the load. As CF patient and advocate Stephanie Stavros explains, "medications for rare diseases are often expensive. In Ontario, the Trillium program will cover the cost of drugs only after patients contribute the equivalent of 4% of their household income. This can be quite a big chunk of money for most dual income families" – especially after you throw in the cost

Canada has the opportunity to implement the very best program in the world for rare disease patients.

Durhane Wong-Rieger, President, Canadian Organization for Rare Diseases

of special diets, equipment, and loss of income due to illness. Indeed, an Ontario family earning $125,000 would face out-of-pocket costs of $5,143 to access the CF drug Trikafta through the province's Trillium drug program.[41] In Quebec, the same family would have to contribute $1,183. As Stavros sees it, "the provinces need to find a way to step up and help rare disease patients that are getting lost in a system that is not designed for them."

EQUITY INITIATIVES IN MOTION

The goal of health equity calls for change on several fronts, from drug development and distribution to access and administration. The past few years have seen patients and their advocates band together, get loud, and redefine what is possible in access, exemplifying the adage that strength lies in numbers. This paradigm shift reflects the increasing prominence of the patient voice in healthcare decision-making, captured in the iconic phrase "nothing about us without us."

Initiatives supporting specific populations

Over the past three years, Boehringer Ingelheim Canada, an Indigenous consultancy called Bimaadzwin, and an Indigenous Advisory Circle have been collaborating to address the needs of this population.[42] Called *PATHWAYS*, the Indigenous-led and Indigenous-informed collaboration intertwines upholding the right to health and access to health services with nation building, reconciliation, and self-governance.

The program's individual projects, which focus on distinct Indigenous communities and regions of the country, include[42]:

- Improving diabetes care in British Columbia's Nuu-chah-nulth Nations in BC
- Leveraging technology to connect patients with resources, such as nurse practitioners, who can assess patients' needs and provide immediate care in Maskwacis, AB
- Point-of-care testing with 1,200 citizens to identify clinical markers for type 2 diabetes in Manitoba
- Engaging multi-disciplinary health care practitioners to support diabetes patients with lifestyle and food security challenges in rural Nova Scotia communities

In marginalized communities such as First Nations, the goal of health equity often requires bridging the cultural gaps that keep access barriers in place. Ontario cancer centres carry out this work with Indigenous Patient Navigators (IPNs), who help to make the cancer journey a culturally and spiritually safe experience for First Nations, Inuit, and Métis patients and their families.[43] One of the first of these navigators, Jeannie Simon, currently works at the Cancer Centre in Thunder Bay. In a video for Canadian Virtual Hospice, Simon explains how she connects with the patients under her watch[44]: "Most of the cancer patients who come to our centre are from fly-in communities... they are overwhelmed and there are so many steps to go through. I sit with them, talk with them before they see the doctor... I am a second ear to them." Not just that, but she offers the invaluable asset of speaking Ojibway.

The University of Toronto at Scarborough, meanwhile, has set up a new Black Health Equity Lab headed by Dr. Notisha Massaquoi, an assistant professor at the university's Department of Health and Society, to tackle health disparities faced by Toronto's Black Community.[45] As its first project, the lab is developing a case-based HIV program aiming to reduce transmission rates and improve health outcomes through early detection, treatment, and support. To ensure immediate support for newly diagnosed patients, the case management team will include a nurse practitioner, social worker, and two community outreach workers.

Funding fairness

As part of its commitment to equity research, the Canadian Cancer society launched the Health Equity Research Grants program in May 2022.[47] The funding program supports research projects that seek to advance cancer-related health equity. To compete for a grant, projects must be co-created by people affected by cancer and by structural marginalization and must address the myriad social determinants of health inequity in Canada.

The inaugural competition yielded 21 full applications and 6 approvals for funding – a 35% success rate – with a total of over $1.6M over the full term of the grants.[47] Successful applications came from Alberta, British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario, and Québec and included projects serving Black, immigrant, 2SLGBTQI+, First Nations, Métis and Inuit communities.

A subject matter expert in health equity, anti-oppression, anti-black racism, and race-based data collection, Dr. Massaquoi will also be leading a new research project that spans the University of Toronto's three campuses.[46] Developed with the Black Research Network, the project will receive $250,000 seed money through the university's Connaught Fund and will see 13 experts from across the university joining forces to address Canada's racial health gap.

Focus on specific therapeutic areas

In tandem with these population-based initiatives, governments and other stakeholders have been developing strategies focused on specific therapeutic areas, with rare diseases as an urgent priority. As a recent Ipsos survey confirmed, Canadians with rare diseases face long delays in diagnosis, lack of accessible care, and lack of access to drugs.[16] These findings may reflect the fact that, until recently, Canada did not have a national plan for rare diseases.

The outlook for rare diseases is poised to improve with the federal government's announcement, in March 2023, of a $1.5 billion investment over three years to implement the Rare Disease Drug Strategy endorsed by the government in 2019.[18] "Canada [now] has the opportunity to implement the very best program in the world for rare disease patients," said Canadian Organization for Rare Diseases (CORD) president Durhane Wong-Rieger in response to the announcement. If all goes as planned, the strategy will accelerate equitable access across Canada with a national formulary covering the medications that these patients have been waiting – and waiting – for.

To assess improvement in access, you need a benchmark. That's exactly what the patient-led Arthritis Consumer Experts (ACE) group seeks to establish with its Arthritis Medications Report Card. The initiative compares the provincial drug plans by tracking the coverage of advanced disease modifying anti-rheumatic drugs (DMARDs) for the most common types of inflammatory arthritis, such as rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis, and groups its findings into 5 categories[48]:

- **Declined:** The provincial/territorial formulary does not reimburse the medication
- **Listed – "CBC":** Reimbursement occurs on a case-by-case basis
- **Listed – "ORC":** The medication is listed, but with overly restrictive criteria
- **Not applicable:** Health Canada has not approved the medication
- **Under review:** The medication is approved, and the province is considering whether to reimburse it

This is not just an academic exercise for ACE: the group intends the information to spur Canadians to action. Specifically, ACE encourages Canadians in poorly performing provinces to "write and speak to your elected provincial or federal representative about the lack of equitable reimbursement access [and thus] choice in treating inflammatory arthritis."[48]

Forward-thinking drug manufacturers also have equity on their radar. When developing patient support programs (PSPs), Hoffman-La Roche recruits patient councils to weigh in on program design – and is experimenting with mixed councils of patients and healthcare professionals. As Anne Marie Hayes, the company's director of patient experience, explains, "we design our programs through the lens of the experts – namely, those living with the condition." The biggest challenge – and opportunity – lies in recruiting patient councils "with a DEI [diversity, equity and inclusion] mindset so their voice is truly representative," she explains. "This mimics the DEI ambitions in our clinical trial programs, and we still have a long way to go."

HOW DATA CAN SUPPORT HEALTH EQUITY

To reach their full potential, these exciting initiatives depend on good data collection, which isn't happening consistently yet. As noted earlier, administrative health data in Canada does not routinely include ethnicity or language.[32] Without the collection, use, and governance of race-based data, the members of the Black Health Equity Working Group assert that "our disproportionate pain and deaths go unacknowledged, unaddressed and invisible."[50]

Routine collection of race and ethnicity data can help researchers and healthcare providers target interventions to underserved groups and reduce inter-group disparities.[34] This is exactly what Cécile Petitgand sought to achieve when she founded Data Lama, a Québec company supporting individuals and organizations

An equity perspective on health policy

For Gail Attara, President & Chief Executive Officer of the Gastrointestinal (GI) Society, the term "health equity" belongs, above all, to patients. This philosophy informed the GI Society's Patient-Focused Health Policy Report,[49] developed under Attara's guidance and with contributions from more than 30 other patient groups. Recognizing "the uniqueness of individuals," the report urges governments to orient the healthcare system toward greater equity, including:

- Providing connectivity for geographical, social, and cultural variances
- Addressing the social determinants of health, such as food security and housing
- Providing timely healthcare access to people with disabilities and communication barriers
- Making treatments available to patients regardless of where they live or relocate in Canada

My goal is to reduce disparities. Data is simply a tool to get there. You can't make decisions without evidence, and I realized that data on Black communities wasn't part of the evidence.

Camille Orridge, Senior Fellow, Wellesley Institute

in ethical data management. "Health data should be evaluated based on its ability to reflect the richness and variety of individuals and communities," says Petitgand, who serves as the company's CEO. "Otherwise, data-driven solutions in healthcare will only cater to the needs and interests of a fraction of society."

Fortunately, interest in including DEI in data collection continues to grow. Dr. Winson Cheung, a professor of medicine at the University of Calgary and principal director at Oncology Outcomes, has noticed the shift: "Years ago, we were told to treat everyone the same without acknowledging inherent differences in people. Now the lens has changed, and not asking people about differences is seen as a missed opportunity to better individualize their care. We see the value of collecting racial and ethnic data, because without collecting it we cannot study it and improve patient outcomes."

Camille Orridge, a senior fellow at Wellesley Institute, a research and policy group that seeks to improve health and health equity in the Greater Toronto Area, has been labouring to put such data on the map for over a decade. "You don't make any decision without evidence, and I realized [that data on Black communities] was not part of the evidence," says Orridge, who ranked among the top 25 Women of Influence in Health in 2012. "My goal was to reduce disparities. Data is simply a tool to get there."[51]

As a testament to Orridge's vision, Statistics Canada recently published mortality data on the Black population for the first time.[50] The findings highlight the urgent need for systematic collection, analysis and use of race-based data. Also encouraging: since 2016, the Canadian Institutes of Health Research (CIHR) has been working to address DEI in the research sphere and plans to update its equity strategy to align with its evolving mandate.[52]

SO WHERE DOES THIS LEAVE US?

Specialty pharmaceutical stakeholders in Canada share the goal of improving patient outcomes – this means outcomes for *all* patients – which will require our full attention and ingenuity. To close systemic equity gaps, pharmaceutical manufacturers, healthcare providers, government agencies, advocacy groups, and patients themselves need to continue to form creative partnerships that put equity at the forefront.

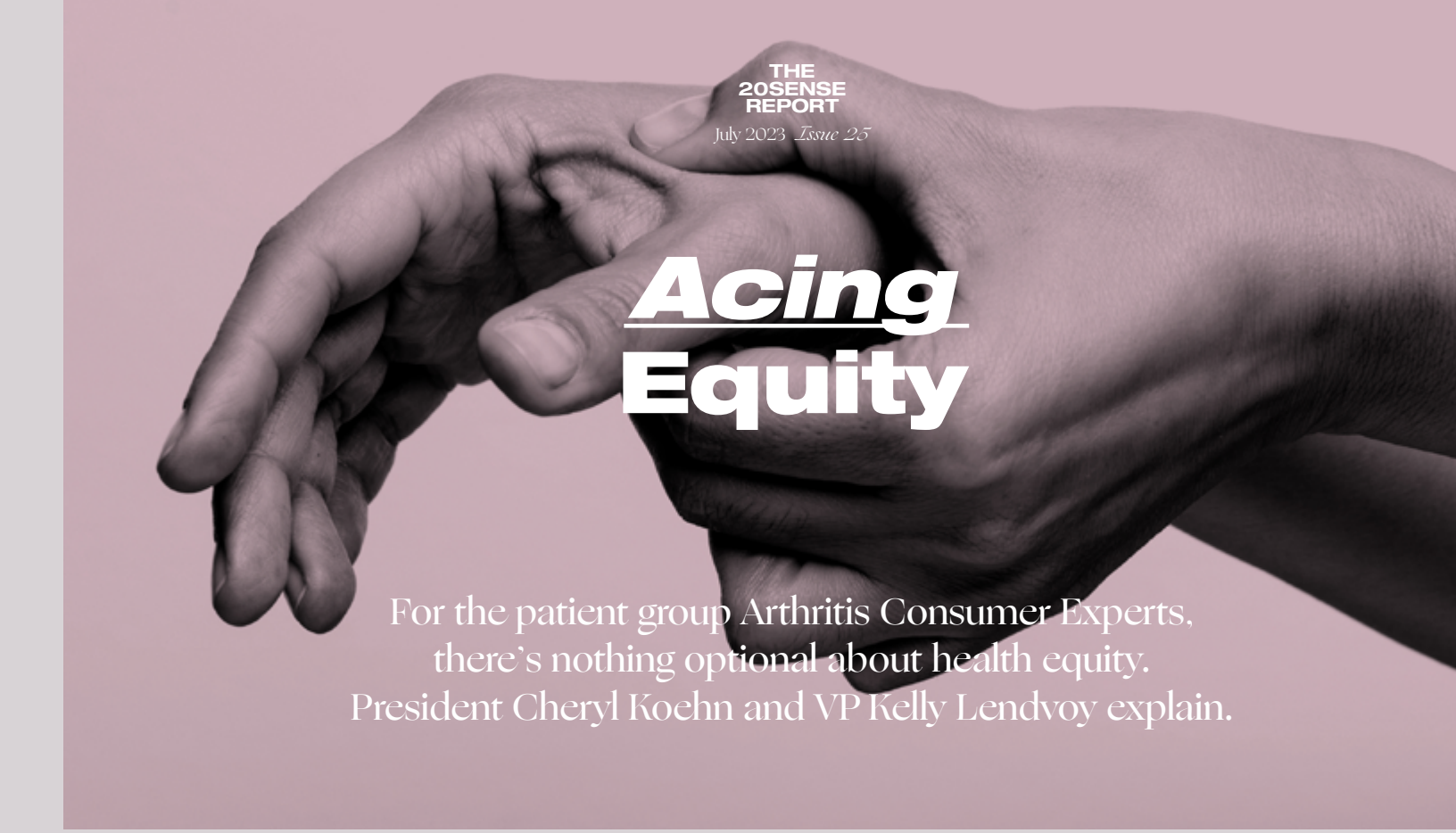
Stakeholders also need to reflect and consider the unpredictable effect of certain initiatives on patient equity. For example, clinical trials – largely conducted in urban centres and inaccessible to many people living far from cities – may inadvertently widen the equity gap. Consider the ongoing trial of Zolgensma (onasemnogene abeparvovec), a gene therapy medication for spinal muscular atrophy, in children aged 2 to 12 years.[53] Described as "ultra-competitive," the multicentre trial has a recruitment target of just 28 patients worldwide. That's great news for the selected 28, but children who live far from the 15 hospital sites face additional barriers to partaking in the trial. This is not to say we must stop conducting clinical trials in urban centres, but that we need take steps to give more participation opportunities to Canadians from all parts of the country.

Most importantly, clinical research in Canada must keep a close eye on the geographic, socioeconomic, ethnic and cultural diversity in the country and represent this diversity in clinical trials and other healthcare initiatives. There's every reason to believe we can do it, especially when we have so much to gain. As DEI strategist Arthur Chan so aptly put it: "Diversity is a fact. Equity is a choice. Inclusion is an action. Belonging is an outcome."[54]

All Canadian patients deserve access to the specialty medicines and other treatments they need. A focus on health equity will ensure they get it.

Diversity is a *fact*.
Equity is a *choice*.
Inclusion is an *action*.
Belonging is an *outcome*.

Arthur Chan, DEI strategist



Acing Equity

For the patient group Arthritis Consumer Experts, there's nothing optional about health equity. President Cheryl Koehn and VP Kelly Lendvoy explain.

Cheryl Koehn is the founder and president of Arthritis Consumer Experts (ACE), Canada's first and largest national patient-led organization that provides science-based information and education programs, and actively advocates on arthritis health and policy issues. A national patient community leader, educator, patient research partner and published author – and having lived with rheumatoid arthritis for over 3 decades – Cheryl understands access and equity – well, in her bones.

With over 30 years experience working in corporate communications and public affairs, **Kelly Lendvoy** is responsible for aligning and integrating ACE's educational and advocacy strategies for patients, healthcare professionals, governments, and other stakeholders.

What led you to found Arthritis Consumer Experts, and how has the organization evolved?

Cheryl: At the time there were no organizations run by patients on the ground, and I saw a gap for people like me. I didn't want to go through my life unsupported, and realized the only way to have the community I wanted was to build it. ACE is now a leading arthritis education and advocacy organization not just in Canada, but also in Europe and the Americas. Our work is featured at scientific meetings. We most recently gave a presentation on health inequities in BIPOC women with arthritis at the European Alliance of Associations for Rheumatology in June 2023. ACE is guided by a strict set of guiding principles, set out by an advisory board comprised of leading scientists, medical professionals, and informed arthritis consumers.

Are there inequities in arthritis compared to other diseases?

Cheryl: Diseases like cancer and HIV get hundreds of drugs listed on the formulary, while it's a continuous struggle to get reasonable listings for arthritis. It's not for nothing that we call arthritis the "forgotten child." Many people still associate arthritis with the creaky joints their grandma had... but, in fact, more than three in five people diagnosed with arthritis are under the age of 65. They don't know there are more than 100 different types of arthritis. The disease affects people of all ethnicities and genders, though some patient populations – like women and Aboriginal Canadians – are more likely to get arthritis than others. ACE is committed to understanding and raising awareness about inequities in arthritis care related to service delivery, treating, and managing arthritis that exist, are persistent, and in some cases, are growing.

For many years now, you have been publishing an Arthritis Medications Report Card, which compares the provincial drug plans coverage of advanced therapies such as biologics and targeted small molecule medications for inflammatory arthritis. What was the impetus for creating this Report Card?

Cheryl: When biologics first entered the market, my colleagues and I watched the painfully slow review process for access to Remicade [an early biologic for arthritis]. It took 983 days for regulatory approval, with an additional 2 years of waiting for drug plans to list it. We went to Ottawa every month and sat in the director's office, just like they do in the movies! We wheeled people over in hospital beds. We sent the B.C. Minister of Health a foam-board invoice for $450 million for the community – that's how much it costs to manage 1,000 people with inflammatory arthritis for 10 years without biologic drugs, including the

We created the report card to make access disparities transparent to the public and spur poorly performing provinces to *get up to speed.*

indirect costs of lost productivity. By comparison, the estimated cost with biologic drugs available is $250 million. With a lawyer's help, we framed the lack of access as a human rights issue. That was the wakeup call they needed to open up access.

Then we started to notice that not all public drug plans defined "access" in the same way. Some provinces would just give biologics what I call a "token listing," with very narrow or overly complex eligibility criteria. ACE created the Report Card to make these disparities transparent to the public and spur poorly performing provincial or territorial formularies to get up to speed. We sift through every formulary every month, check on listing updates, and advocate around medications with a negative recommendation. Our basic position is this: if a medication gets Health Canada approval, it means the government thinks it's good enough for Canadians, so lack of access can't be justified. Preparing the Report Card is a lot of work, and I look forward to the day we can stop doing it – it would be the ultimate victory for equity in medication access.

Kelly: The report card has taken on new meaning as more and more specialty medications for arthritis become available. Public and private plans have identified these medications as key cost drivers, and over the past 10 years many have started tightening coverage. ACE's role is to educate them about what happens to patients who don't get access to the medication. We're also hopeful that the increased use of biosimilars will have a positive effect for both the healthcare system and patients by broadening access for patients who need advanced therapy and addressing the significant and growing cost of biologics.

Can you point to a specific change resulting from the Report Card?

Cheryl: Prior to the report card, Manitoba didn't publish their formulary online. After creating our first Report Card we compelled them to do it – and they did! Now Manitobans know what their options are.

Kelly: With the high concentration of Indigenous People in the province who are at greater risk of having serious inflammatory arthritis diseases and experiencing health inequities, that moment takes on even greater significance.

How might the pharmaceutical industry help increase equitable access to medications in Canada?

Cheryl: Equity begins at the drug development stage. Preparing for a drug trial today should look very different from even two or three years ago. It's not enough to claim that "we didn't have the power to look at subgroups." Some pharmaceutical companies are adapting to – or even leading – this paradigm shift very well and improving representation in clinical trials and research.

Kelly: Covid exposed inequity fault lines, and many pharmaceutical companies are now having new discussions about what health equity means. They're reexamining existing data from the patient perspective, and they are joining us, and other members of the arthritis community, in the call for training of healthcare providers to enable the creation of safe spaces for patients, and to ensure the delivery of equitable care.

Do you see a role for patient support programs (PSPs) in helping reduce inequities?

Cheryl: They play a big role. PSPs should get DEI [diversity, equity, inclusion] training, and I think some have started doing that. Last year ACE conducted a patient survey on reimbursement for inflammatory arthritis medications, which uncovered inequities having to do with paperwork. People who are unfamiliar with the bureaucracy of access find it a very difficult process. Once past their doctor's office, many patients don't even get to the PSP enrolment stage because of these barriers. PSPs can do outreach work to remind healthcare professionals to include people from marginalized groups, starting with helping patients past the enrolment hurdle.

Kelly: Research shows that BIPOC and other underserved populations are at greater risk of getting diagnosed with inflammatory arthritis and having more severe disease. Some may also have difficulty communicating with their healthcare providers and may feel less comfortable discussing their medications. The post-Covid trend of virtual care could add an extra barrier for these groups. PSPs have an opportunity to provide guidance to their enrolees on how to communicate more effectively with healthcare professionals – and vice-versa.

Is there any overall "call to action" you would like to highlight?

Kelly: Teaching and integrating DEI principles is critical. We now have DEI experts in rheumatology. The healthcare provider community has a responsibility to ask themselves: How can I become the kind of practitioner who delivers appropriate care? The answer lies in following basic DEI principles.

Cheryl: Ultimately, every one of us in the healthcare ecosystem has to sit down and reflect on questions like: Who am I? Am I contributing to inequities through my own belief systems? How do I unlearn those things and relearn that I cannot have different access to medicines from the person sitting next to me in the waiting room? So it's an internal exercise as well as a commitment to action.

We need to unlearn our hidden biases and relearn that we cannot have different access to medicines from the person sitting next to us in the waiting room.

On the reading *list*

Informing a framework for anti-racist research at ICES: A vision for community-led data governance

Ensuring equitable access to cancer care for Black patients in Canada

Assessments of the value of new interventions should include health equity impact

Indigenous-led solutions counter a diabetes epidemic

Systemic inequities are putting women's health and lives at risk

Can a focus on equity, diversity and inclusion transform health service research?

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