



Building data capacity to deliver evidence-based cancer care solutions in LMICs

Learnings and next steps

Table of contents

Where did we start?



What have we achieved?



What have we learned?



What's next?



Where did we start?

In March 2020, City Cancer Challenge (C/Can) launched a 2-year strategy to build its data capacity to deliver evidence-based cancer care solutions in cities. Developed through a series of consultations with experts in data science, impact measurement and related fields, the strategy has generated new opportunities and learnings that will inform a new phase of work for 2023-27.

The strategy focused on three core areas:

- I improving the quality of systems-level data for cancer diagnosis, treatment and care collected through the C/Can city engagement process
- II developing the data infrastructure and governance required to effectively store, manage, analyse and share C/Can data
- III identifying concrete use-cases for leveraging C/Can data to generate actionable insights for different stakeholder groups.

What have we achieved?

Throughout C/Can's [city engagement process](#), it brings together local stakeholders from across the public and private sectors including cancer care institutions, government, civil society, and patients to collect cancer care systems data that can inform the planning, design and implementation of local cancer care solutions. This includes data points related to cancer care infrastructure, equipment, healthcare workforce, quality and management of services, and community access to these.

Harnessing the expertise of its global network, and with support from MSD and Roche in 2020/2021, C/Can strengthened its data capacity in targeted areas including:

- Development and launch of a [Responsible Data Framework](#) with guidance, processes and policies designed to improve data quality
- Development and roll-out of a [custom-built data](#) portal to support the collection of cancer care systems data in C/Can cities
- Strengthening C/Can's [data analysis and visualisation capacity](#) to better support local experts in the analysis and prioritisation of cancer care gaps

In Leon, Mexico for the first time, C/Can worked closely with a data analytics and visualisation agency to refine the presentation of data to city stakeholders. Based on data collected through the C/Can [needs assessment](#), the [Situation Analysis Summary for Leon, Mexico](#) provides a high-level overview of the main cancer care needs and challenges identified for the city, as well as proposed solutions. This is supported by a suite of simple visuals highlighting key trends and insights.

The need to strengthen patient navigation for example emerged as a clear priority. Several data points collected through C/Can's needs assessment, including from the patient perspective, are relevant:

- **Less than 50% of patients reported having access to a patient navigator**

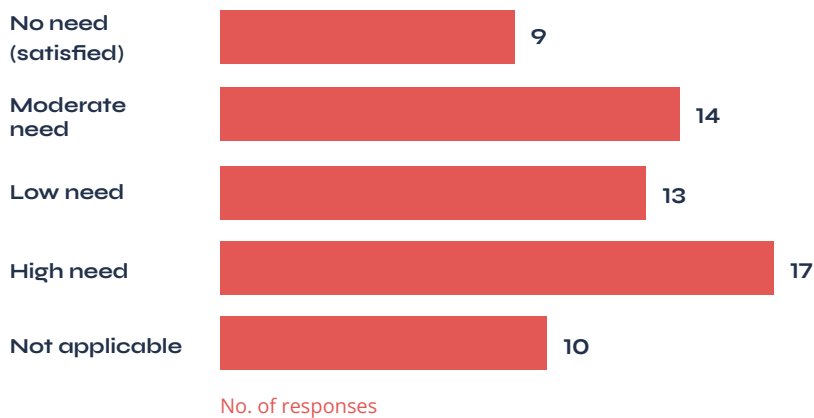
Have you been referred to a patient navigator or equivalent to navigate the health care system?



No. of responses

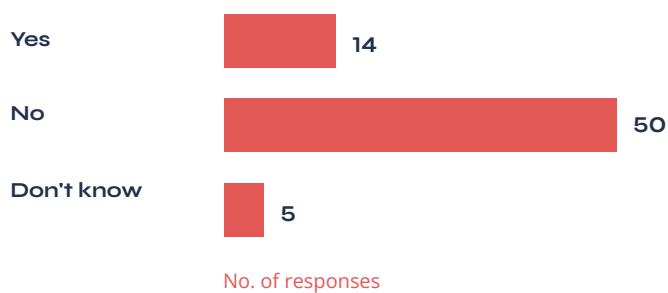
> **50% of patients reported a moderate to high need for support to arrange transport to an appointment**

During your care, what was the level of your need for help in the following areas:
[Help arranging transportation to my appointments]



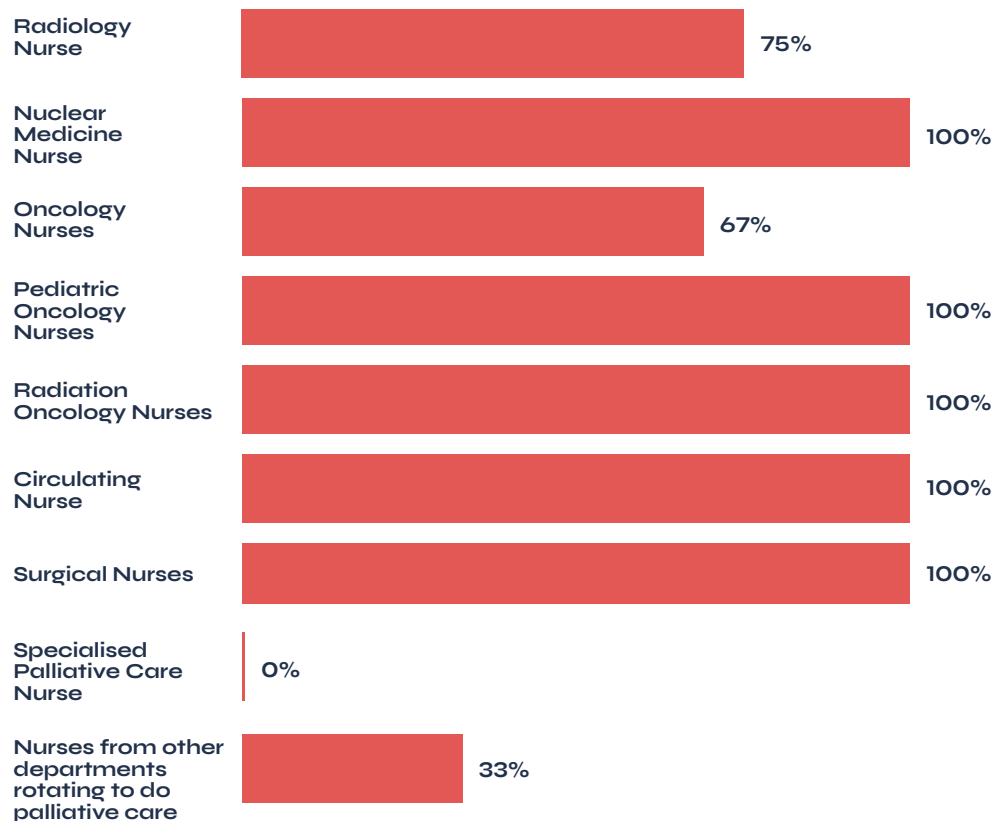
> **More than 75% of patients reported that they did not have access to a support group**

Do you have access to a support group?



- Similarly, the need to develop trained personnel for palliative care, including nurses, was identified as a key challenge. A snapshot of the availability of nurses across speciality areas based on responses from 11 cancer care institutions in Leon supports this finding.

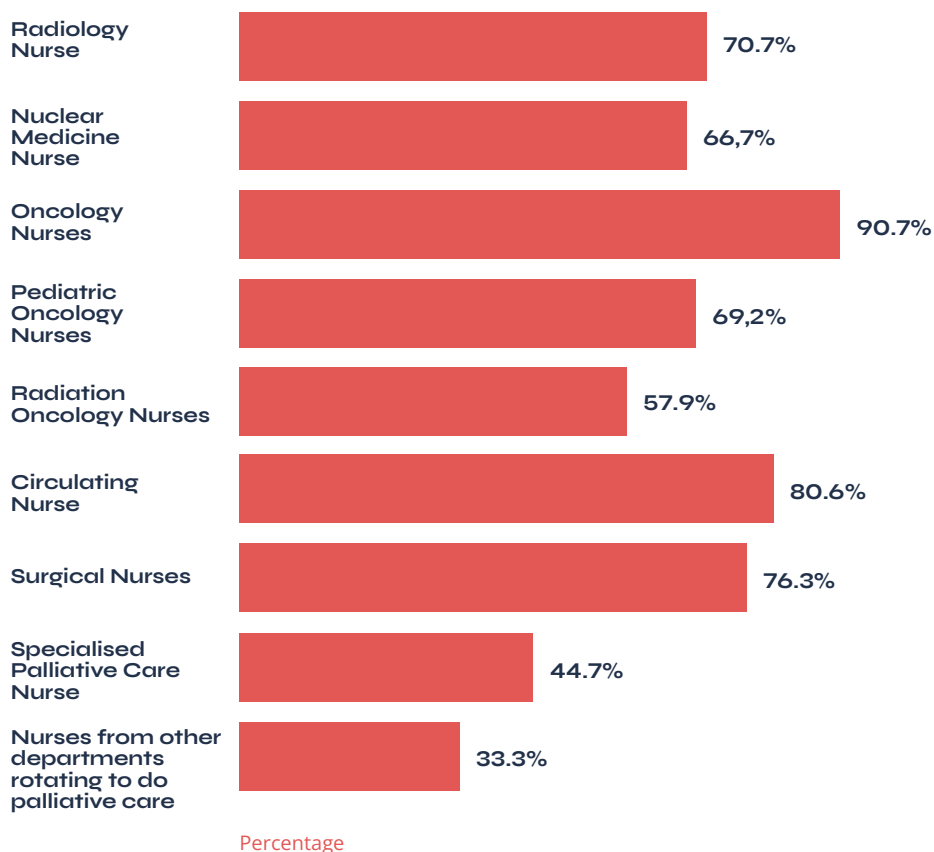
Ratio yes/no of staff availability
LEON



Percentage

- This trend is also observed more widely across C/Can cities, considering data from Kigali, Porto Alegre, Tbilisi, Leon, Kumasi and Cali, from a total of 116 cancer care institutions.

Ratio yes/no of staff availability
GLOBAL



- This trend has also informed the development of C/Can's global capacity development offer for healthcare professionals. [Building on the success of 2021](#), as part of this year's [TeleEcho™](#) programme, [three sessions were offered on palliative care in low- and middle-income countries](#). Facilitated by international experts, the three sessions, delivered separately in English and Spanish, emphasised knowledge that is practical and immediately useful through the sharing of best practices, case-based learning, collaborative problem solving, and peer-to-peer support for healthcare professionals in C/Can cities.

What have we learned?

On 7th June 2022, C/Can brought together over 50 city stakeholders and partners from across regions at a virtual dialogue to:

- Share C/Can's progress, challenges and lessons learned in the collection, management and use of city-wide cancer care systems data as part of the city engagement process.
- Gather input on emerging areas of focus for C/Can's next phase of work.

During the virtual dialogue, Rebecca Morton Doherty, C/Can's Director of Policy and Global Impact, was joined by Gam Dias, a Senior Data Strategist with expertise in analytic products and big data transformation, advisor to C/Can.

Responding to participants' questions and comments, they reflected on key lessons learned over the last two years:

Engaging the right stakeholders will improve data quality

Experience in C/Can's first cities has reinforced the importance of clear communications and engagement with local stakeholders before, during and after data collection processes. In Leon, for example, in addition to regular stakeholder meetings and one-to-one support, C/Can's local Data Coordinator developed a series of video guidance materials to recap the objectives of the C/Can data collection process, and to provide practical tips on how to access and use the data platform. Providing concrete examples of how data will be used and how the process will add value to the work of already over-stretched cancer care professionals is also critical to incentivising participation in the C/Can needs assessment process and to fostering a shared commitment to data quality. Capturing these use cases from existing C/Can cities and showcasing them is a priority for C/Can moving forward.

The flexibility to adapt C/Can's data collection processes to reflect local nuances around who owns, understands and has access to relevant, up-to-date cancer care systems data will also be an important consideration. Experience in C/Can's first cities has shown that depending on the local context, it may be the Ministry of Health, Ministry of Education, municipal authorities, National Cancer Institute or equivalent, National Centre for Disease Control, local clinicians, hospital management/administration, or others that own the data points prioritised in C/Can's needs assessment. Ensuring high quality data will rely on mapping and engaging the "right" stakeholders to collect this data.

Stay focused, ask the right questions to guide data collection

Every aspect of data, from collection to cleaning, management and analysis requires people's time and attention; it's resource intensive. Mindful of the data capacity in the contexts in which we work, it is important to be as targeted as possible, focusing on the "question we want to answer, rather than starting with data and developing insights based on what is happening" as noted by one of the dialogue participants.

In parallel to reviewing our data infrastructure and governance, C/Can has also prioritised continuous review and update of the needs assessment content: what questions are we asking to build a snapshot of city-wide access to equitable, quality cancer care? What metrics are we using to assess the quality of care? How relevant and feasible are they? To this end, in March 2022, C/Can joined forces with the Institute of Cancer Policy, King's College London to lead a comprehensive review of the questionnaire that will support C/Can to assess access and quality in a longitudinal manner, and allow for high-level comparative analyses across cities.

Create a trustful and safe data environment

As highlighted by one of the dialogue participants, part of the challenge in global health is that data can be used punitively rather than productively. Addressing issues around trust and transparency has been a common challenge in C/Can's first cities. Developing a purpose-built data platform for the needs assessment wherein data security and access could be carefully managed was an important first step. Reinforcing the message that institutional level data would only be shared in aggregate with the objective of creating a city-wide picture, rather than pinpointing individual cancer care institutions was also important to building trust with and among local stakeholders.

Listen to the full virtual dialogue [here](#)

What's next?

Building on the learnings from this first phase of work, C/Can has developed a vision for 2023-2027 that positions us to **“leverage C/Can’s unique cancer care datasets to generate insights that support the planning and implementation of quality, equitable cancer care in cities in LMICs.”**

There are 3 facets to our data vision:

1 Continue to invest in and nurture the data asset

- Scale up data collection and analysis capacity to serve more cities
- Refine the focus of C/Can’s needs assessment, focus data collection and insights for improved outcomes

2 Increase our capabilities to generate value through the data

- Operationalize the analysis by creating repeatable and automated processes for analysis, visualisation and communication
- Deepen insight generation abilities using healthcare workforce data collected through the C/Can needs assessment as an initial test case

3 Scale insights and value beyond current cities

Evolving a data sharing platform that will allow cities and stakeholders beyond C/Can’s core set of cities to benefit from data and insights:

- Help them build the motivation to share data within the city, the country and across the region/globally
- Facilitate sharing by providing infrastructure, guidelines, methodology and governance
- Bring to life projects where data can be safely shared and the benefits made public

Over the next 6 months C/Can will continue to work with its network of experts and partners to develop a clear roadmap and resourcing plan for 2023-2027 to operationalise this vision.



<https://citycancerchallenge.org/>

