Championed by a multilayered mixture of governments and philanthropic funders, service providers and policy makers, and shaped by youth and carers, it is not an exaggeration to say that YMH has undergone a paradigm shift in Canada. Novel initiatives – from knowledge mobilization, virtual and bricks-and-mortar clinical services, to implementation-evaluation – have sprung up from coast to coast to coast. All of these have the laudable goal of improving care, services and outcomes through phase-specific, developmentally-aware, youth-friendly programming.

Yet while these efforts are necessary to improve services and the mental health of young people in Canada and beyond, they are not by themselves enough. Knowledge and information is clearly required to understand what an individual youth’s needs and concerns are, what interventions might be beneficial for them, and how services can iteratively adapt and improve themselves. And knowledge and information in turn depends on data.

Understanding and addressing issues around data, its collection and mobilization are complex and challenging at the best of times. For example, how and for what purposes will routinely collected data be used – what is its utility and relevance? How can services and networks put clinically collected data to work, whether for engaging youth in their own care, for strengthening the content and quality of treatments offered based on individual needs and trajectories, or for optimizing the structure and function of the service as a whole? Beyond enthusiastic individuals, what ingredients will it take to implement and deploy measurement-based care and learning health systems platforms? How will we know that these are actually working, and benchmark their impact? Executing on these questions is essential to maintaining public trust in an area of tremendous importance and investment.

Of course, the answers to these questions fundamentally depend on collaboration: the ability and commitment to learn from each other, both within Integrated Youth Services and across the full range of YMH initiatives. I speak in part from the standpoint of leading a national CIHR-funded project that aims to support the data-related needs of youth mental health services: in an era of open science, how can we best encourage and support initiatives to identify salient questions and share key learnings regarding their innovations, successes and failures in these areas? How can we create an ecosystem where openly disclosing roadblocks and failures is appreciated just as much as achievements are? Are challenges due to technical roadblocks, inter-jurisdictional legalities, political will, walled gardens, or something else – and who needs to be part of the conversation if we are to break these logjams? Between rapid advances in technologies, the increasing acceptance of virtual care, and the recognition of value in comparative analyses, we certainly have a unique opportunity to leverage insights from national, provincial, and local levels.
There are also challenges related to the current moment. Historically, it has been (at best) unclear whether and how data has informed the structure and function of mental health services. If we want this to change, we need clarity around what the current and future data-related needs of YMH services are. To take one example, existing physical services rapidly pivoted to data collection online during the Covid-19 pandemic and are considering hybrid models for the future. Other initiatives that emerged during – or in response to – the pandemic have often embraced online approaches from the beginning, but still need to learn to interface with one-on-one care (whether virtual or in person), especially for those who need more intensive services. How can data support smooth transitions between interventions and services in a way that does not fragment the user’s experience? Amidst the waves of technology, how do we keep youth and carers’ needs at the center of everything we do?

And finally, how can data help us to stay focused on the reasons why youth mental health is so important in the first place: the need for early identification and provision of appropriate interventions and services during the period of peak risk and onset of mental health problems? It is ultimately this person-centered objective that data should be put to work to accomplish. The service structures we create, including stepped care approaches, have been touted as major advances compared with traditional diagnostic criteria, and in theory have the capacity to provide well-calibrated supports and services to youth even when they do not meet strict diagnostic thresholds. But as a Frayme-initiated working group that I’m involved with has demonstrated, there exists little consistency or evaluation of stepped care models and outcomes. We need to build a shared terminology and language: basic parameters for what a “step” means, some guidelines to ensure equivalence between step 2 in one model and step 2 in another? This involves data, but is relevant far beyond data. Without it, the infrastructures we build will be “stepped services’ ‘ – fitting youth into a ladder of whatever interventions are available – rather than youth-centered stepped care.

It is my hope that day 2 of the Frayme IYS Forum can begin to unpack these and related issues, all revolving around the need for – and challenges with – collecting, storing, mobilizing, sharing, and transforming youth mental health services on the basis of data.