

Roadmap

for partnering with patients,
families, and caregivers in a
Learning Health System

Foreword

This document was created to support all stakeholders interested or involved in the implementation of a Learning Health System, such as patients, family members, caregivers, citizens, health professionals, researchers, managers, decision-makers, etc.

In order for a Learning Health System (LHS) to be truly co-designed and supported by patient, family, and caregiver partners, it is essential to better understand how these partnerships can be ensured throughout the various stages of a learning cycle. Indeed, the knowledge that patients, families, and caregivers possess and mobilize through their lived experience is an important source for learning and a driving force that can greatly enrich the learning cycles of LHSs.

This roadmap was co-designed with 37 patients, family members, and caregivers. It aims to clarify the roles of patients, family members, and caregivers within an LHS and describe how they can, individually and collectively, contribute to its multiple dimensions.

Glossary

- The term **patient** refers here to any person who has used or may need health and social services, whether currently ill or not. While respectful towards the nuances between terms, in this document the term patient replaces any other similar and commonly used term, such as service user, client, consumer, resident, etc.
- **Engagement** is an approach based on the relationship between patients, their families, and the actors in the health care and social services system.
- A **partnership approach** relies on strong relationships between patients, families, caregivers and other actors in the health and social services system. These relationships are nurtured by the complementarity and sharing of each partner's knowledge, as well as by the ways in which different partners work together. Such relationships fosters a sense of mutual trust and a shared recognition of the importance of each partner's expertise, including the expertise and experiential knowledge of patients, families, and caregivers. (1)
- **Lived experience** refers to all the knowledge and skills that patients have or will acquire during their experiences of living with illness, which enable them to act as partners at different levels: in the health care and social services system, in research and in the training of professionals and students. Patients can share their lived experience through:
 - being partners in their own care;
 - mobilizing and sharing their experiences as a patient partner;
 - being transformational leaders at the systems level (2)
- A **learning health system** (LHS) is a dynamic ecosystem of care in which scientific, social, cultural, technological, political, and ethical dimensions are aligned and allow for continuous cycles of learning between practice, data, and knowledge in the system to be integrated into current practice, thereby improving the value of health care.

More specifically, learning health systems emphasize four functions that are essential to continuous learning in a system: (1) data generation, management, and sharing, (2) the relationship between patients/families/caregivers, researchers, clinicians, and decision-makers, (3) engagement, and (4) the development of a culture of continuous learning, which requires coordinated actions by the entire health system. (3)
- **Value-based healthcare** is defined as achieving the best possible health outcomes or the best possible care at the lowest cost. (4)



Start ! 

Key Messages

“Simply put, the ultimate goal of an LHS should be to provide **better care** by putting **people at the heart of health.**”

All stakeholders in a learning health system are **interdependent** and **learn together**.

Patients, families, and caregivers:

- are **partners in their own care** and, as such, must be considered as **full members** of their care team
- enable the LHS to be anchored in a **common vision for a more humane health system**
- must be **partners throughout the entire cycle** of an LHS, as they play a key role in connecting its various actors
- must be able to **be present and participate in, as well as contribute to the design** of an LHS
- must be able to **participate at the decision-making level**, as they bring a cross-cutting vision that transcends the health system’s silos
- **identify gaps in the system and share best practices** observed inside and/or outside the system with other actors

Guiding Principles

A variety of guiding principles have emerged from current debates and literature in the area of patient partnership. The principles presented in this document were identified by the patients, families, and caregivers who participated in the reflections and discussions.

- Complementary expertise
- Diversity
- Equity
- Humanism
- Inclusion
- Justice
- Reciprocity
- Respect
- Solidarity

Transversal Roles

“Learn from us and with us.”

Patient, families, and caregivers:

- have an **integrated perspective** of health
- have a crucial role in **sense-making** and **defining value in health**
- ensure that the **needs of users** are reflected in the prioritization of care, organization of care, and in research
- are **change agents** of the healthcare system
- can **identify simple solutions** that ensure continuity of information, of relationships, and of organizational approaches
- are important **sources of learning** for the health system’s actors as *lay communicators, coaches/mentors and instructors/advisors* for users, family members and citizens, as well as health professionals, researchers, managers, decision-makers, etc.



WINNING CONDITIONS

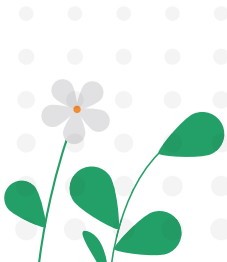
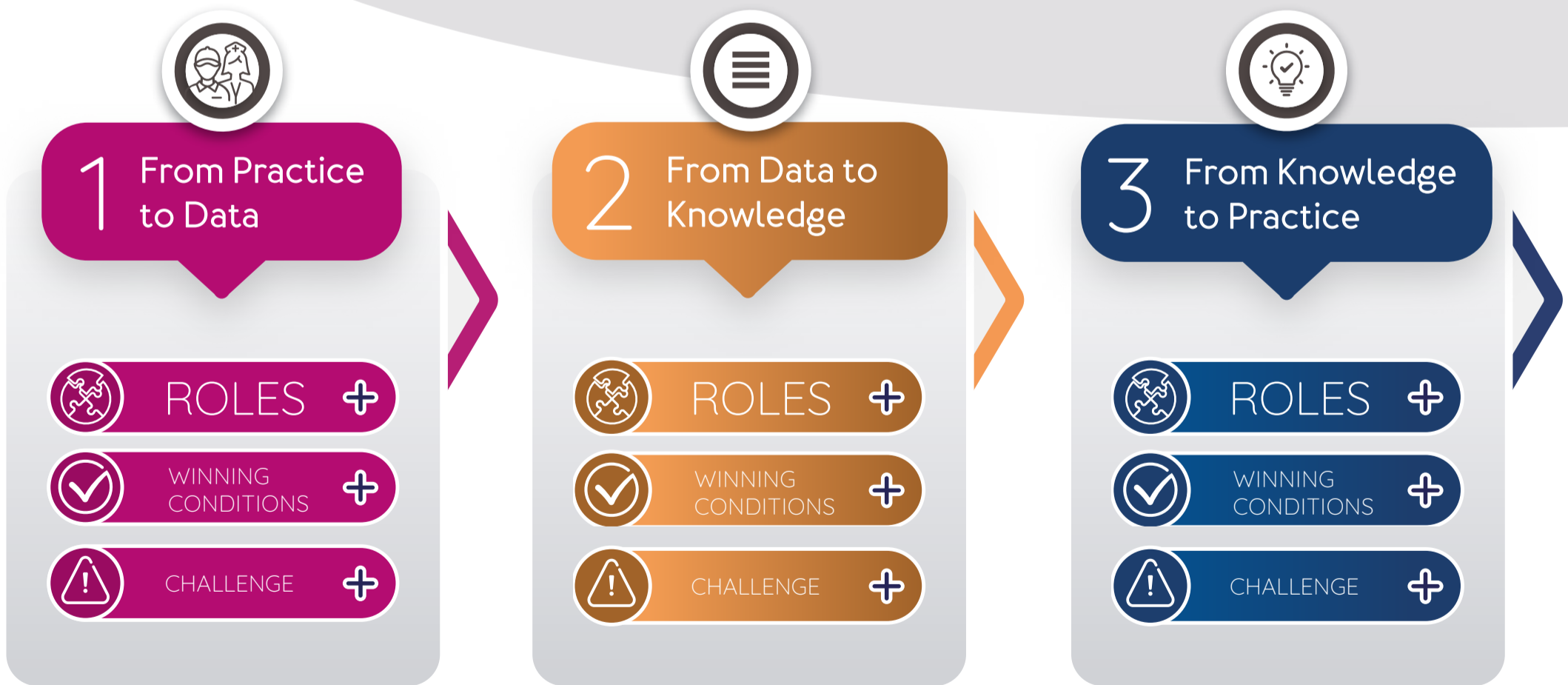
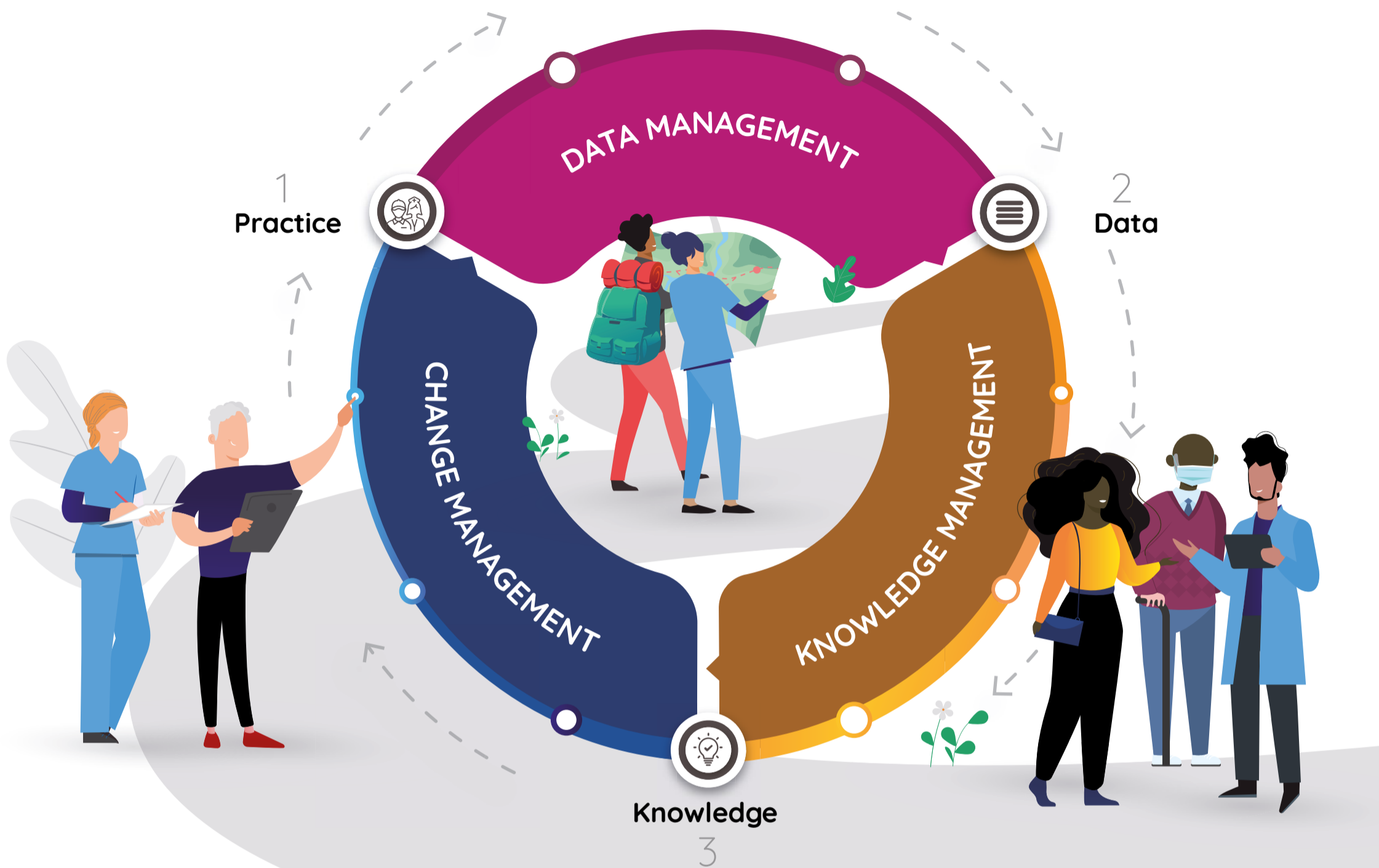
To create an environment conducive to partnering with patients, families, and caregivers within a learning health system, it is important to:

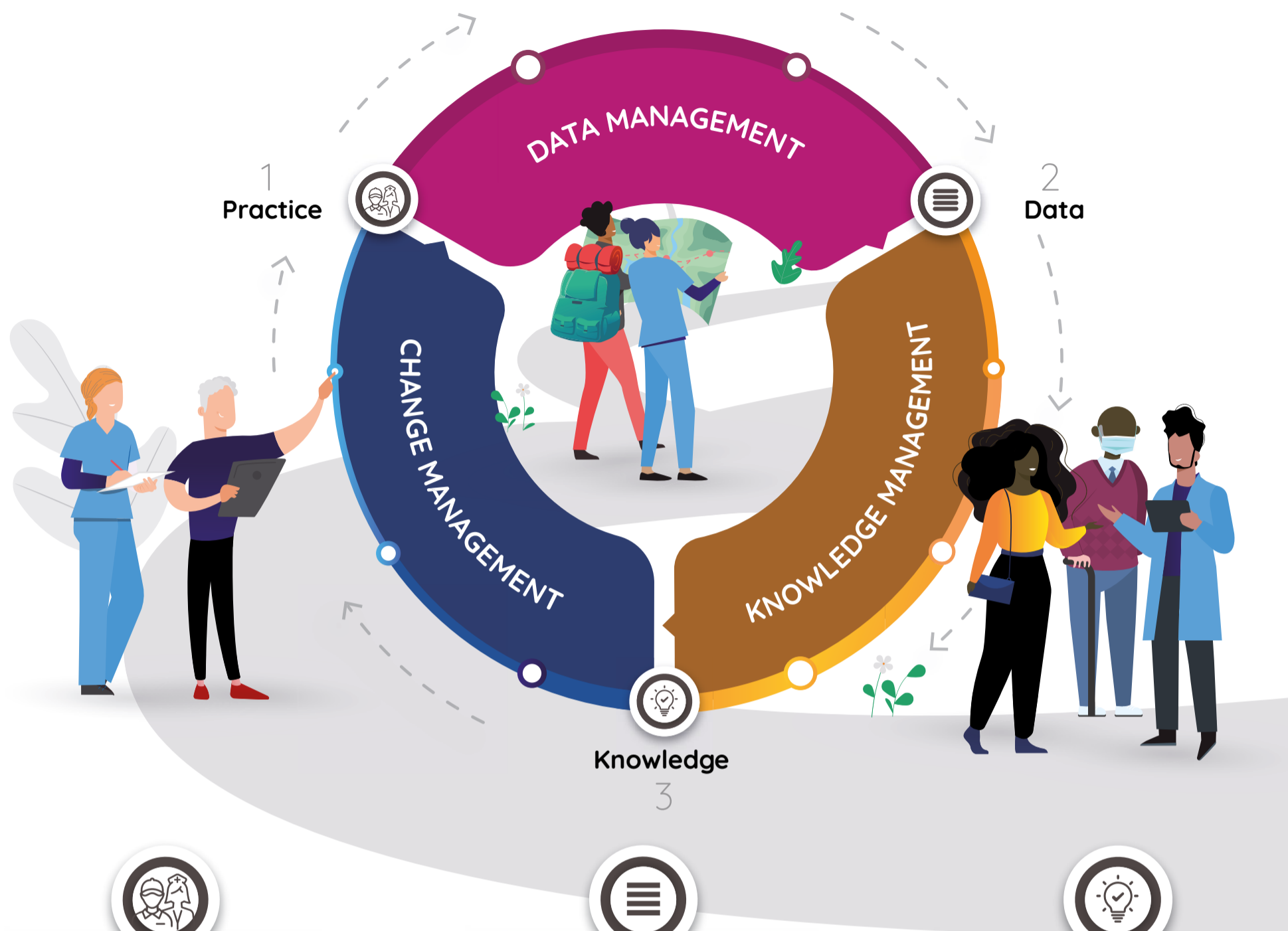
- promote the different possible roles of patients, families and caregivers in the healthcare system
- support the development of **health literacy**
- adopt a **common vision, language, and tools**
- recognize the **value** and **complementarity** of patient knowledge
- **train all the actors** of the healthcare system in patient partnership, as well as in intersectoral collaboration
- foster **transparent** and **continuous communication**
- **provide feedback to patients, families, and caregivers** and communicate concrete actions resulting from their contributions

CHALLENGE

- From a health equity perspective, the **inclusion of diverse perspectives, identities, and experiences** in improving the health and human services system remains a major challenge.







1 From Practice to Data

Definition: This phase focuses on the generation of practice-based data by providers, administrators, patients, families, and caregivers, or other LHS stakeholders. (5)
The central challenge of this phase is **data management**.

ROLES +

WINNING CONDITIONS +

CHALLENGE +

2 From Data to Knowledge

Definition: This phase involves the conversion of data generated by care, research, or quality improvement to knowledge that can drive decision-making, improvement, and innovation within the LHS. (6)
The central challenge for this phase is **knowledge management**

ROLES +

WINNING CONDITIONS +

CHALLENGE +

3 From Knowledge to Practice

Definition: In this phase, the knowledge that emerges from communities of interest is applied to support innovation and improvement and ultimately to deliver greater health. (7)
The central challenge of this phase is **change management**.

ROLES +

WINNING CONDITIONS +

CHALLENGE +



1 From Practice to Data

“The appropriate data must be collected at the appropriate time and in the appropriate way.”

ROLES

Patients, families, and caregivers:

- are **partners in their own care** and, as such, must be considered as **equal and full actors** in care teams
- have a **major role** to play in **data collection** and can **identify the data** that matters most to them
- collect and share their own data and/or, as caregivers, the data of a family member (often in real time and independently)
- participate in the **co-development of data collection tools and methods**
- based on their experience, **identify missing data** and identify **biases** or **gaps** in data collection methods
- can be partners in the **co-development of secure and ethically responsible data management and data sharing systems**

WINNING CONDITIONS

CHALLENGE



2 From Data to Knowledge

“We must ask ourselves the question: what knowledge are we building, and from what data?”

ROLES

Patients, families, and caregiver:

- must participate in conversations around the data that relate to them
- can contextualize data through their **experiences of care and life with illness**
- have a crucial role in **giving meaning to data** and in **confirming its relevance**
- can **share their own knowledge** and contribute to the **generation of new knowledge**

WINNING CONDITIONS

CHALLENGE



3 From Knowledge to Practice

“Patients, families, and caregivers bring a holistic vision of health based on prevention and management of illness.”

ROLES

Patients, families, and caregivers:

- can provide simple, high-impact solutions
- can provide significant support for change management processes:
 - by collaborating in defining change objectives
 - by giving **grounding change in the reality of living with an illness**
 - by helping to **simplify illness journeys**
 - by helping to **reduce stigma**
 - by making it easier to communicate knowledge (Ex. more understandable, more accessible, etc.)

WINNING CONDITIONS

CHALLENGE



1 From Practice to Data

2 From Data to Knowledge

3 From Knowledge to Practice



WINNING CONDITIONS

To ensure that patient, families, and caregivers experiences are reflected in the data:

- consider the **psychosocial dimension** of physical or mental illness, as well as **quality of life**
- be **flexible and innovative** in the data collection methods and tools by considering the context of patients, families, and caregivers
- prioritize **mixed and qualitative data collection methods**, including patient-reported experience measures (PREMS) and patient-reported outcome measures (PROMS)



ROLES



CHALLENGE



WINNING CONDITIONS

To identify and prioritize changes in care and for research:

- data from patients, families, and caregivers must be connected with data from clinicians, managers, and researchers
- **patient, family, and caregiver experiences** must be considered as an **important anchor point**



ROLES



CHALLENGE



WINNING CONDITIONS

To ensure the successful and sustainable improvement of practices, it is important:

- to **integrate ideas and knowledge emerging from patient experiences** and apply them in practice
- to **foster a dialogue** between patients, families, and caregivers and health professionals to ensure a better understanding of their mutual realities
- to **identify and sustain practices** that already work!



ROLES



CHALLENGE



1 From Practice to Data



2 From Data to Knowledge



3 From Knowledge to Practice

CHALLENGE

Patients, families, and caregivers play a crucial role as **partners throughout the learning cycles of an LHS, beginning with needs identification**. As such, it is important to go beyond simple consultation processes (such as through a satisfaction questionnaire) in order to learn about their experiences all along their care journey, and even their life experiences to capture other determinants of their health.

It is essential to consider **targeted collection strategies** for marginalized and stigmatized groups, and/or for ethnocultural groups whose experiences are generally less represented in the data.

WINNING CONDITIONS

ROLES

CHALLENGE

In a learning health system, the **data and knowledge generated by patients** must be **known, recognized, integrated, and valued!**

WINNING CONDITIONS

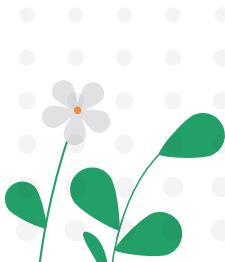
ROLES

CHALLENGE

It is crucial to **verify the relevance of new knowledge with patients, families, and caregivers** to enable its translation into concrete actions and changes in practice.

WINNING CONDITIONS

ROLES



Editors & production

EDITORS

- Myriam Fournier-Tombs
- Sylvain Bédard

SCIENTIFIC DIRECTORS

- Audrey L'Espérance
- Matthew Menear

RESEARCH ASSISTANT

- Marie-Anne Fillion

PATIENT CONSULTING PARTNER

- Christian Chabot

GRAPHIC DESIGN

- Christine St-Onge • www.ateliercri.com

TO CITE THIS DOCUMENT:

- Fournier-Tombs, Myriam; Bédard, Sylvain; Menear, Matthew and L'Espérance, Audrey. (2022). Roadmap for partnering with patients, families and caregivers in a Learning Health System.

Acknowledgements

We would like to express our deepest gratitude to the 37 patients, family members, and caregivers who collectively participated in a dozen hours of co-design workshops, as well as in the editing and verification of the contents of this tool:

- Kelvin Arroyo, Christiane Asselin, Sylvie Beaulieu, Sylvain Bédard, René Benoît, Pierre-Charles Bertrand, Colette Bérubé, Janie Boulianne Gref, Pierre Cardinal, Christian Chabot, Denis Cormier-Piché, Madeleine Côté, Simon Courtemanche, Clara Dallaire, Annie Descoteaux, Marie-Anne Fillion, Rona Fleming, André Gaudreau, Annie-Danielle Grenier, Debby J-Lessard, Daniel Landry, Micheline Laverdure, Catherine Lemyze, Juliette Lévesque, Louis Lochhead, Virgil Luca, Sonia Lussier, Vincent Montpetit, Lise Pelletier, Marie-Dominique Poirier, Guy Poulin, Francine Roberge, Ghislaine Rouly, Bernard Saulnier, Lise Viens, Catherine Wilhelmy.

We would like to sincerely thank our colleague Catherine Purenne for her remarkable support in the administrative management of this project.

Finally, we would like to thank our dear colleagues at the SSA Quebec Support Unit for their continued support and openness:

- Myra Drolet, Antoine Groulx, France Lemieux and Mylène Lévesque.

References

- (1) Ministère de la Santé et des Services sociaux. (2018). Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux.
- (2) Direction collaboration et partenariat patient. (2015). Terminologie de la pratique collaborative et du partenariat patient en santé et services sociaux. Université de Montréal.
- (3) Unité de soutien au système de santé apprenant Québec. (2022).
- (4) Menear M., Blanchette, MA., Demers-Payette, O., Roy, D. (2019) A framework for value-creating learning health systems. Health Research Policy and Systems.
- (5) IBID
- (6) IBID
- (7) IBID



Created by the Centre of Excellence on Partnership with Patients and the Public and supported by the Unité de soutien SSA Québec

