

April 6, 2022

Commissioned Paper for National Academy of Sciences, Engineering, and Medicine

Board on Health Care Services, Health and Medicine Division

Consensus Study: Transforming Health Care to Create Whole Health – Strategies to Assess, Scale and Spread the Whole Person Approach to Health

Title of Paper: Evidence on Patient-Centeredness, patient-centered systems, and implementation and scaling of whole person health.

Moira Stewart, PhD  
Distinguished University Professor Emeritus  
Western University  
London ON  
Canada

Email: [moira@uwo.ca](mailto:moira@uwo.ca)

## Table of Contents

EXECUTIVE SUMMARY

CHAPTER 1: Introduction

CHAPTER 2: Define Whole Person Care and Scoping Review of Models

Definition and History of the Patient-centered Clinical Method

Elements of Patient-Centered Care from the Literature

The Whole Health Model and the Patient-centered Clinical Method

Key Messages

CHAPTER 3: Evidence on Patient-centered Clinical Outcomes

Results from a New Review

*Effects on Patient Outcomes*

*Barriers to Implementation of Patient-centered Interventions*

*Equity Issues*

*Value of Qualitative Findings*

Key Messages

CHAPTER 4: Patient-centered Systems Approaches

An Evidence-based Framework

Key Messages

CHAPTER 5: Lessons and Steps to Move from Implementation to Scaling-up

Defining Scaling-up

Attributes and Frameworks of Scaling-up

*Theme 1: Sequence*

*Theme 2: Context*

*Theme 3: Infrastructure Requirements*

*Theme 4: Embedded Research*

Key Messages

CHAPTER 6: Conclusions

## List of Tables and Figures

Table 1: Seven Approaches to Patient-centered Concepts

Table 2: Comparison of Seven Patient-Centered Frameworks

Table 3: Complementarity of the Patient-centered Clinical Method and the Whole Health Model

Table 4: Description of Intervention Studies

Table 5: Outcome Measures: Type, Number of Measures and Percent of Measures Significant

Table 6: Infrastructure Requirements for Scaling-up

Figure 1: Evidence-based Framework for Patient-centered Integrated Systems

# Evidence on Patient-Centeredness, patient-centered systems, and implementation and scaling of whole person health

Report to NASEM April 2022

## EXECUTIVE SUMMARY

The report contains six Chapters. After an introductory Chapter 1, Chapter 2 compares and contrasts seven conceptual frameworks of patient-centered/whole-person care and finds four universal components. Chapter 3 reports a review of 16 recent trials of patient-centered interventions. Chapter 4 describes evidence-based elements for a co-ordinated patient-centered health care system. Chapter 5 reveals themes from a scoping review of 49 papers on scaling-up of co-ordinated health care systems.

The key messages in these Chapters are:

The universally agreed upon four components of patient-centered care are: 1) the patients' experience, including illness, thoughts and feelings; 2) the person in context especially family; 3) mutual discussion of goals, preferences and decisions; and 4) relationship between the patient and clinician, including empathy, emotion and sharing power.

Patient-centered interventions most strongly influence patients' experience of care, less strongly influence patients' reported outcomes and least strongly affect clinical or physiologic outcome measures.

Patient-centered interventions can be a force for equity, in that they are effective across all levels of deprivation, BUT only if out-of-pocket expenses to patients are covered.

Implementation failures for patient-centered interventions arise from lack-of-fit with clinicians' values, lack of training on teamwork and stressful health care contexts.

Key elements of a patient-centered, co-ordinated health care system are: shared vision; linkages; training; and strong partnerships with patients.

Scaling-up a co-ordinated health care system requires human elements such as leadership, partnering, promotion and learning/training, as well as technical elements such as organization management, data systems and financing.

Finally, there is an overarching key message which appeared in different forms in each Chapter, a message of adaptation and flexibility in order to succeed:

The clinician must be flexible in response to patients' goals and preferences.

The interventions must fit with the values of the clinician in order for successful implementation.

A co-ordinated health care system must achieve a shared vision.

Scaling-up requires partnering and adapting in response to the adopting community.

## CHAPTER 1: INTRODUCTION:

The Veterans Administration (VA) Whole Health Initiative is a potential leader in a resurgence of patient-centered, whole-person approaches to health care. After a period of several decades of quiescence, during which more focused approaches such as shared decision-making and goal-directed care, were front-and-center, the broader, more comprehensive perspectives are regaining prominence.

For the past 20 years, since Mead and Bower in 2000 and the Institute of Medicine in 2001, there has been a dearth of contributions on patient-centered concepts (only three in 2012 and 2013, McMillan et al. (2013); Morgan & Yoder (2012); Dwamena et al. (2012)). But more recently a spate of review papers appeared, including Langberg (2019), Jonas & Rosenbaum (2021), Fortin et al. (2022) and Sturgiss et al. (submitted), according to this author's searches of the literature. The time is right for an up-to-the-minute review of patient-centered, whole-person concepts, their evolution, their similarities and differences, and their impacts on patient health as well as ways to scale them up.

In tracing the evolution of patient-centered concepts and approaches for this report, I have unearthed several learnings which need to be our starting point. One of these learnings is that some writings on patient-centered care focused on the clinical encounter between the patient and the clinician, while others added elements of the health care system such as co-ordination of care and continuity of care. Therefore, the organization of the report will reflect this important distinction.

## CHAPTER 2: DEFINE WHOLE PERSON CARE AND SCOPING REVIEW OF MODELS

### Introduction to Chapter 2

I am starting with the framework called the Patient-Centered Clinical Method for several reasons: it is most familiar to me; it has been labelled as the most comprehensive definition of patient-centeredness (Mead & Bower, 2000); and it has several foundational differences from the other frameworks being reviewed later in this report, making it a complementary approach, not one that will replace or usurp any of the other approaches. Indeed, my later recommendations will include one saying that the Patient-Centered Clinical Method is a useful complement to the Whole Health Model and that the two could well be used in tandem. In order to build that case, I will cover: first, the nature of the patient-centered clinical method, then a review of other definitions and, finally a head-to-head comparison of the patient-centered clinical method with the Whole Health Model.

### Definition and History of the Patient-Centered Clinical Method

The term patient-centered was first used by Enid and Michael Balint in the 1960s to describe care that understood "the patient as a unique human being" (E. Balint, 1969) and went beyond the traditional diagnosis to a "deeper more holistic diagnosis" (M. Balint, 1957). This language grew out of the context of British General Practitioners working with psychiatrists of the psychotherapeutic tradition. McWhinney brought these ideas to North America in his NEJM paper of 1972 (McWhinney 1972) on the patients' real reason for their visit, highlighting the need for the clinician to look beyond the presenting problem and its traditional diagnosis – to look deeper and discern to what extent the presenting problem was a sign of the patients' limit of tolerance for the discomfort or the anxiety or even a signal of another problem altogether. Subsequent research on the broad range of issues experienced by patients, demonstrated that a "holistic" approach (in which clinicians respond not only to the presenting complaint but also to a broad range of problems including physical, emotional, functional and life problems) was associated with better patient reported outcomes (Stewart et al., 1979). This broad way of thinking about clinical encounters was also revealed by Levenstein et al. (1986) in their early definitions of patient-centered care which coalesced into the comprehensive definition in the 1995 book Patient-Centered Medicine – Transforming the Clinical Method and updated in the book's second and third editions (Stewart et al., 2014). This history represents the shift from doctor or disease centered medicine to patient-centered medicine.

The key messages of these writings are to remind clinicians not to be constrained by the diagnosis of the physical problem but rather to broaden the lens to include the patients' emotional life, spiritual life, expectations and goals for life and health.

A crucial, singular aspect of the patient-centered clinical method is that it arose from a two-year process, led first by Levenstein and then by Weston, of family physicians reflecting on what went well in their visits with patients (Levenstein et al., 1986; Weston et al., 1989). When the ideas were being formally written, the authors made a conscious decision to address the concepts as guidance for clinicians (i.e. injunctions for practice) in contrast to two other ways of writing: the list of specific clinician behaviours; or the broad conceptual framework stated as a high-level model. The patient-centered clinical method falls between these two extremes and is therefore called a clinical method not a conceptual model.

## Elements of Patient-Centered Care from the Literature

This section asks and answers the question – how similar or different are the literature's conceptual frameworks that are called patient-centered.

The definition of patient-centered care or patient-centeredness has been criticized as lacking in clarity (Sturgiss et al., submitted). Such wooliness can be seen as holding back progress in creating coherent education programs and robust interventions. But, on the contrary, the most recent literature review of 159 research, conceptual and editorial papers (Sturgiss et al., submitted) tells us that there are "few discrepancies among definitions of various types of centeredness". Furthermore, no matter what the

country, no matter what discipline and regardless of what the preceding word is patient/person/relationship/family centeredness, the core concepts remain consistent. In order to explore these statements further, I propose, in the next few pages, to present a deeper dive, showing the seven key concept papers/reviews from the past 20 years (including the two most relevant here, i.e. the Patient-Centered Clinical Method and the Whole Health Model), detailing the dimensions of patient-centeredness in each paper and how they compare, in order to help us understand the various dimensions involved in patient-centered care.

To do this, I have created Table 1, showing details on each of the seven papers: The Patient-Centered Clinical Method (Stewart et al., 2014); VA Whole Health Model (VA Whole Health, 2022; Jonas & Rosenbaum, 2021); Mead & Bower (2000); Institute of Medicine (2001); Morgan & Yoder (2012); Langberg et al. (2019); and Sturgiss et al. (submitted). A large literature underpins Table 1 because four of the seven citations were review papers summarizing the views of numerous authors.

Table 1: Seven Approaches to Patient-centered Concepts

Patient-Centered Clinical Method Patient at the Centre	VA Whole Health Model/Initiative "Me" at the Centre	Mead & Bower,2000	Institute of Medicine, 2001	Morgan & Yoder, 2012	Langberg et al., 2019	Sturgiss et al., 2022
<b>Exploring Health, Disease and the Illness Experience</b> <ul style="list-style-type: none"> <li>- Symptoms, Signs, Laboratory results</li> <li>- Patient's meaning of what health is and aspirations for life</li> <li>- Patient's illness experience including feelings, ideas, function and expectations</li> </ul>	You are <b>expert</b> on your life #1 Aware of your <b>thoughts and feelings</b> #2 <b>Spirituality</b> – what gives meaning to life #9	<b>Biopsychosocial</b> – <i>Social and psychological factors</i> <ul style="list-style-type: none"> <li>- full range of difficulties</li> <li>- health promotion</li> </ul> <b>Patient as Person</b> – <i>Patient's experience</i> <ul style="list-style-type: none"> <li>- eliciting patient expectations, feelings, ideas</li> </ul>	<b>Respectfulness to patients' values, preferences and expressed needs #1</b>	<b>Individualized care</b> <ul style="list-style-type: none"> <li>- unique needs, preferences, and health concerns</li> </ul> <b>Holistic Care</b> <ul style="list-style-type: none"> <li>- physical, cognitive and psychosocial functioning</li> </ul> <b>Respectful Care</b> <ul style="list-style-type: none"> <li>- strengths and abilities</li> </ul>	<b>Biopsychosocial</b> <ul style="list-style-type: none"> <li>- involving physical, cognitive, emotional, behavioural, social and spiritual domains</li> </ul> <b>Patient-as-Person</b> <ul style="list-style-type: none"> <li>- uniqueness of each patient</li> <li>- patient perspective</li> <li>- patients experience illness differently</li> <li>- explore both the disease and the illness experience</li> </ul>	<b>Biopsychosocial</b> <ul style="list-style-type: none"> <li>- social determinants of health</li> </ul> <b>Patient as a person</b> <ul style="list-style-type: none"> <li>- strengths based</li> </ul>
<b>Understanding the Whole person in Context</b> <ul style="list-style-type: none"> <li>- Patient as a person</li> <li>- An individual developmental trajectory and personality</li> <li>- A family, social support and work</li> <li>- Community and culture</li> </ul>	<b>Surroundings</b> – home, work place, neighbourhood, climate and environment <b>Experiences that affect emotions #4</b> <b>Personal Development</b> – ways you can grow #5 <b>Family, friends, coworkers</b> can affect emotions, mental and physical health <ul style="list-style-type: none"> <li>- Reduce stress through relationships #8</li> </ul>	<b>Patient as Person</b> – within his or her unique context	<b>Involving family and friends for decision making and support #6</b>	<b>Individualized Care</b> <ul style="list-style-type: none"> <li>- personality</li> </ul> <b>Holistic Care</b> <ul style="list-style-type: none"> <li>- responding to the needs of the whole person in context</li> <li>- the family, cultural and religious context</li> </ul>	<b>Biopsychosocial</b> <ul style="list-style-type: none"> <li>- "holistic", "whole person"</li> </ul> <b>Patient-as-Person</b> <ul style="list-style-type: none"> <li>- patient experience differs depending on current life situation</li> </ul>	<b>Biopsychosocial</b> <ul style="list-style-type: none"> <li>- social determinants of health</li> </ul> <b>Patient as a person</b> <ul style="list-style-type: none"> <li>- person as part of a collective</li> <li>- spirituality, cultural needs</li> </ul>
<b>Finding Common Ground</b> <ul style="list-style-type: none"> <li>- Mutual discussion between the patient and clinician of           <ul style="list-style-type: none"> <li>- the nature of the problems</li> <li>- the goals</li> <li>- the roles of each</li> </ul> </li> <li>- Reaching mutual agreement</li> </ul>	<b>Your values, goals and priorities #1</b> <b>Set your health and well-being goals</b> <b>Moving the body #3</b> <b>Food and drink #6</b> <b>Recharge #7</b> <b>Power of the mind – mind-body approaches #10</b>	<b>Sharing power and responsibility</b> <ul style="list-style-type: none"> <li>- encourage patient involvement in care</li> <li>- recognise patient's preferences</li> </ul> <b>Therapeutic Relationship</b> <ul style="list-style-type: none"> <li>- common understanding of goals and requirements of treatment</li> </ul>	<b>Providing information, communication and education #3</b> <ul style="list-style-type: none"> <li>- so patients can be properly equipped to take part in medical decisions</li> </ul> <b>Ensuring physical comfort, #4</b>	<b>Individualized Care</b> <ul style="list-style-type: none"> <li>- an individual Care Plan</li> </ul> <b>Respectful Care</b> <ul style="list-style-type: none"> <li>- patients' preference</li> <li>- supporting goals</li> </ul> <b>Empowering Care</b> <ul style="list-style-type: none"> <li>- self-confidence</li> <li>- participation in decision-making</li> </ul>	<b>Sharing power and responsibility</b> <ul style="list-style-type: none"> <li>- encouraging patient participation</li> <li>- shared decision-making</li> <li>- empowerment</li> <li>- common ground</li> </ul>	<b>Sharing power</b> <ul style="list-style-type: none"> <li>- seen as equals</li> <li>- empowerment</li> </ul> <b>Sharing responsibility</b>
<b>Enhancing the Patient-Clinician Relationship</b> <ul style="list-style-type: none"> <li>- Surfacing emotion</li> <li>- Compassion, caring, empathy and trust</li> <li>- Power in the relationship</li> <li>- Continuity of the relationship and constancy</li> <li>- Engendering healing and hope</li> <li>- Clinician self-awareness</li> <li>- Transference and counter-transference</li> </ul>	<b>Reduce stress through relationships</b> (including Patient-clinician relationship) #8 <b>Relationships can affect emotional health #8</b> <b>Be aware of thoughts and feelings #2</b>	<b>Sharing power and responsibility</b> <ul style="list-style-type: none"> <li>- egalitarian relationships</li> </ul> <b>Therapeutic Relationship</b> <ul style="list-style-type: none"> <li>- empathy, congruence and unconditional positive regard</li> <li>- develop the emotional context in consultations</li> </ul>	<b>Providing emotional support,#5</b> <ul style="list-style-type: none"> <li>- relieving fear and anxiety</li> </ul>	<b>Respectful Care</b> <ul style="list-style-type: none"> <li>- listening</li> <li>- autonomy</li> <li>- effective communication</li> </ul>	<b>Sharing power and responsibility</b> <ul style="list-style-type: none"> <li>- egalitarian partnership</li> <li>- respect for patient autonomy</li> </ul> <b>Therapeutic Alliance</b> <ul style="list-style-type: none"> <li>- valuing the relationship</li> <li>- constructive relationship</li> <li>- respectful communication</li> <li>- mutual respect</li> </ul>	<b>Therapeutic relationship/bond/alliance</b> <ul style="list-style-type: none"> <li>- compassion</li> <li>- emotional engagement</li> </ul>
		<b>The Doctor as person</b> <ul style="list-style-type: none"> <li>- doctor and patient influence each other</li> <li>- attention to cues to the affective relationship</li> </ul>			<b>The Doctor as a Person</b>	<b>Provider as person</b> <ul style="list-style-type: none"> <li>- professional clinical responsibilities</li> <li>- advocate for the patient</li> </ul>
			<b>Co-ordinated and integrated care #2</b>		<b>Co-ordinated Care</b> <ul style="list-style-type: none"> <li>- Accessibility, Co-ordination and continuity</li> <li>- A care pathway</li> </ul>	<b>Co-ordinated care, Access, Continuity of care</b>



There are six rows in Table 1 depicting the dimensions of patient-centeredness most commonly revealed. The first three of these rows focus on the patient-clinician encounter. The fourth row deals with the relationship over time. The fifth row addresses the clinician as person. The sixth row presents the health care system's co-ordination as an element of patient-centeredness, foreshadowing the increasingly frequent health system interventions which this report describes in a later section.

Each of the seven papers presents **Main Headings** which are represented in **bold**; the *Subheadings* are shown in *Italics*. The reader will note that the **Main Headings** do not line up in lock-step; however, the *Subheadings* do line up and are often worded quite similarly. In other words, ideas of what constitutes patient-centeredness are universal; however, the way these ideas are grouped by authors under **Main Headings** is more idiosyncratic.

Let us consider just a few examples of similarities and differences.

The first two rows can be said to be the least clearly delineated. The first row, dealing with a broad range of patient issues and strengths, overlaps often with the next row on the patient as a unique person in context. Mead and Bower, Langberg et al. and Sturgiss et al., demonstrated this overlap and called their first component **Biopsychosocial** and the second **Patient as Person**. But the papers they reviewed placed certain *Subheadings* under different **Main Headings**. For example, spiritual domains fell under the **Biopsychosocial Main Heading** in Langberg et al. but under Patient as a Person in Sturgiss et al.

The third row, dealing with the patient and clinician working out what to do, showed **Main Headings** of **Sharing Power, Sharing Responsibility, Relationships** and **Empowering Care**. But the subheadings were very similar from one author to another such as: *common understanding of goals; supporting goals; encouraging patient participation; finding common ground; and empowerment*.

Perhaps the clearest category was the fourth row on the Relationship, variously called the **Therapeutic Relationship, Emotional support, Respectful Care, Therapeutic Alliance, Therapeutic Relationship/Bond/Alliance**. This category's *Subheadings* were similar including *emotional connection, empathy, compassion and respect*, except for sometimes including considerations of power which most authors had placed in the third row.

The most different conceptual framework was Morgan and Yoder (2012) whose *Subheadings* are similar to those of other authors but whose **Main Headings** combined the *Subheadings* in ways that other authors did not. For example, their category labelled **Individualized Care** had sub elements that fell into three rows in Table 1. Similarly, **Respectful care** fell under three of the rows used by most other frameworks: strengths and abilities fell into the first row; patients' preferences and goals fell into the third row; and listening, autonomy and effective communication fell into the fourth row.

Two additional points are raised by Table 1. First, the Institute of Medicine (IOM) framework reads most like the Patient-Centered Clinical Method in that it states guidance/injunctions for clinicians.

Second, as was stated before, the distinction between patient-centered clinical encounters and patient-centered health system co-ordination/integration is introduced by the three authors in Table 1 who included **Co-ordination of Care** as a **Main Heading**. These two types of patient-centeredness, i.e. at the clinical and the health systems level, appear again in the next Chapter.

The conclusion of this section is a lack of consistency in labelling the **Main Headings**. Nonetheless, there was clarity and consistency in the *Subheadings*, the actual substance of what is meant to be patient-centered. Using the words most commonly found in the seven papers, here are the six components of patient-centered care over the decades and across the world:

- 1) **Patient** Experience (thoughts and feelings)
- 2) **Person** in Context (especially family)
- 3) **Discussion** of Goals, Preferences and Shared Decisions
- 4) **Relationship** including Empathy, Emotion and Sharing Power
- 5) **Clinician as Person**
- 6) **Co-ordination**.

The bottom line of this 20-year analysis is, the concepts are remarkably similar. To appreciate this more clearly, let us look at Table 2. All 7/7 papers contained the first four components; 3/7 included Clinician as Person; and 3/7 highlighted the health care system by including Co-ordination of Care (and sometimes Access and Continuity as well). Table 2 demonstrates the universality of the first four concepts within patient-centeredness.

Table 2: Comparison of Seven Patient-Centered Frameworks

	Patient-Centered Clinical Method	Whole Health Model	Mead & Bower	Institute of Medicine	Morgan & Yoder	Langberg et al.	Sturgiss et al.	TOTAL #
<b>Patient</b>	✓	✓	✓	✓	✓	✓	✓	7/7
<b>Person</b>	✓	✓	✓	✓	✓	✓	✓	7/7
<b>Discussion</b>	✓	✓	✓	✓	✓	✓	✓	7/7
<b>Relationship</b>	✓	✓	✓	✓	✓	✓	✓	7/7
<b>Clinician as Person</b>	X	X	✓	X	X	✓	✓	3/7
<b>Co-ordination</b>	X	X	X	✓	X	✓	✓	3/7

## The Whole Health Model and the Patient-Centered Clinical Method

This chapter concludes with a head-to-head comparison of the Whole Health Model and the Patient-Centered Clinical Method to highlight their complementarity.

The Whole Health Model, with its focus on what matters to the patient in the 10 areas suggested in the Circle of Health and the Patient-Centered Clinical Method, complement each other. Whole Health takes the patient's perspective; the Patient-Centered Clinical Method takes the clinician's perspective, answering: how can the clinician support the patient in discerning and prioritizing the areas to focus on or, to put it another way, what guidance can be provided to clinicians to support the patient in Whole Health?

For the patient to become an integrated person, the care must model that integration, in my view. At the most basic level, the care should be anchored by a single clinician who helps the patient pull together all 10 areas of the Whole Health Model. I strongly recommend a generalist primary care clinician as the desired conduit of this basic level of integration. Developing a strong trusted patient-clinician relationship over time is a potent force for health and healing (Pereira-Grey et al., 2018). Therefore, the following statements of the complementarity of the Whole Health Model and the Patient-Centered Clinical Method are predicated on the notion of one primary care clinician working with the patient in a continuity of care situation. Each patient has a personal primary care clinician who is patient-centered (Green, 2017).

As can be seen in Table 3, the head-to-head comparison of the Patient-Centered Clinical Method and the Whole Health Model, the elements of each line up well.

Table 3: Complementarity of the Patient-Centered Clinical Method and the Whole Health Model

<u>Patient-Centered Clinical Method</u> <u>Patient at the Centre</u>	<u>Whole Health Model/Initiative</u> <u>"Me" at the Centre</u>
<p>Exploring Health, Disease and the Illness Experience by following cues to:</p> <ul style="list-style-type: none"> <li>- Symptoms, Signs, Laboratory and other results</li> <li>- Meaning of health to the patient and aspirations for life</li> <li>- Patient's illness experience including feelings, ideas, function and expectations</li> <li>-</li> </ul>	<p>You are expert on your life #1            Aware of your thoughts and feelings #2</p>
<p>Understanding the Whole person in Context</p> <ul style="list-style-type: none"> <li>- Patient as a person</li> <li>- An individual developmental trajectory and personality</li> <li>- Spiritual dimensions</li> <li>- A family, social support and work</li> <li>- Community and culture</li> </ul>	<p>Surroundings – home, work place, neighbourhood, climate and environment            Experiences that affect emotions #4            Personal Development – ways you can grow #5            Family, friends, coworkers can affect emotions, mental and physical health  <ul style="list-style-type: none"> <li>- Reduce stress through relationships #8</li> </ul>           Spirituality – what gives meaning to life #9</p>
<p>Finding Common Ground</p> <ul style="list-style-type: none"> <li>- Mutual discussion between the patient and clinician on               <ul style="list-style-type: none"> <li>- the nature of the problems</li> <li>- the goals</li> <li>- the roles of each</li> </ul> </li> <li>- Reaching mutual agreement</li> </ul>	<p>Your values, goals and priorities #1            Set your health and well-being goals            Moving the body #3            Food and drink #6            Recharge #7            Power of the mind – mind-body approaches #10</p>
<p>Enhancing the Patient-Clinician Relationship</p> <ul style="list-style-type: none"> <li>- Surfacing emotion</li> <li>- Compassion, caring, empathy and trust</li> <li>- Power in the relationship</li> <li>- Continuity of the relationship and constancy</li> <li>- Engendering healing and hope</li> <li>- Clinician self-awareness</li> <li>- Transference and counter-transference</li> </ul>	<p>Reduce stress through relationships (including Patient-clinician relationship) #8            Relationships can affect emotional health #8            Be aware of thoughts and feelings #2</p>

The first of four components of the Patient-Centered Clinical Method is Exploring Health, Disease and the Illness Experience: the clinician exploring the patients' disease (symptoms, signs, laboratory and other investigations), health (patients' meaning of what health is and aspirations in life) and patients' illness experience including their feelings, ideas, function and expectations. This component aligns with the 1<sup>st</sup> and 2<sup>nd</sup> areas of focus in the Whole Health Model's Circle of Health, i.e. 1<sup>st</sup> You are expert on your life; and 2<sup>nd</sup> Be aware of your thoughts and feelings.

The second component of the Patient-Centered Clinical Method is Understanding the Whole Person, the patient as a person with: an individual developmental trajectory and personality; spiritual dimensions; a family, social support and work; and a community and culture. This component ties in almost word-for-word with the Whole Health's: 4<sup>th</sup> focus on Surroundings (home, work place, neighbourhood, climate and environment); 5<sup>th</sup> focus on Personal Development; 8<sup>th</sup> focus on family, friends and co-workers who may affect health in positive or stressful ways; and 9<sup>th</sup> What gives meaning to your life – spirituality.

The third component of the Patient-Centered Clinical Method is Finding Common Ground which promotes a mutual discussion between the patient and clinician of the nature of the problems, the goals and the roles of each culminating in mutual agreement of the way forward. The Whole Health Model promotes in the 1<sup>st</sup> focus, the patients' reflection on their values, goals and priorities and patients setting their own health and well-being goals. This is a more strength-based thought than in the Patient-Centered Clinical Method which in its third component is more problem-based. Next, the Whole Health Model explores four specific foci for patients to consider as part of their plan: 3<sup>rd</sup> Moving the Body; 6<sup>th</sup> Food and Drink; 7<sup>th</sup> Recharging approaches; and 10<sup>th</sup> Mind-Body approaches. The Patient-Centered Clinical Method would recommend that patients and their personal clinician discuss these approaches in relation to the patients' goals and ability to carry out the role required and come to mutual agreement on the foci to be included in the current plan, always updating the plan as the patient evolves.

The fourth component of the Patient-Centered Clinical Method, Enhancing the Patient-Clinician Relationship, describes surfacing emotion through compassion, caring, empathy and trust. It deals with power in the relationship. It stresses continuity of the relationship and consistency (a maintained presence) as essential ingredients. It describes the healing and hope engendered. It talks of clinician self-awareness and wisdom as well as transference and counter-transference. The Whole Health Model speaks of, in the 2<sup>nd</sup> focus, promoting the patients' awareness of thoughts and feelings; in the 8<sup>th</sup> focus, relationships and their effect on emotional health and reducing stress through relationships. I would add that the patient-clinician relationship can model positive relationships potentially improving emotional health.

In summary the complementary nature of the Patient-Centered Clinical Method and the Whole Health Model is striking. Nonetheless, they each have a different purpose. The Whole Health Model outlines for the patient an array of ways of being and a range of options to consider. The model begs the question – Who will help the patient weigh

these options and explore deeply the competing needs and aspirations to reveal a unique and patient-owned plan? One answer to this question is – clinicians who know how to be patient-centered, how to create a longstanding personal relationship of depth and trust which will help patients steer their own unique course. This is what the Patient-Centered Clinical Method offers – a framework for clinicians to hold in their heads – a way of approaching complex patients with broad needs. The Patient-centered Clinical Method has the potential to actuate the Whole Health Model.

### Key Messages in Chapter 2:

Most frameworks on patient-centeredness are conceptual models, while some are clinical methods i.e. how-to guides to clinicians.

Patient-centered frameworks show striking similarities in their elements; but the headings under which the elements are grouped use different terms from framework to framework.

Four components are universal in the literature: The Patient; The Person; The Discussion; and The Relationship.

The Whole Health Model and the Patient-centered Clinical Method complement each other.

Of all the frameworks, only the Patient-centered Clinical Method was derived from clinicians reflecting on what worked in practice; most of the others were based on a synthesis of literature.

## CHAPTER 3: EVIDENCE ON PATIENT-CENTERED CLINICAL OUTCOMES

### Results from a New Review

#### *Effects on Patient Outcomes*

A review of 16 papers was conducted to answer the question: what clinical outcomes have been used in trials of patient-centered interventions, and what outcomes were positively affected by such interventions? All papers chosen reported pragmatic randomized controlled trials since 2010 sourced from two systematic reviews (Smith et al., 2021; McMillian et al., 2013) and two recent papers which reviewed trials (Fortin et al., 2022; Stewart et al., 2021). I included only trials for which a main component of the intervention was directed at the patient-clinician clinical encounter. There may have also been components addressing the co-ordination of the health care system.

Table 4 shows that one-quarter (4 of 16) of the trials were conducted in the USA (Boyd et al., 2010; Hochhalter et al., 2010; Lynch et al., 2014; Wagner et al., 2012). Three were from the UK (Ford et al., 2019; Mercer et al., 2016; Salisbury et al., 2018), and three from the Netherlands (Nijhof et al., 2012; Spoorenberg et al., 2018; Verdoorn et

al., 2019). Two trials were conducted in Ireland (Garvey et al., 2015; O'Toole et al., 2021) and two in Canada (Fortin et al., 2021; Stewart et al., 2021). The remaining two were from elsewhere (Kari et al., 2021; Nygårdh et al., 2012). As required by the inclusion criteria, all 16 of the interventions were directed at the patient level (the patient-clinician encounter) but, seven of the 16 contained elements addressing the organizational level (co-ordination of care) and seven of the 16 included a training component for the clinicians. The vast majority (15 of 16) trials aimed the intervention at improving the patient and clinician's discussion of goals, preferences and shared decisions; two of these 15 also had elements of improving the care of the patients' experience (thoughts and feelings). One trial addressed improving the relationship between patient and clinician (empathy, emotion and sharing power). Given that there was so little variation in the types of interventions at the patient level, no comparisons could be made. Comparisons of the trials whose interventions included patient level only, patient level and organizational level, and those with training components, showed no discernable differences on outcomes.



Table 4: Description of Intervention Studies (Country, Intervention Type)

Country	#	%			
USA	4	25.0%			
UK	3	19.0%			
Netherlands	3	19.0%			
Ireland	2	12.5%			
Canada	2	12.5%			
Other	2	12.5%			
TOTAL	16	100.5%			
Intervention Type				#	% of 16
Patient Level				16	100%
Patient Experience			*2		
Person in Context			0		
Discussing Goals			15		
Relationship			1		
Organizational Level				7	44%
Training				**7	44%

\*Both of these studies also included Discussing Goals in the intervention.

\*\*Not necessarily the same studies as in the Organization Level.

Table 5 shows the types of outcome measures included in the trials as well as the number of different measures used and how many showed statistically significantly better outcomes in the intervention group compared to the control group. Clinical status outcome measures were used in two of the 16 studies; three measures in one study (HbA1c; percent reduction of HbA1c; and systolic blood pressure, Lynch et al., 2014) and blood pressure in the second study (Ford et al., 2019). Of these four measures only one (percent reduction in HbA1c) was significant, i.e. 25% (1 of 4).

Table 5: Outcome Measures: Type, Number of Measures and Percent of Measures Significant

Type of Outcome Measure	Studies Using this Type of Outcome		Number of Measurements		
			# used	# and % significant	
	#	% of 16		#	%
Clinical Status Measures	2	0.13%	4	1	25%
Patient Reported Outcome Measures – PROMs	14	87.5%	49	21	43%
Patient Reported Experience Measures – PREMs	5	31.3%	13	10	77%

Patient reported outcome measures (PROMs), such as activities of daily living and quality of life, were more frequently measured than were the clinical measures. Fourteen of the 16 trials used 49 measurements of which 21 (43%) were significant.

Patient reported experience measures (PREMs), such as ratings of continuity and coordination of care, and patient-perception of patient-centeredness, were somewhat frequently reported. Five of the 16 trials measured 13 PREMs of which 10 (77%) were significant.

One sees that the majority of trials say that patients are reporting better care; a substantial minority of trials report that patients' self-reported health is better; and only one-quarter reported improvements in clinical status measures. This suggests a mechanism whereby outcomes are affected by patient-centered interventions i.e. patients must notice that care is better (more patient-centered), then some patients may feel better as a result and for some (but fewer) patients, feelings are translated into physiologic improvements.

The most striking point from Table 5 is the paucity of clinical measures of patient outcomes. Patient reported outcomes were vastly preferred by the researchers who study patient-centered interventions. This preference for patient reported outcomes aligns philosophically with a commitment to testing patient-centered innovations. In addition, the importance of patient reported outcomes is supported by a robust literature which directly connects self-rated health and mortality (Idler et al., 1997). Patient-reported health outcomes are not to be dismissed as soft and unworthy. On the contrary, they represent the winning combination of both the preferred principle, given their fit with a patient-centered orientation, and the consequential construct, in that the measures show significant impact on mortality.

The review of 16 studies revealed three other themes relevant to the Whole Health Initiative: barriers to implementation; equity issues; and the value of qualitative findings.

#### *Barriers to Implementation of Patient-centered Interventions*

Implementation failures have occurred because of inadequate time for training the team (Fortin et al., 2021; Ngangue et al., 2021) and the stressful context of practice (Salisbury et al., 2018; Mann et al., 2019). Some crucial components of their interventions were not actually implemented by some participating practices. The degree to which the intervention was created by the clinicians (and valued by the clinicians) may affect implementation (Stewart et al., 2021). Mercer et al. (2016), in particular, co-created the intervention with clinicians and its intent was to strengthen the very aspects of practice highly valued by the clinicians, i.e. more time with the patient and continuity of care. It is worth noting that Mercer et al.'s study found strong associations with positive outcomes. It seems that an intervention may not be fully implemented unless, first, it is congruent with clinicians' values and, second, the context is helpful.

#### *Equity Issues*

Patient-centered care has been found to be a force for equity (in Jani et al.'s 2012 prospective observational study), in that the care was effective across all levels of deprivation, supporting its unifying potential. However, this can only be the case if specific, mutually agreed-upon treatments are cost neutral to the patient, as was found by Stewart et al. (2021).

### *Value of Qualitative Findings*

The implementation and equity issues were not revealed by the trials themselves but by qualitative studies aligned/embedded in the trials. Three in particular, are noteworthy. Salisbury et al.'s trial showed non-significant impact of the patient-centered intervention on all PROMs; but their qualitative study uncovered specific implementation failures, including participating clinicians dropping major components because of lack of staff support and pressures in the health care system (Mann et al., 2019). Fortin et al.'s trial showed implementation and training issues in their qualitative study (Ngangue et al., 2021). Stewart et al.'s 2021 trial showed effectiveness of the patient-centered intervention only for patients with an income of >\$50K CAD per year; their qualitative study revealed that crucial aspects of the intervention actually accrued out-of-pocket expenses for patients and therefore were not accessible universally. These nuances regarding implementation barriers and equity in patient-centered care were only evident from robust qualitative studies accompanying the trials

### Key Messages in Chapter 3

Improving patients' health clinical/physiologic status through patient-centered interventions has proved to be an elusive goal. Clinical status measures were used infrequently in the studies reviewed, and were affected by the intervention only 25% of the instances in which they were measured.

Patient-reported outcome measures (PROMs) were most commonly used and they were affected 43% of the time.

Patient-reported experience measures (PREMs) were somewhat common and they were influenced 77% of the time.

Barriers to implementation explained the lack of effect of some interventions.

Patient-centered interventions can be a force for equity.

Qualitative studies made major contributions to our understanding of how patient-centered care works and are highly recommended.

## CHAPTER 4: PATIENT-CENTERED SYSTEMS APPROACHES

### An Evidence-based Framework

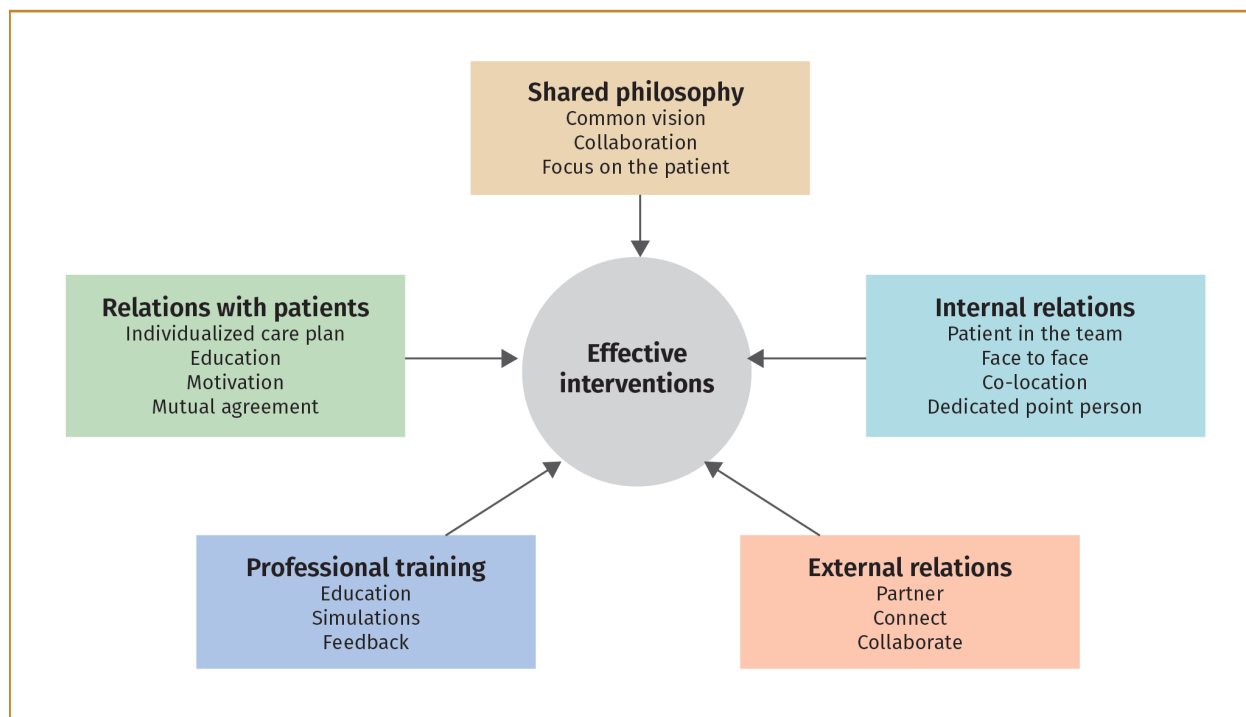
We are now shifting our gaze from the clinical encounter to the health care system. We seek guidance on how to successfully create a more patient-centered health care system. A useful evidence-informed framework is presented here which was selected for several reasons: it takes a systems view; it is adaptable to different types of new or ongoing integrated programs; its principles, based in the world literature, are somewhat universal and not wedded to one jurisdiction; it is inspired by valuing patient input; it is founded on real-world naturally occurring experiments for which qualitative and/or quantitative evaluations were conducted. This framework has much in common with the more generic Consolidated Framework for Implementation Research (Damschroder et al., 2009) except the framework presented here is rooted in patient-centered care.

In prior sections of this report we noted that interventions to improve patient-centered care addressed three levels for consideration: the patient level; the organizational level; and the training approach. The framework presented here also subsumes these levels and explains how they can fit together and what elements fall within these levels.

The evidence for this framework arises from two sources: a scoping review of the English language literature (53 papers, Poitras et al., 2018); and a realist synthesis of Canadian innovations (12 innovations) which had thorough evaluations (Brown et al., 2015). The framework used key findings from both sources to highlight the evidence-informed components for a patient-centered integrated and co-ordinated system of care.

Five overarching components are shown in Figure 1 (Fortin & Stewart, 2021). Each component includes several smaller elements. The components were predicated on evidence of positive effects on patient health outcomes and health care use.

Figure 1: Evidence-based Framework for Patient-centered Integrated Systems \*



\*Reprinted from Fortin and Stewart (2021) with permission of the authors and publisher.

Given the focus of this report up to now, we can first consider the upper left of the diagram in Figure 1, Relations with Patients. The ideas here are quite congruent with the previous sections of this report. A key ingredient is a care plan based on patient goals, respecting patient values and relying on either explicit questions/prompts or on the clinicians listening closely and following patients' cues. Any patient education is built on patient request and their specific needs; this is accompanied by attention to motivating the patient and sustaining that motivation. This component is based on patient contexts with sufficient time for discussion of patient goals and achieving mutual agreement.

We next consider Professional Training seen in the lower left of Figure 1. The education targeted the skills on how to do integrated care as well as how to engage in patient-centered care including careful listening and following the patients' cues. The recommended ways to conduct this education were proactive with simulated patients or role playing plus feedback from peers.

Two components of this framework explicitly concentrate on the integration and co-ordination of care, seen on the right side of Figure 1. Internal Relations refers to how the team members, probably working in close proximity, co-ordinate and communicate with each other. The patient ought to be considered a full member of the team. There needs to be an identified point-person to bridge the patient to all professionals involved (co-located or not). Meetings of all team members need to foster cooperative relationships and positive team functioning.

At a wider level, is the component called External Relations. The care team connects with local and regional decision-makers to avoid duplication of services and confusion for the patient. There must be strong links with hospitals particularly to arrange better transitions of care. Partnerships with community organizations are recommended to offer patients more options for assistance, as are connections with home care and other support services.

At the apex of this diagram in Figure 1 is perhaps the most essential aspect of integrated and co-ordinated health care systems, a Shared Philosophy. Time used in a process to create a shared philosophy is well worth the effort; such a process may culminate in a vision statement or terms of reference. A collaboration in action requires an accompanying sharing of roles and professional experiences identifying gaps and redundancies which might involve compromise. Strong leadership is needed. A focus on the patient tends to be the unifying idea that harnesses the centrifugal forces.

These elements are not simply opinions of the authors. They are the elements which were linked, in the papers reviewed, with positive patient health outcomes or reduced utilization of services.

Key Messages in Chapter 4



Evidence shows that high functioning health care systems are anchored in a shared philosophy of patient-centeredness.

Training of all players and attention to internal team relationships as well as linkages to community agencies and hospitals, are highlighted.

## CHAPTER 5: LESSONS AND STEPS TO MOVE FROM IMPLEMENTATION TO SCALING-UP

We have just seen the complexity of a co-ordinated health care system with its five evidence-based elements in Chapter 4. How can one think about replicating, spreading, adapting and sustaining such a successful system in other locales? To assist in this daunting task I have reviewed the literature on scaling-up. The purpose of this Chapter is to help define scaling-up and explain its attributes, based on scaling-up frameworks found in a scoping review of the world, English-language literature

### Introduction:

Scaling-up is of great interest to researchers and innovators in health services across the globe. Nonetheless, Ben Charif et al. (2017) found that “scaling-up is an ill-defined and under-theorized concept... there was little guidance on how to assess or report scaling-up strategies...most studies focused on the evidence-based practice itself” rather than its scaling-up. Furthermore, the “blueprint approaches to scaling-up health services do not fit the dynamic and unpredictable ways in which health services can expand and be sustainable” (Paina & Peters, 2012). To amplify this point, authors have found that “more than anything else, scaling-up is about... leadership, vision, values and mindset... and... incentives...” (Hartmann & Linn, 2008).

This rich and complex process deserves more attention.

### Defining Scaling-up:

The terms spread and scaling-up are sometimes confused. Spread is replication or adoption of an innovation somewhere else (Barker et al., 2016; Ben Charif et al., 2017; Milat et al., 2015; Greenhalgh & Papoutsi, 2019). Scaling-up, on the contrary, is “expanding, adapting and sustaining successful programs... in different places and over time to reach a greater number of people” (Hartmann & Linn, 2008). The increase in coverage may be from one geographic location to another or from one population to another (Pallas et al., 2013); this type of expansion is called horizontal scaling (Bennett et al., 2017; ExpandNet & World Health Organization, 2010; Euregio & World Health Organization, 2016). Vertical scale-up is institutionalization through a comprehensive change in policy, political, legal, budgetary and other system changes (ExpandNet & World Health Organization, 2010). Several authors stress that scaling-up is a process or series of processes to expand the coverage and equitable access of an innovation (Milat et al., 2015; Willis et al., 2016).

## Attributes and Frameworks of Scaling-up

Papers reviewed for this Scoping Review were selected based on a search strategy focusing on primary care and public health. After reviewing abstracts of 202 papers, the research team and I selected 49 for an in-depth review, inspecting the scaling-up frameworks and other relevant attributes; 25 are cited below.

From the 49 papers on frameworks for scaling-up, four themes emerged:

1. frameworks describing the sequence of scaling-up activities;
2. frameworks stressing context and environmental factors;
3. infrastructure requirements for scaling-up; and
4. research and evaluation embedded in scaling-up.

### *Theme 1: Frameworks Describing the Sequence of Scaling-up Activities*

Eleven frameworks used stages or steps to describe scaling-up. Nine of these included three of four stages, such as Milat's four stages: access, develop, prepare and implement (Centre for Epidemiology and Evidence, 2014; Milat et al., 2015; Milat et al., 2016; Euregio and World Health Organization, 2016). A more helpful series of steps is proposed by the WHO ExpandNet & World Health Organization program (ExpandNet & World Health Organization, 2010) with nine steps:

- 1) planning actions to increase the scalability;
- 2) increasing the capacity of the end user organization;
- 3) assessing the environment and planning actions to increase the potential for success;
- 4) increasing the capacity of the resource team to support scale up;
- 5) making strategic choices to support vertical scaling up;
- 6) making strategic choices to support horizontal scaling up (expansion/replication);
- 7) determining the role of diversification;
- 8) planning actions to address spontaneous scaling up;
- 9) finalizing the scaling-up strategy and identifying next steps.

These nine steps begin to uncover some complexities in the scaling-up process that foreshadow the next section on context.

### *Theme 2: Frameworks Stressing Context and Environmental Factors*

Seventeen papers of the 49 discussed notions on a different plain than the sequential steps we read in the preceding paragraph. One author said, "Context is an actor in the drama rather than background" (Øvretveit et al., 2017). Authors speak of adoption mechanisms such as: leadership; communication; social network; culture; and persistence (Barker et al., 2016). Another author presents the ideas of: acknowledging unpredictability; recognising self-organization; facilitating interdependencies, encouraging sense making; developing adaptive capability in staff; attending to human relationships; and harnessing conflict productively (Greenhalgh & Papoutsis, 2019).

Ideas arising from the 17 papers array themselves from a narrow focus to a broad societal lens. The first, most focused idea attends to the interventions themselves: how simple or complex are they (Bennett et al., 2017); what is the level of evidence supporting the innovation (Atun et al., 2010); in what ways is it suitable for scaling-up (ExpandNet & World Health Organization, 2010; Centre for Epidemiology and Evidence, 2014); can the intervention be adapted to different locales (Bennett et al., 2017). To answer these questions, the intervention should be clarified (ExpandNet & World Health Organization, 2010) with a clear vision of its goal (Gillespie et al., 2015) and its key features described. Leaders articulate the unifying vision (ExpandNet & World Health Organization, 2010).

Next are the implementers; the catalysts and champions (Gillespie et al., 2015) who want to adapt and spread the intervention (Bennett et al., 2017) and the team that supports the catalysts in this task of explaining, advocating, and expressing the vision (Gillespie et al., 2015; ExpandNet & World Health Organization, 2010).

Next comes ensuring a fit of the innovation with the user (i.e. the adopting community) (Pallas et al., 2013; Milat et al., 2015). Some considerations are the strength of the adopting community's leadership, and the extent and diversity of engagement at the local level (Atun et al., 2010). There ought to be supportive policies and programs (Spicer et al., 2014).

This leads directly to the next idea, the notion of promoting community acceptance (Arrossi et al., 2017), an explicit process of preparing the context by giving support to (rather than hindering) positive evolution and by assessing readiness for change (Øvretveit et al., 2017). One may need to increase the capacity of both the implementers and the adopting community and be ready to delay implementation until the context is ready (Øvretveit et al., 2017).

There must be political support and a supportive policy environment (Hirschhorn et al., 2013). Institutions must be willing to change (Hartmann & Linn, 2008). To encourage government institutions to adopt and finance the innovation, one must: provide advocacy; present evidence; involve government; invoke policy champions and networks; and harmonize and align policies (Spicer et al., 2014). This is predicated on a deep understanding of the political, social and cultural context of the adopting community (ExpandNet & World Health Organization, 2010).

### *Theme 3: Infrastructure Requirements for Scaling-up*

Thirteen papers listed infrastructure requirements of which the three most common were: 1) organizational and management systems (n=10); 2) financing (n=8); and 3) learning/training support (n=5). Table 6 lists all the infrastructure requirements grouped according to a recommended typology of: structure, strategy and support (Øvretveit et al., 2017). These provide ideas that include technical aspects of an innovation such as organizational management; data systems; and financing. However, also highlighted are ideas of facilitation and networking noted in Theme 2, such as planning, leadership, promotion, learning, partnering and garnering political support. One author reminds us

that "the larger, more ambitious and more politically contested the spread challenge, the more ecological and social practice perspectives will need to supplement (or replace) 'mechanical' efforts to replicate an 'intervention" (Greenhalgh & Papoutsi, 2019).

Table 6: Infrastructure Requirements for Scaling-up

Type of requirement	Requirement	# of papers (out of the 13)	References
Structure	- Organizational management, governance and co-ordination systems	10	ExpandNet & World Health Organization, 2010; Pallas et al., 2013; Euregio & World Health Organization, 2016; Arrossi et al., 2017; Øvretveit et al., 2017; Gillespie et al., 2015; Hirschhorn et al., 2013; Pérez-Escamilla et al., 2018; Milat et al., 2015
	- Data systems and analysis support	1	Barker et al., 2016
Strategy	- Planning	1	Milat et al., 2015
	- Leadership, vision, values	1	Hartmann & Linn, 2008
	- Promotion	2	Pérez-Escamilla et al., 2018; Milat et al., 2015

Support	- Learning/curriculum support	5	Barker et al., 2016; Euregio & World Health Organization, 2016; Pérez-Escamilla et al., 2018; Milat et al., 2015; ExpandNet & World Health Organization, 2010
	- Partnering to enable the context, attending to cultural issues	2	Euregio & World Health Organization, 2016; Gillespie et al., 2015
	- Financing	8	ExpandNet & World Health Organization, 2010; Euregio & World Health Organization, 2016; Pérez-Escamilla et al., 2018; Milat et al., 2015; Subramanian et al., 2011; Hirchhorn et al., 2013; Øvretveit et al., 2017
	- Political support	1	Euregio & World Health Organization, 2016

One begins to understand the diverse talents needed on a scaling-up team. There must be strengths in planning as well as in implementation (Subramanian et al., 2011). The team must balance flexibility with the value of standardization; the team must be wise about transferring ownership of the program to the receiving community (Hirschhorn et al., 2013).

Individuals on the team may need to have diverse skills themselves as well as the team as a whole requiring a diversity of talents (Milat et al., 2015; ExpandNet & World Health Organization, 2010) from the technical to the facilitating to the political.

#### *Theme 4: Research and Evaluation Embedded in Scaling-up*

We learned in Chapter 3 that implementing patient-centered interventions took more time and training than had been expected (Fortin et al. 2021). Similarly, scaling-up is a lengthy process. It can/ought to begin with research that provides practice-based evidence on real-world experiences to inform the development of the intervention in the first place (Stewart et al., 2021; Reis et al., 2016). Next is the research evaluating the early intervention in order to provide fodder for advocacy for scaling-up (Reis et al., 2016). During the lengthy scaling-up process, there are a number of useful strategies for monitoring, evaluation and research (Subramanian et al., 2011; Øvretveit et al., 2017; ExpandNet & World Health Organization, 2010; Hartmann & Linn, 2008; Pérez-Escamilla et al., 2018; Milat et al., 2015; Arrossi et al., 2017). It is helpful for the monitoring and its data-collection to be specific and thoroughly embedded in the process of scaling-up by regular use of the information for adaptive decision-making (ExpandNet & World Health Organization, 2016) and for the planning of learning opportunities (Gillespie et al., 2015). This requires clarity and unanimity of goals and sub-goals, accompanied by ways of measuring these sub-goals. A somewhat similar line of reasoning recommends that multiple perspectives be sought to discern the sub-goals, recognising that there may be a variety of pathways to the desired overarching goal (Hanson et al., 2010).

As well, it is noted that evaluation approaches should use a number of designs including quantitative and qualitative, taking account of the complexity of both the interventions and the process of scaling-up.

In addition to the attainment of specific sub-goals mentioned above, scaling-up projects typically use the RE-AIM outcomes, i.e. reach, effectiveness, adoption, implementation and maintenance (Arrossi et al., 2017) or similar outcomes (Hirschhorn et al., 2013; Milat et al., 2015; Menon et al., 2014). Furthermore, the equity of the program must be assessed (Hirschhorn et al., 2013; Menon et al., 2014), as well as its social impact (Fixsen et al., 2017).

#### Key Messages in Chapter 5:

Just as a patient-centered approach adapts to the patients' preferences, experience and context, so too does a scaling-up process engage with the adopting community's acceptance, strengths and context.

Just as a patient-centered clinician must be flexible in response to the patient's goals, the scaling-up must be flexible in adapting the intervention to suit the new context.

The nine requirements for scaling-up include human elements of leadership, partnering, promotion and learning, as well as technical elements of organization management, data systems and financing.

## CHAPTER 6: CONCLUSIONS

After reviewing the literatures on patient-centered concepts, the effectiveness of patient-centered interventions, frameworks for co-ordinated health care systems and scaling-up, we can confidently conclude that a Whole Health Initiative that includes the four patient-centered components, will result in a positive patient experience of care and considerable improvement in patients' self-rated health.

The four universal patient-centered components are: 1) the patients' experience including illness, thoughts and feelings; 2) the person in context especially family; 3) mutual discussion of goals, preferences and decisions; and 4) relationship between the patient and clinician, including empathy, emotion and sharing power.

We can also have confidence that a Whole Health Initiative combined with patient-centered components, will work for patients at all levels of deprivation, if patient out-of-pocket expenses are covered.

To implement and scale-up the Whole Health Initiative, a nuanced program should be envisaged to meet the unique needs of patients, clinicians, clinical teams and the community who seeks to adopt the initiative. Finding common ground, sharing a vision, leadership, flexibility, along with technical support, are required to fulfill this destiny.



## References

- Arrossi S, Paolino M, Thouyaret L, Laudi R, Campanera A. Evaluation of scaling-up of HPV self-collection offered by community health workers at home visits to increase screening among socially vulnerable under-screened women in Jujuy Province, Argentina. *Implement Sci.* 2017 Feb 13;12(1):17. doi: 10.1186/s13012-017-0548-1. PMID: 28193227; PMCID: PMC5307871.
- Atun R, de Jongh T, Secci F, Ohiri K, Adeyi O: Integration of targeted health interventions into health systems: a conceptual framework for analysis. *Health Policy Plan* 2010, 25:104-111.
- Balint E. The possibilities of patient-centered medicine. *J R Coll Gen Pract.* 1969 May;17(82):269-76.
- Balint M. *The doctor, his patient, and the illness.* New York, NY: International Universities Press; 1957.
- Barker PM, Reid A, Schall MW. A framework for scaling up health interventions: lessons from large-scale improvement initiatives in Africa. *Implement Sci.* 2016 Jan 29;11:12. doi: 10.1186/s13012-016-0374-x. PMID: 26821910; PMCID: PMC4731989.
- Ben Charif A, Zomahoun HTV, LeBlanc A, Langlois L, Wolfenden L, Yoong SL, Williams CM, Lépine R, Légaré F. Effective strategies for scaling up evidence-based practices in primary care: a systematic review. *Implement Sci.* 2017 Nov 22;12(1):139. doi: 10.1186/s13012-017-0672-y. PMID: 29166911; PMCID: PMC5700621.
- Bennett S, Mahmood SS, Edward A, Tetui M, Ekirapa-Kiracho E. Strengthening scaling up through learning from implementation: comparing experiences from Afghanistan, Bangladesh and Uganda. *Health Res Policy Syst.* 2017 Dec 28;15(Suppl 2):108. doi: 10.1186/s12961-017-0270-0. PMID: 29297353; PMCID: PMC5751808.
- Boyd CM, Reider L, Frey K, Scharfstein D, Leff B, Wolff J, Groves C, Karm L, Wegener S, Marsteller J, Boult C. The effects of guided care on the perceived quality of health care for multi-morbid older persons: 18-month outcomes from a cluster-randomized controlled trial. *J Gen Intern Med.* 2010 Mar;25(3):235-42. doi: 10.1007/s11606-009-1192-5.
- Brown JB, Chouinard M-C, Ryan BL, Januzi L, Diallo BB, Bouhali T, Stewart M, Fortin M. Facets of Interventions Associated with Outcomes of Chronic Disease Prevention and Management Programs in Two Canadian Provinces: A Realist Synthesis, Paper Presentation at NAPCRG 43rd Annual Meeting, Oct 27, 2015, Cancun, Mexico.

Centre for Epidemiology and Evidence. Milat AJ, Newson R, and King L. Increasing the scale of population health interventions: A guide. Evidence and Evaluation Guidance Series, Population and Public Health Division. Sydney: NSW Ministry of Health, 2014.

Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009 Aug 7;4:50. doi: 10.1186/1748-5908-4-50. PMID: 19664226; PMCID: PMC2736161.

Dwamena F, Holmes-Rovner M, Gauden CM, Jorgenson S, Sadigh G, Sikorskii A, Lewin S, Smith RC, Coffey J, Olomu A. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev.* 2012 Dec 12;12:CD003267. doi: 10.1002/14651858.CD003267.pub2.

Euregio MR, and World Health Organization. "Scaling up projects and initiatives for better health: from concepts to practice." (2016).

ExpandNet, World Health Organization. Nine steps for developing a scaling-up strategy, 2010, <https://expandnet.net/PDFs/ExpandNet-WHO%20Nine%20Step%20Guide%20published.pdf>. NOTE: this is the overarching expand net website Expandnet Scaling-Up Health Service Innovations. [<http://www.expandnet.net>].

Fixsen DL, Blase KA, Fixsen AA. Scaling effective innovations. *Criminol Public Policy.* 2017;16:487-99.

Ford JA, Lenaghan E, Salter C, Turner D, Shiner A, Clark AB, Murdoch J, Green C, James S, Koopmans I, Lipp A, Moseley A, Wade T, Winterburn S, Steel N. Can goal-setting for patients with multimorbidity improve outcomes in primary care? Cluster randomised feasibility trial. *BMJ Open.* 2019 Jun 3;9(6):e025332. doi: 10.1136/bmjopen-2018-025332.

Fortin M, Stewart M, Ngangue P, Almirall J, Bélanger M, Brown JB, Couture M, Gallagher F, Katz A, Loignon C, Ryan BL, Sampalli T, Wong ST, Zwarenstein M. Scaling up patient-centered interdisciplinary care for multimorbidity: a pragmatic mixed-methods randomized controlled trial. *Ann Fam Med.* (2021) 19:126-34. doi: 10.1370/afm.2650 8.

Fortin M, Stewart M. Implementing patient-centred integrated care for multiple chronic conditions: Evidence-informed framework. *Can Fam Physician.* 2021 Apr 1; 67 (4): 235-238, DOI: 10.46747/cfp.6704235.

Fortin M, Stewart M, Almirall J, Beupré P. Challenges in Multimorbidity Research: Lessons Learned From the Most Recent Randomized Controlled Trials in Primary Care. *Front Med (Lausanne)*. 2022 Feb 24, 9: p.815783, DOI: 10.3389/fmed.2022.815783.

Garvey J, Connolly D, Boland F, Smith SM. OPTIMAL, an occupational therapy led self-management support programme for people with multimorbidity in primary care: a randomized controlled trial. *BMC Fam Pract*. 2015 May 12;16:59. doi: 10.1186/s12875-015-0267-0.

Gillespie S, Menon P, Kennedy AL. Scaling up impact on nutrition: what will it take? *Adv Nutr*. 2015 Jul 15;6(4):440-51. doi: 10.3945/an.115.008276. PMID: 26178028; PMCID: PMC4496740.

Green LA. Will people have personal physicians anymore? Dr Ian McWhinney Lecture, 2017. *Can Fam Physician*. 2017 Dec;63(12):909-912.

Greenhalgh T, Papoutsi C. Spreading and scaling up innovation and improvement. *BMJ*. 2019 May 10;365:l2068. doi: 10.1136/bmj.l2068. PMID: 31076440; PMCID: PMC6519511.

Hanson K, Cleary S, Schneider H, Tantivess S, Gilson L. Scaling up health policies and services in low- and middle-income settings. *BMC Health Serv Res*. 2010 Jul 2;10 Suppl 1(Suppl 1):l1. doi: 10.1186/1472-6963-10-S1-l1. PMID: 20594366; PMCID: PMC2895744.

Hartmann A, Linn JF. Scaling up: a framework and lessons for development effectiveness from literature and practice. *Development*. Washington (DC): Wolfensohn Center for Development, Brookings Institution; 2008.

Hirschhorn LR, Talbot JR, Irwin AC, May MA, Dhavan N, Shady R, Ellner AL, Weintraub RL. From scaling up to sustainability in HIV: potential lessons for moving forward. *Global Health*. 2013 Nov 7;9:57. doi: 10.1186/1744-8603-9-57. PMID: 24199749; PMCID: PMC3826849.

Hochhalter AK, Song J, Rush J, Sklar L, Stevens A. Making the Most of Your Healthcare intervention for older adults with multiple chronic illnesses. *Patient Educ Couns*. 2010 Nov;81(2):207-13. doi: 10.1016/j.pec.2010.01.018

Idler EL, Benyamini Y. Self-rated health and mortality: a review of twenty-seven community studies. *J Health Soc Behav*. 1997 Mar;38(1):21-37.

Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington (DC): National Academies Press (US); 2001.

Jani B, Bikker AP, Higgins M, Fitzpatrick B, Little P, Watt GC, Mercer SW. Patient centredness and the outcome of primary care consultations with patients with depression in areas of high and low socioeconomic deprivation. *Br J Gen Pract.* 2012 Aug;62(601):e576-81. doi: 10.3399/bjgp12X653633.

Jonas WB, Rosenbaum E. The Case for Whole-Person Integrative Care. *Medicina (Kaunas).* 2021 Jun 30;57(7):677. doi: 10.3390/medicina57070677.

Kari H, Äijö-Jensen N, Kortejärvi H, Ronkainen J, Yliperttula M, Laaksonen R, Blom M. Effectiveness and cost-effectiveness of a people-centred care model for community-living older people versus usual care – A randomised controlled trial. *Res Social Adm Pharm.* 2021 Jul 30:S1551-7411(21)00283-7. doi: 10.1016/j.sapharm.2021.07.025.

Langberg EM, Dyhr L, Davidsen AS. Development of the concept of patient-centredness - A systematic review. *Patient Educ Couns.* 2019 Jul;102(7):1228-1236. doi: 10.1016/j.pec.2019.02.023.

Levenstein JH, McCracken EC, McWhinney IR, Stewart MA, Brown JB. The patient-centred clinical method. 1. A model for the doctor-patient interaction in family medicine. *Fam Pract.* 1986 Mar;3(1):24-30. doi: 10.1093/fampra/3.1.24.

Lynch EB, Liebman R, Ventrelle J, Avery EF, Richardson D. A self-management intervention for African Americans with comorbid diabetes and hypertension: a pilot randomized controlled trial. *Prev Chronic Dis.* 2014 May 29;11:E90. doi: 10.5888/pcd11.130349.

Mann C, Shaw ARG, Guthrie B, Wye L, Man MS, Chaplin K, Salisbury C. Can implementation failure or intervention failure explain the result of the 3D multimorbidity trial in general practice: mixed-methods process evaluation. *BMJ Open.* 2019 Nov 6;9(11):e031438. doi: 10.1136/bmjopen-2019-031438. PMID: 31699734; PMCID: PMC6858134.

McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ. Patient-centered approaches to health care: a systematic review of randomized controlled trials. *Med Care Res Rev.* 2013 Dec;70(6):567-96. doi: 10.1177/1077558713496318. PMID: 23894060.

McWhinney IR. Beyond diagnosis: an approach to the integration of behavioral science and clinical medicine. *N Engl J Med.* 1972 Aug 24;287(8):384-7. doi: 10.1056/NEJM197208242870805.

Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med.* 2000 Oct;51(7):1087-110. doi: 10.1016/s0277-9536(00)00098-8.

Menon P, Covic NM, Harrigan PB, Horton SE, Kazi NM, Lamstein S, Neufeld L, Oakley E, Pelletier D. Strengthening implementation and utilization of nutrition interventions through research: a framework and research agenda. *Ann N Y Acad Sci* 2014;1332:39-59.

Mercer SW, Fitzpatrick B, Guthrie B, Fenwick E, Grieve E, Lawson K, Boyer N, McConnachie A, Lloyd SM, O'Brien R, Watt GC, Wyke S. The CARE Plus study - a whole-system intervention to improve quality of life of primary care patients with multimorbidity in areas of high socioeconomic deprivation: exploratory cluster randomised controlled trial and cost-utility analysis. *BMC Med*. 2016 Jun 22;14(1):88. doi: 10.1186/s12916-016-0634-2.

Milat AJ, Bauman A, Redman S. Narrative review of models and success factors for scaling up public health interventions. *Implement Sci*. 2015 Aug 12;10:113. doi: 10.1186/s13012-015-0301-6. PMID: 26264351; PMCID: PMC4533941.

Milat AJ, Newson R, King L, Rissel C, Wolfenden L, Bauman A, Redman S, Giffin M. A guide to scaling up population health interventions. *Public Health Res Pract*. 2016 Jan 28;26(1):e2611604. doi: 10.17061/phrp2611604. PMID: 26863167.

Morgan S, Yoder LH. A concept analysis of person-centered care. *J Holist Nurs*. 2012 Mar;30(1):6-15. doi: 10.1177/0898010111412189. PMID: 21772048.

Ngangue P, Brown JB, Forgues C, Ag Ahmed MA, Nguyen TN, Sasseville M, et al. Evaluating the implementation of interdisciplinary patient-centred care intervention for people with multimorbidity in primary care: a qualitative study. *BMJ Open*. (2021) 11:e046914. doi: 10.1136/bmjopen-2020-046914

Nijhof SL, Bleijenberg G, Uiterwaal CS, Kimpfen JL, van de Putte EM. Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial. *Lancet*. 2012 Apr 14;379(9824):1412-8. doi: 10.1016/S0140-6736(12)60025-7.

Nygårdh A, Malm D, Wikby K, Ahlström G. Empowerment intervention in outpatient care of persons with chronic kidney disease pre-dialysis. *Nephrol Nurs J*. 2012 Jul-Aug;39(4):285-93; quiz 294.

O'Toole L, Connolly D, Boland F, Smith SM. Effect of the OPTIMAL programme on self-management of multimorbidity in primary care: a randomised controlled trial. *Br J Gen Pract*. 2021 Mar 26;71(705):e303-e311. doi: 10.3399/bjgp20X714185.

Øvretveit J, Garofalo L, Mittman B. Scaling up improvements more quickly and effectively. *Int J Qual Health Care*. 2017 Dec 1;29(8):1014-1019. doi: 10.1093/intqhc/mzx147. PMID: 29177491.

Paina L, Peters DH. Understanding pathways for scaling up health services through the lens of complex adaptive systems. *Health Policy Plan* 2012;27:365-73.

Pallas SW, Minhas D, Pérez-Escamilla R, Taylor L, Curry L, Bradley EH. Community health workers in low- and middle-income countries: what do we know about scaling up and sustainability? *Am J Public Health*. 2013 Jul;103(7):e74-82. doi: 10.2105/AJPH.2012.301102. PMID: 23678926; PMCID: PMC3682607.

Pereira Gray DJ, Sidaway-Lee K, White E, Thorne A, Evans PH. Continuity of care with doctors-a matter of life and death? A systematic review of continuity of care and mortality. *BMJ Open*. 2018 Jun 28;8(6):e021161. doi: 10.1136/bmjopen-2017-021161. PMID: 29959146; PMCID: PMC6042583.

Pérez-Escamilla R, Hromi-Fiedler AJ, Gubert MB, Doucet K, Meyers S, Dos Santos Buccini G. Becoming Breastfeeding Friendly Index: Development and application for scaling-up breastfeeding programmes globally. *Matern Child Nutr*. 2018 Jul;14(3):e12596. doi: 10.1111/mcn.12596. PMID: 29468832; PMCID: PMC6866061.

Poitras ME, Maltais ME, Bestard-Denommé L, Stewart M, Fortin M. What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC Health Serv Res*. 2018 Jun 14;18(1):446. doi: 10.1186/s12913-018-3213-8. PMID: 29898713; PMCID: PMC6001147.

Reis RS, Salvo D, Ogilvie D, Lambert EV, Goenka S, Brownson RC; Lancet Physical Activity Series 2 Executive Committee. Scaling up physical activity interventions worldwide: stepping up to larger and smarter approaches to get people moving. *Lancet*. 2016 Sep 24;388(10051):1337-48. doi: 10.1016/S0140-6736(16)30728-0. PMID: 27475273; PMCID: PMC5193005.

Salisbury C, Man MS, Bower P, Guthrie B, Chaplin K, Gaunt DM, et al. Management of multimorbidity using a patient-centred care model: a pragmatic cluster-randomised trial of the 3D approach. *Lancet*. 2018 Jul 7;392(10141):41-50. doi: 10.1016/S0140-6736(18)31308-4.

Smith SM, Wallace E, O'Dowd T, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. *Cochrane Database Syst Rev*. 2021 Jan 15;1(1):CD006560. doi: 10.1002/14651858.CD006560.pub4.

Spicer N, Bhattacharya D, Dimka R, et al. Scaling-up is a craft not a science: Catalysing scale-up of health innovations in Ethiopia, India and Nigeria. *Soc Sci Med*. 2014;121:30-8.

Spoorenberg SLW, Wynia K, Uittenbroek RJ, Kremer HPH, Reijneveld SA. Effects of a population-based, person-centred and integrated care service on health, wellbeing and self-management of community-living older adults: A randomised controlled trial on Embrace. *PLoS One*. 2018 Jan 19;13(1):e0190751. doi: 10.1371/journal.pone.0190751.

Stewart M, McWhinney IR, Buck CW. The doctor/patient relationship and its effect on outcome. *J R Coll Gen Pract*. 1979;29(199):77-81.

Stewart M, Brown JB, Weston WW, McWhinney IR, McWilliam CL, Freeman TR. *Patient-Centered Medicine: Transforming the Clinical Method*, 3rd Edition, Radcliffe Publishing Ltd, Oxford UK, 2014.

Stewart M, Fortin M, Brown JB, Ryan BL, Pariser P, Charles J, Pham TN, Boeckxstaens P, Reichert SM, Zou GY, Bhattacharya O, Katz A, Piccinini-Vallis H, Sampalli T, Wong ST, Zwarenstein M. Patient-centred innovation for multimorbidity care: a mixed-methods, randomised trial and qualitative study of the patients' experience. *Br J Gen Pract*. 2021 Mar 26;71(705):e320-e330. doi: 10.3399/bjgp21X714293.

Stewart M, Weston WW, Brown JB, McWhinney IE, McWilliam C, Freeman TR. *Patient-Centered Medicine: Transforming the Clinical Method*, Thousand Oaks, CA: Sage Publications, 1995.

Sturgiss E, Pearl A, Richard L, Ball L, Hunik L, Chai TL, Lau S, Vadasz D, Russell G, Stewart M. Who is at the centre of what? A scoping review of the conceptualisation of 'centredness' in healthcare, *BMJ Open* (submitted), 2022.

Subramanian S, Naimoli J, Matsubayashi T, Peters DH. Do we have the right models for scaling up health services to achieve the Millennium Development Goals? *BMC Health Serv Res*. 2011 Dec 14;11:336. doi: 10.1186/1472-6963-11-336. PMID: 22168915; PMCID: PMC3260120.

VA Whole Health. [va.gov/wholehealth/circle-of-health/index.asp](https://va.gov/wholehealth/circle-of-health/index.asp). Accessed Feb 23, 2022.

Verdoorn S, Kwint H-F, Blom JW, et al. Effects of a clinical medication review focused on personal goals, quality of life, and health problems in older persons with polypharmacy: a randomised controlled trial (DREAMeR-study). *PLoS Med*. 2019 May 8;16(5):e1002798. doi: 10.1371/journal.pmed.1002798.

Wagner PJ, Dias J, Howard S, Kintziger KW, Hudson MF, Seol YH, Sodomka P. Personal health records and hypertension control: a randomized trial. *J Am Med Assoc*. 2012 Jul-Aug;19(4):626-34. doi: 10.1136/amiainl-2011-000349.

Weston WW, Brown JB, Stewart MA. Patient-centred interviewing. Part I: Understanding patients' experiences. *Can Fam Physician*. 1989; 35: 147–51.

Willis CD, Riley BL, Stockton L, Abramowicz A, Zummach D, Wong G, et al. Scaling up complex interventions: insights from a realist synthesis. *Health Res Policy Syst*. 2016;14:88.