World Health Organization

European Region

Therapeutic patient education

An introductory guide

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ABSTRACT

Therapeutic patient education is a structured person-centred learning process that supports individuals living with chronic conditions to self-manage their own health by drawing on their own resources, supported by their carers and families. It is carried out by trained health professionals and is adapted to the patient and their condition and continues over the patient's lifetime. It is an integral part of treatment for chronic conditions and can lead to better health outcomes and improved quality of life, while making best use of health-care services and other resources. The purpose of this guide is to equip policy-makers and health professionals to provide better access to effective therapeutic patient education for all patients who are living with chronic conditions and can benefit from this approach. Specifically, the guide is for those responsible for designing, delivering or commissioning therapeutic patient education services for people living with chronic conditions and training programmes for health professionals who provide therapeutic patient education.

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FOREWORD

Therapeutic patient education is an effective intervention that has been shown to help people living with chronic conditions to better manage their illness and thereby achieve improved health outcomes, use of resources and quality of life. It has great potential for improving the lives of patients, while simultaneously easing the strain on health systems.

While it is widely implemented across the WHO European Region, there are opportunities for improving delivery and outcomes.

In 1998, the WHO Regional Office for Europe published a working paper on therapeutic patient education which served as an important resource for leaders and practitioners in the field. Developed with a group of academics, clinicians and educators from countries throughout the WHO European Region, it served to define therapeutic patient education, specify the skills that patients with chronic diseases should be taught, describe the content and structure of several interventions, and identify areas for action.

Now, 25 years later, there have been significant developments in the evidence base, clinical practice and the context in which therapeutic patient education – and broader self-management support - is provided.

What has also occurred in those 25 years are vast societal and demographic developments. The proportion of the Region's population that lives with a chronic condition is growing – and so are their needs. Those aged 65 and over are expected to make up one quarter of the population in the Region by 2050; a rise of over 70% over 20 years. The population pyramid is changing. And as we age, the likelihood of multimorbidity – the presence of two or more chronic conditions – grows.

At the same time, faced with multiple and complex threats to public health, health and care workforce shortages and competing calls on public finances; our health systems are rapidly and fundamentally changing, adapting, advancing, restructuring, digitizing, innovating and learning.

All of the above makes this new guide a timely and a necessary resource, taking into account current thinking and practice in order to equip policy-makers and health professionals across the WHO European Region to provide better access to effective therapeutic patient education for all patients living with chronic conditions.

Whether you are contributing to therapeutic patient education services for people living with chronic conditions or training health professionals to do so, I encourage you to use this guide to inform your work, so that we can achieve the best possible outcomes for patients and people with chronic conditions everywhere.

Hans Henri P. Kluge
Director
WHO Regional Office for Europe

ACKNOWLEDGEMENTS

ABBREVIATIONS

COPD	chronic obstructive pulmonary disease
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (programme)
IPF	idiopathic pulmonary fibrosis
NCD	noncommunicable disease
ORCHA	Organization for the Review of Health and Care Apps
PDSA	plan–do–study–act (cycles)
PREM	patient-reported experience measure
PROM	patient-reported outcome measure
SMART	specific, measurable, achievable, realistic and time-limited

1

INTRODUCTION

Chronic conditions[1] can be a huge burden on the health and well-being of individuals and communities. Many people living with one or more chronic condition are able to lead a healthy and fulfilling life. However, for some, it can restrict their ability to fully participate in home life and society.

> *Patients spend on average 2 hours per year with their health-care provider; the rest of the time they need to care for themselves.*
>
> **Professor Karin Lange, Head of the Medical Psychology Unit, Hannover Medical School, Hannover, Germany**

Therapeutic patient education is a "structured person-centred learning process" that supports individuals living with chronic conditions to "self-manage" their own health by drawing on their own resources, supported by their carers and families. It is carried out by trained health professionals and comprises several types of self-management support interventions. It is adapted to the patient and their condition and continues over the patient's lifetime. It is an integral part of treatment for chronic conditions and can lead to better health outcomes and improved quality of life *(1)*, while making best use of health-care services and other resources (Box 1).

Box 1. Note on terminology

This guide will use the term **person living with a chronic condition** to describe someone living with a chronic condition, and the term **patient** when a person living with a chronic condition interacts with the health system.

1.1 WHAT IS THE PURPOSE OF THE GUIDE?

Therapeutic patient education is a cost-effective intervention that has been shown to improve outcomes and quality of life for people living with chronic conditions *(2–4)*. However, even though it is carried out widely, it is not always provided effectively or well understood *(5,6)*.

This means that many people are suffering unnecessarily from chronic conditions, and resources in the health system and the wider society may be wasted.

The purpose of this guide is to equip policy-makers and health professionals across the WHO European Region to provide better access to effective therapeutic patient education for all patients who are living with chronic conditions and can benefit from this approach.

Specifically, the guide is for those responsible for designing, delivering or commissioning:

- therapeutic patient education services for people living with chronic conditions; and

- training programmes for health professionals who provide therapeutic patient education.

This guide was produced by WHO Regional Office for Europe to support countries in the Region, but it is likely to be of interest to those working in other parts of the world.

1.2 WHAT IS THE SCOPE OF THE GUIDE?

This guide is designed to give the reader enough information about therapeutic patient education so that they can confidently work with experts in their country to set up effective services. It is not intended to be used as a comprehensive textbook, but the guide does provide references and signposting to other resources that provide a more detailed discussion of topics.

The WHO Regional Office for Europe produced a working paper on therapeutic patient education in 1998 *(1)*. Since then, significant work in the field of self-management support and other related topics such as health literacy has furthered the understanding of therapeutic patient education. This guide takes account of these emerging approaches, concepts and modalities of delivery.

As the field has developed, key terms have been used in different ways and some definitions have remained imprecise, leading to difficulty in understanding and comparing research outcomes *(7)*. The guide addresses this by providing definitions for the reader throughout, while acknowledging where there are issues or inconsistencies in definition or usage.

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[1] Sometimes referred to as long-term conditions.

Therapeutic patient education brings together several types of intervention that support self-management. Although this guide focuses on therapeutic patient education, it also references other types of self-management support interventions and discusses the importance of using these interventions alongside therapeutic patient education.

Although a therapeutic patient education approach may be relevant for a wide range of conditions and ages, this guide has primarily focused on the experience of adults living with chronic noncommunicable diseases (NCDs) such as cardiovascular diseases (hypertension, heart failure), chronic respiratory diseases (asthma and chronic obstructive pulmonary disease (COPD)) and diabetes.

> *On average, a person with diabetes thinks about their disease every 20 minutes, every day, for the rest of their life.*
>
> **WHO Regional Office for Europe** *(8)*.

1.3 HOW WAS THE GUIDE DEVELOPED?

To support development of the guide, the WHO Regional Office for Europe convened two groups, one comprising people living with chronic conditions such as cardiovascular diseases, chronic respiratory conditions or diabetes and the other comprising academics and health professionals from relevant disciplines such as cardiology, diabetology, health literacy, nursing, psychology and public health. During 2022 WHO representatives met these groups separately and together seven times to discuss the approach, outline and draft text; incorporate their suggestions and recommendations over several drafts; and draw together examples of lived experience and professional practice to illustrate the guide.

The guide was informed by the evidence and existing literature in this field. There are multiple systematic reviews on the effectiveness of therapeutic patient education and self-management support, with some focusing on specific conditions *(9–13)* and others looking at the impact of therapeutic patient education or self-management support in settings such as hospitals or primary care *(14)*.

The reader should be aware that analysing the evidence in this field is complex, as most studies and systematic reviews consider specific interventions in defined patient groups and frequently measure different outcomes, making it difficult to generalize all therapeutic patient education interventions for all patient conditions. A number of reports and studies have attempted to overcome this difficulty by synthesizing this large body of work to draw conclusions on the effectiveness of therapeutic patient education and self-management support more generally, and these have been used to inform this guide *(2–4,14–16)*.

Throughout the guide, pertinent or relevant evidence is highlighted in orange boxes. Readers looking for evidence regarding specific interventions are advised to consult systematic reviews *(2–4)*, evidence resources such as the Cochrane Library *(17)*, or the COMPAR-EU platform *(18)* that aims to identify, compare and rank the most effective and cost-effective self-management interventions in Europe for adults living with four high-priority chronic diseases.

1.4 HOW IS THE GUIDE ORGANIZED?

To help readers to get the most out of the guide, key messages are provided at the beginning of each chapter.

The reader will find background information such as a discussion of cost–effectiveness, the policy context, as well as some of the underpinning concepts of therapeutic patient education in Chapters 2 and 3.

Chapter 4 describes how to provide therapeutic patient education as an integral part of the clinical care of people living with chronic conditions.

Chapter 5 discusses how to design and deliver training programmes for health professionals in therapeutic patient education as part of a broader training in self-management support interventions for patients.

The final two chapters of the guide focus on the health system and therapeutic patient education services. Chapter 6 identifies factors in the health system that can act as facilitators and barriers to delivering therapeutic patient education services and discusses how policy-makers might address these factors. Chapter 7 looks at operational issues in developing and implementing a thera-

peutic patient education service, such as how to set up a service, inequalities in access, and how to drive up quality and evaluate a service.

Key terms are shown in bold at relevant points in the text and quotations have been inserted to illustrate the experiences of people living with chronic conditions and approaches used by health professionals and policy-makers.

Specific information has been boxed and grouped:

- a key message box is given at the start of each chapter;

- important terminology or ideas are given in green boxes;

- evidence to support proposed approaches is given in red boxes;

- case studies from countries in the WHO European Region are given in gold boxes; and

- the stages of a patient's story are given in blue boxes.

2
CONTEXT

Therapeutic patient education draws together several types of self-management support interventions. It can be cost-effective and can deliver benefits for individuals living with chronic conditions, the health system and the wider society.

This chapter looks at some of the important contextual factors that shape therapeutic patient education services, including the concepts of self-management support and self-management support interventions. It also looks at the broad policy context of NCDs.

The aim of therapeutic patient education is for patients to be able to **self-manage** their chronic conditions over their lifetime; it adapts to their changing circumstances, as well as to changes in their condition and treatment.

Self-management is what patients living with chronic conditions do in order to manage their disease and prevent complications [1], balancing their lives with the illness and its daily challenges so as to achieve their best outcomes, and shift the perspective from illness to wellness.

The person living with chronic conditions has three fundamental, interdependent self-management tasks [19]:

- managing the medical aspects of the illness;

- managing life roles, including changes in roles brought on by the illness; and

- managing the psychological and emotional consequences of chronic illness.

Self-management support interventions are interventions that are systematically delivered to increase patients' knowledge, skills and confidence in their ability to manage chronic conditions. Their purpose is to actively engage patients (and informal caregivers where appropriate) in the management of their conditions [7]. Interventions usually combine several techniques as this is more effective than carrying out a single technique in isolation [2,4].

Interventions can be provided by health professionals and/or patients. Patients can also have a key role in shaping services through processes such as co-design (see Chapters 3 and 7).

2.1 WHAT DOES THERAPEUTIC PATIENT EDUCATION MEAN?

Therapeutic patient education can be conceived of as **educational interventions** to improve clinical outcomes carried out by trained health professionals to support patients to self-manage their chronic conditions with the support of their carers and families.

Definitions are not consistent across disciplines and texts, so this guide will use the term **therapeutic patient education** to describe an activity that is:

- **therapeutic**, that is, it can have a therapeutic effect on clinical outcomes either independently of or in addition to other therapeutic interventions (for example, pharmacological or physical therapy);

- for a **patient and/or their carers** and offered as part of the health-care pathway; and

- **educational**, that is, it is a structured process adapted to the patient to support them to acquire or maintain competencies to be self-managing through:

  - setting goals, planning action and taking decisions based on a common understanding of the patient's situation and needs; and

  - sharing information about the condition, health risks and management options and providing training in practical skills (including self-monitoring of the condition).

2.2 THERAPEUTIC PATIENT EDUCATION: PART OF THE FAMILY OF SELF-MANAGEMENT SUPPORT INTERVENTIONS

Self-management support interventions are a complex family of interventions [20]. Table 1 illustrates their breadth using a taxonomy that has been developed as part of a European Union project that is evaluating their effectiveness and cost–effectiveness [7] and classifies interventions using domains.

Therapeutic patient education draws together several types of self-management support intervention. Although the distinction between therapeutic patient education and other self-management support interventions is not rigid, the taxonomy can be used to distinguish those interventions that can be considered to be predominantly therapeutic patient education and those that are usually considered to be part of the broader family of self-management support interventions.

Table 1. Classification of self-management support interventions

Subdomain	Elements
Domain 1. Self-management intervention characteristics	
1.1 Support technique	Sharing information, skill training, stress and/or emotional management, shared decision-making, goal setting and action planning, problem-solving skill enhancement, self-monitoring training and feedback, using prompts and reminders, encouraging the use of services, providing equipment, social support, coaching and motivational interviewing
1.2 Delivery method	Clinic visit, support session and self-guided intervention, telephone calls, smart phones, Internet and specific devices
1.3 Encounter type	Face-to-face intervention, distance/remote interventions
1.4 Recipient	Individual, group and specific populations
1.5 Provider type	Physician, nurse, pharmacist, physiotherapist, occupational therapist, social worker, psychologist, dietitian/nutritionist, health-care assistant, peer, layperson and service provider
1.6 Location	Hospital (inpatient care), long-term centre/nursing home care, community-based care, home care, primary care, outpatient setting, workplace
Domain 2. Expected patient/caregiver self-management behaviours	
2.1 Lifestyle related	Eating behaviours, physical activity/exercise, smoking cessation or reduction, cessation or reduction of the consumption of alcohol or other harmful substances, healthy sleep habits
2.2 Clinical management	Condition-specific behaviours, self-monitoring, medication use and adherence, early recognition of symptoms, asking for professional help or emergency care when needed, device management and physical management
2.3 Psychological management	Handling/managing emotions
2.4 Social management	Fitting in at work, social roles and being able to work
2.5 Working with a health-care/social care provider	Communicating with a health-care and/or social care provider
Domain 3. Outcomes	
3.1 Basic empowerment/competencies	Level of knowledge, level of health literacy, level of skill acquisition, level of self-efficacy and level of patient activation
3.2 Adherence to self-management behaviours	Lifestyle, clinical, psychological, social, interactions and communication with health-care/social care providers
3.3 Clinical outcomes	Disease progression (clinical markers, symptoms) complications, adverse events and mortality
3.4 Patient/caregiver quality of life	Overall quality of life, physical functioning, psychological and emotional functioning, social functioning, sexual functioning and burden of treatment
3.5 Care perception/satisfaction	Overall satisfaction with self-management interventions, perceptions of being well and sufficiently informed (quality of information provision), perceptions of the patient–provider relationship, and personalized care

Table 1. contd

Subdomain	Elements
3.6 Health-care use	Type and number of visits, hospital admissions and readmissions, and emergency care
3.7 Costs	Health-care costs for patients, health-care costs, direct nonmedical costs and societal costs

Note: based on the taxonomy used for self-management interventions in the COMPAR-EU project. Domains that have been used to distinguish therapeutic patient education from other self-management support interventions are Domain 1 (self-management interventions characteristics) and Domain 3 (outcomes).
Source: adapted from Orrego et al. *(7)*. Reproduced under CC BY 4.0 licence (https://creativecommons.org/licenses/by/4.0/).

Compared with other self-management support interventions, the primary purpose of therapeutic patient education is to improve clinical outcomes and quality of life. The support techniques include sharing information, skills training, shared decision-making, goal setting and action planning, self-monitoring training, and feedback. The provider is a health professional.

Self-management support interventions that are not usually considered to be therapeutic patient education include those with empowerment or adherence to self-management behaviours as their primary purpose. These support techniques include encouraging the use of services, providing equipment, social support, coaching and motivational interviewing; and providers may include not only health professionals but also laypeople and patients.

The scope of this guide is focused on therapeutic patient education, while recognizing that practitioners of therapeutic patient education will sometimes deploy other self-management support interventions to adapt their support to individual patient needs.

2.3 WHY IS THERAPEUTIC PATIENT EDUCATION IMPORTANT?

Therapeutic patient education is central to the management of chronic NCDs such as diabetes, hypertension and respiratory diseases.

NCDs are a rising problem both globally and within the WHO European Region. Ischaemic heart disease, stroke, diabetes and COPD comprise four of the five leading conditions of disability, as measured by disability-adjusted life-years in adults aged over 50 years *(21)*. There has also been a significant upward trend in the prevalence of diabetes and the number of people living with more than one chronic condition *(22)*.

In the WHO European Region, people living with chronic conditions are an expanding group with increasing needs. This is partly because there is a higher proportion of older people in the population, who have an increased risk of developing a chronic condition, may have more than one condition and may be less able to self-manage. In addition, exposure to less healthy environments is predisposing to a rise in risk factors such as poor nutrition and lack of physical exercise, which in turn leads to an increase in conditions such as cardiovascular diseases and diabetes.

Therapeutic patient education is important because it:

- supports people with chronic conditions to make choices about their health and well-being and so improve their clinical outcomes and quality of life *(2,4,16)*;

- contributes to a more effective and cost-effective health-care system *(4,23)* and, thus, has the potential to reduce health service utilization and related costs (Box 2); and

- supports people living with chronic conditions to achieve their full potential, thereby contributing more to society and requiring less support, which can represent a significant economic and social gain.

> Tessa lives in a third-floor apartment and has COPD, emphysema, rheumatoid arthritis and fibrosis. She relies on an oxygen supply, which she carries around.
>
> "Having COPD is boring. If you're walking, you struggle to maintain oxygen intake so your concentration is all on that. You can lose contact with the world around you."
>
> **Living with COPD: Tessa, aged 78 years, retired manager**

Box 2. What is the evidence that self-management support and therapeutic patient education interventions are cost-effective and can reduce health-care utilization?

Fewer systematic reviews and studies have looked at the cost–effectiveness of self-management support and therapeutic patient education than at their effectiveness.

The evidence indicates that self-management support interventions and therapeutic patient education are cost-effective, but it also highlights that this is influenced by the costs associated with the chosen delivery method *(23,24)*. Some studies have demonstrated that self-management support can be cost-effective through reducing the long-term complications of chronic conditions *(25,26)*.

There is evidence that supporting self-management can reduce the use of health services. In this regard, disease-specific programmes may be more effective than generic programmes *(3)*. Reviews have found that self-management education and care planning leads to fewer hospital admissions, unscheduled visits to the doctor and days off work or school for people with asthma and may also reduce hospital admissions for people with COPD *(3)*.

The COMPAR-EU project collates and analyses information on estimated costs and cost–effectiveness for different types of self-management support interventions for four common conditions *(18)* and is a useful resource for readers.

2.4 THE POLICY CONTEXT

Several global and WHO European Region health policies and initiatives provide contextual background for the provision of therapeutic patient education services for chronic conditions and NCDs.

At global level, the three United Nations high-level meetings and resolutions on the prevention and control of NCDs *(27–29)* in 2011, 2014 and 2018 acknowledged the burden of NCDs and reaffirmed the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

The Sustainable Development Goals were adopted in 2015; within Goal 3 on good health and well-being are the associated Target 3.4 to reduce the risk of premature mortality from major NCDs by one third by 2030 and Target 3.8 to achieve universal health coverage *(30)*. In a 2020 follow-up report, the lack of progress demonstrated by countries suggested that many health systems are not keeping pace with the rising NCD burden *(31)*.

The WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2030 *(32,33)* recommends taking action to empower people with NCDs to manage their own condition better, and to provide education, incentives and tools for self-care and self-management; this is echoed in the equivalent WHO European Region action plan on NCDs *(34)*. Regarding specific chronic conditions, World

Health Assembly resolution 74/4 (2021) related to diabetes urged Member States to, among other things, strengthen health systems and high-quality, integrated and people-centred primary health services for all; ensure an adequate and well-trained and equipped health workforce; and strengthen health promotion and improve health literacy, including through ensuring access to understandable and high-quality, patient-friendly information and education *(35)*.

The WHO Thirteenth General Programme of Work, 2019–2023 *(36)* and the European Programme of Work 2020–2025 *(37)* both have a strong focus on the achievement of universal health coverage, and there have been both global *(38,39)* and WHO European Region *(40)* frameworks for strengthening people-centred health services. Furthermore, the European Programme of Work also sets out flagship initiatives on empowerment through digital health to support countries in digital transformation for better health *(41)* and on healthier behaviour that takes account of social, behavioural and cultural factors, including health literacy, in understanding human behaviour *(42)*.

3

UNDERSTANDING THERAPEUTIC PATIENT EDUCATION

The principles of therapeutic patient education have developed from evidence-informed concepts and models from a number of disciplines, including behavioural sciences, health systems and adult education.

This chapter explores a number of important models and concepts that inform therapeutic patient education and that are influenced by disciplines such as behavioural sciences, health systems and adult education.

3.1 UNDERSTANDING THERAPEUTIC PATIENT EDUCATION IN THE CONTEXT OF A PATIENT'S PSYCHOLOGICAL AND SOCIAL ENVIRONMENT

3.1.1 Emotional state

A patient's emotional state can play an important part in how that individual can benefit from therapeutic patient education. There appears to be a relationship between negative emotions (such as distress, depression, anger/hostility and anxiety) and chronic diseases *(43)*. Furthermore, the emotional burden associated with the treatment of a chronic disease or with the risk of serious complications with the disease has itself been associated with poorer self-management behaviours *(44)*.

Emotional distress and depression can impact adherence to treatment and can moderate the effect of health literacy on self-management behaviours. In other words, emotional distress, whether or not it relates to the chronic condition, may prevent patients from being able to use health information to perform adequate self-management behaviours *(45)*.

3.1.2 Carers and families

Carers and families often play a central role in the life of a person living with a chronic condition by providing both practical and emotional support. They may be involved in administering medicines or using the equipment needed to monitor a condition, preparing food, or enabling an individual to exercise and attend hospital appointments. They can play an important role in maintaining the emotional well-being of the individual and may affect an individual's motivation to engage with self-management and therapeutic patient education.

Carers and families may need to address their own knowledge, skills and confidence to support an individual living with chronic conditions. In some cases, they may need support dedicated to their own needs, such as carers' courses.

Individuals living alone may face additional challenges in self-managing their condition and may need to find help and support across peers and their broader community.

> "
> *I was diagnosed with chronic obstructive pulmonary disease 4 years ago. I had to attend a pulmonary rehabilitation course of 2 hours a week for 6 weeks. … It was good. If I hadn't gone to that, I wouldn't be here. But then we were told, "You're on your own now", and we were.*
>
> *So to keep the momentum going, I set up a local group. We found and hired a specialist exercise coach and we meet weekly to exercise at a community centre. I have had to navigate bureaucratic challenges, but our group is now 20 people and it makes a crucial difference to us all.*
>
> **Living with COPD: Tim, aged 72 years, founder of a community group for people living with chronic lung disease**
> "

3.1.3 Community and peer support

Individuals living with chronic conditions may seek support from community members and peers who have the same condition. These groups are important resources for self-management support for people living with chronic conditions *(46)*.

Peer groups can act as advocates for people living with chronic conditions by raising awareness among health-care providers and society of people's needs and experiences of services. They can promote and support user participation in service design and delivery.

Peer groups can be important sources of reliable information and support for people with chronic conditions. Groups of this type may be more accessible than health professionals and can offer practical approaches to problems faced by people living with chronic conditions. They may also provide advice for problems that are not directly related to health care but have a significant impact on people's lives, such as managing chronic conditions in the workplace.

Peer or patient groups can either meet in person or online and can be facilitated and moderated by patients or people living with a condition, such as groups run by charities or associations. There are also informal groups on social media platforms.

3.2 CONCEPTS UNDERPINNING SELF-MANAGEMENT

Several concepts drawn from health systems and behavioural sciences can help policy-makers and health-care professionals to understand the factors that may promote self-management by an individual. This section does not attempt to discuss these concepts in detail but rather illustrate how they may be useful in the design and evaluation of therapeutic patient education services and health professional training programmes. Readers are advised to consult the relevant literature for more information on these topics.

Health literacy is an important concept derived from social and behavioural sciences *(47)*. It encompasses a person's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take everyday decisions about health care, disease prevention and health promotion in order to maintain or improve their quality of life throughout the life-course *(48)*.

The aims of initiatives addressing low health literacy, self-management support and therapeutic patient education have much in common, although the focus and approaches may differ. Measures to address low levels of health literacy include raising the level of health literacy in the population through public health strategies, as well as adapting communications and changing organizational policies to accommodate the needs of people with low health literacy. By contrast, therapeutic patient education is clinically driven and involves interventions for individuals with chronic conditions.

A high level of health literacy enables people to make informed decisions about their health, be active partners in their care, and effectively navigate health systems. Therefore, health literacy has a crucial role to play in supporting people, and their carers and families, in self-management of their condition.

Health literacy has a dynamic quality and is context specific, so that its levels may change throughout the life-course depending on health conditions, health-related demands and contexts. Concentrating education around the individual means that strategies also have to be adapted to their level of health literacy *(48)*.

Therapeutic patient education can have a positive impact on health literacy. In addition, condition-specific health literacy can be regarded as an outcome of therapeutic patient education, while general health literacy can moderate the effectiveness of outcomes of therapeutic patient education *(49)*.

The related concepts of **patient-centred care, person-centred care, people-centred care and meaningful engagement of people with lived experience** refer to the relationship between individuals and health-care providers.

The term **patient-centred care** focuses on the experience of people who are receiving health care. Patient-centred care has been defined as providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions *(50)*.

Person-centred care focuses on the goal of a meaningful life, which is broader than decision-making about clinical care. Person-centred care has four principles:

- affording people dignity, compassion and respect;

- offering coordinated care, support or treatment;

- offering personalized care, support or treatment; and

- supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life *(46)*.

People-centred care additionally focuses on health systems that are organized around the comprehensive needs of people rather than individual diseases *(51)*.

As terminology is imprecise and terms are sometimes used interchangeably *(6,52)*, this guide uses the term person-centred care as defined above to cover these concepts.

The term **meaningful engagement** of people with lived experience *(53)* covers similar ground to person-centred care but with additional focus on the patient's role in shaping services as an equal partner. WHO has defined meaningful engagement as "the respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes".

There are common themes between person-centred care, self-management support and therapeutic patient education. All recognize the importance of a partnership between the patient and health professional working together to achieve a shared understanding of the patient's situation and priorities and to devise a workable plan to meet the goals of care *(15,54–56)*. The concept of patient partners *(54,57–59)*, in particular, refers to patients who work with health professionals not just for their own care but also in shaping services (see Chapter 7).

Therapeutic patient education is all about giving the patient more responsibility for their own health. I don't know if the medical community is ready to handle this power. I don't know if patients are either. It can be a challenge. But being patient centred is one of the main principles of family medicine. Our doctors trained in family medicine and general practice gain a lot of satisfaction from it. It's not just medical outcomes that improve: the patient is involved, more skilled, happier and less depressed, and the doctors too.

Professor Mehmet Ungan, Professor of Family Medicine in Türkiye, former President of the World Organization of Family Doctors

Shared decision-making is an important component of person-centred care and therapeutic patient education interventions. Health professionals and patients work together to select diagnostic tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences.

> For shared decision-making to take place, both parties must commit to sharing information and decision-making responsibility, recognising the need for this, and respecting each other's point of view *(60)*.

From the study of psychology, four concepts may help those working in health care understand why people living with chronic conditions may or may not engage with their self-management (Fig. 1).

- **Self-efficacy** can be defined as an individual's belief in their capacity to carry out actions that will lead to a desired result *(61)*. A patient's sense of self-efficacy is an important predictor of success of self-management interventions *(19)*.

- **Patient autonomy** is the experience of acting from choice, rather than feeling pressured to act. This form of autonomy is considered a fundamental psychological need that predicts well-being *(62)*.

- **Self-assessment** considers the capacity of an individual to continually assess the effectiveness of their own actions alongside the expected results. This includes monitoring test results and having self-confidence in their own ability to address problems.

Patient empowerment refers to a patient's ability to control their health, as well as their ability to be actively involved in their care *(63)*. Interventions to support and empower patients in caring for themselves can be effective in improving patient self-confidence, autonomy, knowledge, self-care behaviours, adherence and health outcomes *(64)*.

A behavioural concept that has been widely used to design and evaluate self-management support interventions is **patient activation**. It is defined as "an individual's knowledge, skill and confidence for managing their health and health care" *(65)*. Patients with high levels of activation understand their role in the care process and feel capable of fulfilling that role. Individuals who are more highly activated are more likely to engage in positive health behaviours and to manage their chronic conditions more effectively *(65)*.

Fig. 1. Illustration of some concepts that can be useful in understanding self-management

I am confident that I know the steps in looking after my heart problem

Self-efficacy

I made a decision about my care that meets my needs

Patient autonomy

My doctor and I actively discussed my treatment options and I said what would be best for me – together we found the best solution

Patient–empowerment

I checked my test results and they are improving month to month

Self-assessment

3.3 EFFECTIVE HEALTH-CARE COMMUNICATION

Health-care communication is a complex process to support patient care that integrates verbal and non-verbal behaviour, as well as visual aids and other supporting materials (such as infographics, leaflets and digital tools). The setting can also affect communication; for example, noisy consulting rooms, inappropriate room layout or interruptions can impede effective communication.

Effective health-care communication is based on the fundamental values of respect, compassion and collaboration *(55,66,67)*. The choice of language by a health professional can affect a patient's view of their condition and their self-efficacy in relation to their ability to effectively manage their condition. The language used with, and also about, patients can influence their engagement in health care. The language of the health professional used to introduce key tasks of the consultation can signal either a partnership or a passive role for the patient (Table 2).

Table 2. Example of language signalling either an active or passive role for a patient

Task	Active patient role	Passive patient role
Agenda setting	How can I help you today? What would you like to discuss today?	What *seems* to be the problem? Your test results haven't improved since last time
Establishing the patient's needs, preferences and concerns	What matters most to you? What is important that we cover today?	Any questions? Do you understand?

A particular word choice or phrase can imply that the patient is passive or implicitly blame the patient *(67–69)*. This includes language that is commonly used by health professionals (shown in Table 3).

Table 3. Examples of the negative effects of language

Topic	Example	Negative effect
The process of health care	History taking	Implies that the person is passively having information extracted
The patient	42-year-old obese diabetic	Defines the person by their clinical condition and can be stigmatizing
Expectations of patient behaviour	Compliance	Implies that the patient is expected simply to follow orders

Language that appears to blame or belittle patients can stigmatize people living with chronic conditions. This can lead to a loss of self-efficacy and reduced trust in health professionals *(70)*. Language can also reflect the perceived value of a decision or behaviour and appear judgemental. For example, if the health professional describes changes to a diet or physical activity as baby steps while the patient views them as very significant, it may affect the patient's engagement and their adoption of a change.

Health professionals need to be skilled in using language that is appropriate for different patients' needs. This should recognize a patient's level of health literacy and cultural factors.

Patients with lower levels of health literacy are less likely to actively participate in consultations,

> *One of my main messages to health professionals is simply to be kind, and not to tell us off like children when we don't do what we should. Explain the science to us – you don't need to be patronizing.*
>
> *I remember as a teenager one consultant coming into my hospital ward one day trailing 12 medical students. He didn't say hello to me or my mother. He just turned to the students and pointing at me and, referring to the breath that people with diabetes have when they are unwell, said to them "Can you smell it? Sugary cereal!" and walked out.*
>
> **Living with diabetes: Matt, aged 52 years, gardener**

less likely to disclose information due to feelings of shame or stigma, and more likely to defer decision-making to the health professional *(71)*.

Cultural differences between patients and professionals may or may not be accompanied by language discordance, which occurs when the professional and patient do not share a common understanding of certain words or phrases, for example words used to describe parts of the body or bodily functions.

Health professionals can address these problems by working with people with chronic conditions and with patients to develop a vocabulary that is respectful and empowering. For example, health professionals can develop health information for groups of patients through a process of co-design and user testing to ensure that language and graphics are inclusive and culturally appropriate *(72)*. Further discussion of effective healthcare communication can be found in Chapter 4.

3.4 ADULT LEARNING

The principles of adult learning are central to therapeutic patient education. Adult learning is relevant to both the interaction between a **patient and health professionals** and the **design and delivery of training programmes for health professionals**.

Adult Learning Theory suggests that learning is enhanced by building on an individual's previous knowledge and experience *(73)*. This approach may be relevant when designing new courses, for example by engaging existing patients who are experienced in self-management of their condition in the design and content of therapeutic patient education programmes or engaging

health professionals in the formulation of the curriculum of training programmes for health professionals.

The implications of adult learning are that *(74)*:

* learners should be respected for their previous experiences (for patients, this will be their personal experience of their condition);

* a spirit of mutual cooperation should exist between the teacher and learner;

* teachers should assist learners to self-diagnose their learning needs;

* learners should be involved in planning how their learning needs will be met;

* the teacher is a guide who helps an individual to learn, rather than an instructor in charge of knowledge – teachers assist learners to assess the progress they are making towards their goals; and

* both teachers and learners together should evaluate a course or academic programme.

The types of learning experience that have more meaning for the adult learner include group discussions, case studies, simulations *(75)*, role plays, and seminars that tap into the learners' reservoir of experience *(74)*.

3.5 MULTIDISCIPLINARY AND INTERDISCIPLINARY TEAMS

As health systems have developed to treat chronic illness, a broader range of health professionals have been trained to provide direct

patient care. This has resulted in the growth of both multidisciplinary and interdisciplinary teams *(76)*.

Multidisciplinary refers to team members from different disciplines relying on their different knowledge and skills to work together to deliver comprehensive patient care. A more profound level of collaboration exists in an **interdisciplinary approach**, in which team members from different disciplines work collaboratively with one another and with the patient, with a common purpose to understand the patient's situation and needs, set goals, make decisions, and share resources and responsibilities to produce an integrated plan *(77)*.

Many different professionals can be involved in the care of an individual patient with a chronic condition. For example, the health-care team for a person with diabetes may include a family doctor, practice nurse, consultant diabetes

specialist, specialist nurse practitioner, dietitian, podiatrist, ophthalmologist, pharmacist, psychologist and exercise physiologist.

Care provision within multidisciplinary and across interdisciplinary services requires effective coordination, collaboration, communication and record keeping, and regular assessment of results. This is facilitated through training, protocols, registries, data-sharing and health information systems. At times, this may be difficult to accomplish; for example, when there is high staff turnover and changes in the health system patients may often not have a single professional–patient relationship at the core of their care but instead have multiple professional–patient contacts spread across services. In these circumstances, patients are often the single point of continuity in their own care and are best placed to have an overview of how the management plan meets their needs.

> 66
>
> *My health-care providers went above and beyond to give me the support I needed at the beginning of my journey. It was a team effort but the most help has come from the specialist nurse consultant, the respiratory physiotherapist and the support worker. These three have given me the support and education to live a pretty normal life and self-manage my condition. The support I got came in the form of [advice on] smoking cessation, inhaler management, emergency antibiotics and steroids tablets kept at home and replaced when used.*
>
> *The pulmonary rehabilitation was brilliant, with education on how to manage your condition and individually tailored exercises. Health professionals need to listen to patients and give them the opportunity to self-manage and the tools to do so.*
>
> **Living with COPD: Tim, aged 72 years, founder of a community group for people living with chronic lung disease**
>
> 99

4
THERAPEUTIC PATIENT EDUCATION INTERVENTIONS

Therapeutic patient education is a structured, person-centred, continuous learning process that supports patients to gain competencies in knowledge, skills and confidence relevant to the self-management of their condition. It is adapted to the patient's life and their condition and has two essential components: (i) goal setting, action planning and shared decision-making; and (ii) delivering educational interventions.

This chapter looks at how a health professional provides effective therapeutic patient education. It discusses the two essential components:

- goal setting, action planning and shared decision-making; and

- delivering educational interventions.

4.1 THERAPEUTIC PATIENT EDUCATION

Therapeutic patient education is a structured, person-centred learning process. It is an integral part of treatment for chronic conditions that continues over the patient's lifetime and is adapted to the patient and their condition, including their family and social circumstances and the course of their disease.

Therapeutic patient education focuses on interventions that lead to improved clinical outcomes and quality of life. This may require interventions that address a number of different aspects of a patient's life such as lifestyle choices or emotional support, alongside improved clinical management of their condition. In addition, it is important to remember that therapeutic patient education should be provided in the broader context of self-management support, the overall purpose of which is to support people to live well with their condition *(15)*.

There are two components to therapeutic patient education. The first is techniques that help people to think about their strengths and abilities and to identify their needs and the changes they can make to take control of their lives, reach their goals and maintain their health and well-being *(46)*. These include techniques such as **goal setting, action planning and shared decision-making**, which are based on a common understanding of the patient's situation and needs.

The second component is concerned with delivering educational interventions that support the patient to gain knowledge, skills and confidence, predominantly through information sharing and skills training.

Both components are important, and therapeutic patient education is most effective at improving health outcomes when they are interlinked (Box 3).

Box 3. What makes therapeutic patient education effective?

- In large reviews of self-management support interventions, the provision of information about a person's condition was invariably part of all effective interventions *(4)*.

- Sharing information as part of a multicomponent intervention that includes skills training, goal setting and action planning is effective and can deliver improved health outcomes. Information sharing is less effective in changing behaviour if it is provided as an isolated activity *(4)*.

- Structured, culturally appropriate and patient-specific teaching was found to be better than ad hoc teaching or generalized teaching *(11)*.

- Self-management support and therapeutic patient education are most effective when integrated into the routine care of patients living with chronic conditions *(4)*.

4.2 USING COMPETENCIES TO DESIGN THERAPEUTIC PATIENT EDUCATION INTERVENTIONS

Therapeutic patient education is conceived as education that helps patients (and their families and carers) to acquire or maintain the competencies they need to self- manage, as best as possible, their lives with chronic conditions *(1)*.

The competencies that an individual patient requires will vary according to their condition, life-course and adaptation processes. For example, a patient living with asthma may need to know how different types of medication are used to treat asthma and how their condition is

affected by their emotions. They will need the skills to measure their peak flow and adjust their medication when they exercise.

However, knowledge and skills are not in themselves enough to support a patient to self-manage their condition. The patient also needs to be confident to self-manage their condition. For example, a person with asthma might have inadequate coping strategies and needs to build confidence in how to adapt their self-

management if they get a chest infection. Together, knowledge, skills and confidence can lead to a change in behaviour and an ability to self-manage their condition and its consequences.

- These three competencies form a patient competency framework, which underpins the design of self-management support and therapeutic patient education interventions (Fig. 2).

Fig. 2. Patient competency framework

Skills

Knowledge

Confidence

- **Knowledge.** The individual has accurate and relevant knowledge of their medical condition. This includes its likely progression, options for treatment, associated risks and uncertainties, and ways to alleviate its consequences. This knowledge enables the patient to make an informed decision about their health care.

- **Skills.** The individual has specific skills to self-manage their condition. This could include being able to use medical equipment, such as oxygen apparatus or insulin pumps,

and to alter the dose of their medication if their condition alters. It includes being able to undertake the tasks of daily living, for example a person with limited mobility learning how to dress unaided, as well as understanding the interrelationship between these skills and how these are integrated into their everyday life. The skill set may also include the individual's ability to access, understand, appraise and apply relevant information for their condition (in other words, a sufficient health literacy level).

- **Confidence.** The individual feels and believes that they have the capacity and capability to self-manage their condition, both in day-to-day life and in problem-solving when faced with unfamiliar circumstances.

The three competencies do not operate independently of one another. The more knowledge and skills that a person acquires about their condition, the more confident they are likely to feel. Similarly, gaining confidence in themselves and their judgement can encourage people to gain more skills in managing their condition.

To be of practical use, this framework needs to be translated into a **patient competency profile**, which describes the specific knowledge, skills and confidence that patients living with a particular chronic condition need to effectively self-manage that condition (Box 4).

Box 4. What is a competency profile?

A competency profile is the collection of competencies needed to be successful in a role.

A **patient competency profile** lists the competencies that a patient needs to successfully self-manage their condition.

A **health professional competency profile in therapeutic patient education** (see Chapter 5) lists the competencies that a health professional needs to successfully provide therapeutic patient education.

Patient competency profiles act as reference documents for health professionals to develop personalized plans for individual patients and curricula for educational interventions such as a course for people newly diagnosed with COPD. The following sections describe how this is done and Table 4 is an example of a patient competency profile for patients living with asthma.

Table 4. An example of a patient competency profile for patients living with asthma

Patient competency framework	Patient competency profile for patients with severe asthma
Knowledge	What is asthma? – airway hyper-responsiveness, obstruction and inflammation
	What happens in an asthma episode? – airways swell, become inflamed and produce more mucus
	What is asthma control? – no sleep disruption, rarely missing school or work, minimal emergency visits/hospitalization, normal activity levels, etc.
	What are triggers for attacks? – allergens, irritants, infections, exercise, emotional factors, gastro-oesophageal reflux
	What are the signs and symptoms? – coughing, wheezing, shortness of breath, tightness in the chest, drop in peak flow, exercise intolerance, nocturnal waking, behaviour change, e.g. irritability
	What are the warning signs and symptoms of a potential attack?
	When to seek help?

Table 4. contd

Patient competency framework	Patient competency profile for patients with severe asthma
Skills	How to use inhaler/nebulizer – dose, timing, technique, how much is left in the inhaler
	How to measure peak flow lung function – peak flow zones, when to measure peak flow
	How to use medication – corticosteroids, antibiotics
	What to do if peak flow drops
	Management of triggers – avoidance of allergens and irritants, e.g. tobacco smoke, cooking fumes, diet, emotional
	Keeping healthy – diet, exercise, emotional well-being
	Ability to assess any change to physical and emotional health and well-being that can impact the condition
	Ability to assess any change in condition or illness and response to treatment over time
Confidence	Confidence to manage the condition – confidence to keep fatigue, physical discomfort, emotional distress and other symptoms from interfering with activities
	Confidence to manage the different medications, tasks and activities needed to manage their health condition so as to reduce the need to see a doctor
	Confidence to do things other than taking medication to reduce how much the illness affects their everyday life
	Confidence to ask a health professional questions about the illness and well-being
	Confidence to work out differences with a health professional when they arise

Sources: based on WHO Regional Office for Europe *(1)*, Asthma + Lung UK *(78)* and the Asthma Initiative of Michigan *(79)*.

4.3 ESSENTIAL COMPONENTS OF THERAPEUTIC PATIENT EDUCATION

This section discusses in detail the two components of therapeutic patient education and how they link together. In order that the reader can understand what is entailed in providing these two components, they are presented as two distinct aspects of care, although in reality clinicians may integrate both components into a single interaction with a patient.

Fundamental to the effective delivery of therapeutic patient education interventions is that the health professional is trained in and uses evidence-informed techniques for adult learning (see Chapters 3 and 5).

Henrik's story provides an example of how therapeutic patient education interventions can work in practice. It describes Henrik's interaction with his health professionals at five different points in the therapeutic patient education process, starting with diagnosis (Box 5).

4.3.1 Goal setting, action planning, and implementation

Goal setting and action planning are effective in achieving behaviour change by engaging and involving patients in their own care through shared decision-making. These techniques can play an important role in developing an individu-

al's confidence and self-efficacy, as well as supporting behaviour change. The process starts by developing a common understanding between the health professional and patient of the patient's situation, needs, preferences and values.

We should always start by asking our patients, how much does your disease or condition affect your life? Just ask that question. Then we also have to ask ourselves a question as GPs [general practitioners] – how seriously do we take patient education and patient empowerment? Do we have time, do we want to do it, and do we understand it? Those are the questions in my mind. These questions come up regularly in medical schools in Turkey.

Professor Mehmet Ungan, Professor of Family Medicine in Türkiye, former President of the World Organization of Family Doctors

Goal setting and action planning can be carried out regularly throughout a patient's life: first when a patient is diagnosed with their condition to support the patient to gain core knowledge, skills and confidence, and then again as the patient's condition or circumstances change.

The steps in goal setting, action planning and implementation are illustrated in Fig. 3 and discussed in detail below.

Fig. 3. Steps in goal setting, action planning and implementation

24
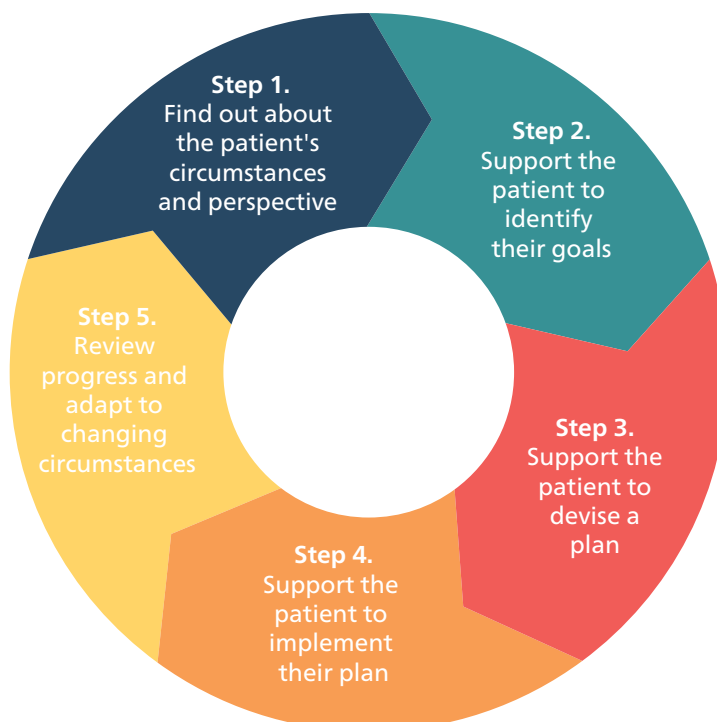
4.3.1.1 Step 1: find out about the patient's circumstances and perspective

It is important for the health professional to work collaboratively with the patient to understand the patient's circumstances and perspective in order to build a common understanding of the patient's situation, needs (what matters most to the patient) and adaptive processes: this is sometimes referred to as an **educational diagnosis**. This process recognizes the patient's strengths and assets, such as whether they like to exercise or whether they have a supportive spouse or partner.

It can also include understanding the stage of the patient's acceptance of their chronic condition, as well as their emotional status, cognitive function, health literacy level, and family and social circumstances.

All of these factors can influence how the patient engages with the goal-setting and action-planning process. In addition, the patient's response to the process can alter at different stages of the condition and with their age and psychological state.

Ascertaining a patient's circumstances and perspective can be complex (Box 6). Health professionals should be trained in effective communication, with specific attention to how to determine the patient's perspective of their condition and the likelihood of possible consequences or complications of the condition, and the treatment. Health-care communication skills are discussed further in Chapters 3 and 5.

Box 6. Henrik's story, part 2: 1 month later — finding out about Henrik's life

Henrik has been to see his family doctor several times. He has started taking some medication but remains confused and anxious about his diabetes and treatment.

Henrik goes to see the nurse in his health centre who runs a clinic for patients with diabetes.

The nurse starts by finding out about Henrik's life, listening to him, noticing his distress and anxiety, and asking him about what is important to him and what concerns him most about his diabetes. The nurse explains that together they will make a plan to address his concerns.

She asks Henrik to make several appointments to see her as it will take a little time to develop a plan.

4.3.1.2 Step 2: support the patient to identify their goals

Following the conversation with a patient about their circumstances, perspectives and understanding of their condition, the health professional can then explore with the patient how their chronic conditions are affecting their health and well-being and what they would like to change. The health professional can use this information to support the patient to identify their **goals** for their care based on what matters to them.

It is important that these goals are expressed in ways that are meaningful for the patient. Here are some examples of person-centred goals.

- A 64-year-old man living with recent-onset angina wants to feel less tired so that he can play with his grandchildren. He decides that he will lose 5 kg in weight.

- A 40-year-old woman living with severe asthma and frequent hospital admissions wants to stop being admitted to hospital.

- A 55-year-old man living with type 2 diabetes is treated with insulin and has frequent hypoglycaemic episodes that interrupt his work activities. He wants to discuss with a health professional how to adjust his insulin to avoid these episodes.

The process of identifying goals may require the health professional to offer choices or suggestions, such as other goals or lifestyle changes that the patient may not have considered, for example stopping smoking. Health professionals can also help patients to make their goals SMART (**s**pecific, **m**easurable, **a**chievable, **r**ealistic and **t**ime-limited). Table 5 gives an example of person-centred SMART goals.

Table 5. An example of a plan for a 69-year-old woman with ischaemic heart disease and hypertension

What's my problem	My goals	How am I going to achieve my goals
I've been told my blood pressure is too high. I'm worried I'm going to have a stroke or another heart attack. But I don't like taking my blood pressure tablets because of the side-effects	I want to reduce my fear of another heart attack or stroke and not have side-effects from my tablets	I will measure my blood pressure regularly according to the schedule I discussed with my doctor I will take my new medication regularly and I will go back to the doctor if any side-effects don't settle
I stopped smoking after my heart attack, but I've started again. I know it's bad for me and my children don't like it, but I am finding it hard to stop	I want to have quit smoking by my 70th birthday in 5 months' time	I will join a local smoking cessation group I will use nicotine patches I will ask my family to help me stop smoking
I don't do enough exercise. I don't like going to the gym but I enjoy walking and dancing. I just don't have enough time	I will go for a 30-minute walk three times per week	I will contact a friend who enjoys walking and we will go for a walk together every week I will walk to the shops rather than drive at least once each week

4.3.1.3 Step 3: support the patient to devise a plan

The next step in the educational process is supporting the patient to make a plan that describes how they will achieve their goals.

The plan should address two aspects: what knowledge, skills and confidence (competencies) does the patient need to achieve their goal and how are they going to acquire them.

The health professional can support the patient to identify what competencies they need to achieve their goal by using a general patient competency profile (see Table 4). Together the patient and health professional can decide which ones are pertinent to their circumstances and condition and draw up a personalized competency list (Table 6).

Table 6. Patient competency profile for patients living with asthma and an example of a personalized competency list for an individual patient

Patient competency framework	General patient competency profile for patients with severe asthma	An example of a list of personalized competencies for a 55-year-old man with severe asthma[a]
Knowledge	What is asthma? – airway hyper-responsiveness, obstruction and inflammation	I know about asthma; I don't need to know any more
	What happens in an asthma episode? – airways swell, become inflamed and produce more mucus	I know what happens in an asthma episode, I don't need to know any more
	What is asthma control? – no sleep disruption, rarely missing school or work, minimal emergency visits/hospitalization, normal activity levels, etc.	**I need to know more about my asthma control and what it should be**

Table 6. contd

Patient competency framework	General patient competency profile for patients with severe asthma	An example of a list of personalized competencies for a 55-year-old man with severe asthma[a]
Knowledge	What are triggers for attacks? – allergens, irritants, infections, exercise, emotional factors, gastro-oe-sophageal reflux	I know enough about what triggers my attacks
	What are the warning signs and symptoms? – coughing, wheezing, shortness of breath, tightness in the chest, drop in peak flow, exercise intolerance, nocturnal waking, behaviour change – irritability	**I need to know more about warning signs and symptoms**
	What are the warning signs and symptoms of a potential attack?	
	When to seek help	**I need to know when I should contact my respiratory nurse**
Skills	How to use inhaler/nebulizer – dose, timing, technique, how much is left in the inhaler	**I need to know how to use my inhaler/nebulizer – dose, timing, technique and how much is left in the inhaler**
	How to measure peak flow lung function – peak flow zones, when to measure peak flow	I can measure my peak flow lung function
	How to use medication – corticosteroids, antibiotics	I can use my corticosteroids; **I need to know more about using my antibiotics**
	What to do if peak flow drops	**I need to know more about what to do if my peak flow drops**
	Management of triggers – avoidance of allergens and irritants, e.g. tobacco smoke, cooking fumes, diet and emotional	I can avoid triggers – second-hand smoke at home, foods/diet that exacerbate reflux and lead to an acute attack
	Keeping healthy – diet, exercise, emotional well-being	I know how to maintain my diet. **I need to know more about how to increase my exercise without getting short of breath**
		I know how to seek emotional support if I need it
	Ability to assess any change to physical and emotional health and well-being that can impact the condition	I can tell when my general health and emotions are affecting my asthma

Table 6. contd

Patient competency framework	General patient competency profile for patients with severe asthma	An example of a list of personalized competencies for a 55-year-old man with severe asthma[a]
Skills	Ability to assess any change in condition or illness and response to treatment over time	**I need to know more about when my condition or my response to treatment is changing**
Confidence	Confidence to manage the condition – confidence to keep fatigue, physical discomfort, emotional distress, other symptoms from interfering with activities	**I need to gain more confidence so that I can keep the fatigue, physical discomfort and emotional distress caused by my disease from interfering with the things I want to do**
	Confidence to manage the different medications, tasks and activities needed to manage their health condition to reduce the need to see a doctor	**I need to gain more confidence so that I can do the different tasks and activities needed to manage my condition in order to reduce my need to see a doctor**
	Confidence to do things other than taking medication to reduce how much the illness affects the person's everyday life	I am confident that I can do things other than just taking medication to reduce how much my illness affects my everyday life
	Confidence to ask a health-care professional questions about the illness and well-being	I am confident that I can ask my doctor things that concerns me about my illness and well-being
	Confidence to work out differences with health-care professional when they arise	I am confident that I can work out differences with my doctor if they arise

[a] Competencies to be acquired are shown in bold.
Sources: based on WHO Regional Office for Europe *(1)*, Asthma + Lung UK *(78)* and the Asthma Initiative of Michigan *(79)*.

In most cases, patients will need to address their knowledge and skills gaps through educational interventions that share information and provide skills training. There are many ways to do this, and these are discussed under the second component of therapeutic patient education (section 4.3.2). It may also be appropriate to include the patient's carers and family in these discussions.

The health professional's role is now to support the patient in considering the options and deciding how to gain these competencies. For example, the patient may prefer to learn one to one with their clinician rather than in a group setting or online. It is important for health professionals to support patients to devise a realistic plan that is broken down into feasible elements that enable the patient to achieve success and strengthen their self-efficacy. The plan can be developed through negotiation and shared decision-making.

The framework for the process of shared decision-making includes a three-step model that professionals can use in a consultation to support patients in making informed decisions about their care *(80,81)*. The stages include:

- **team talk** – the health professional supports the patient to identify their goals, describes their choices and offers support;

- **option talk** – the health professional discusses alternatives with the patient using risk communication principles; and

- **decision talk** – the health professional establishes the patient's informed needs, preferences and values, and supports the patient in making a decision.

The plan devised by the patient supported by the health professional can have several goals (Box 7). Some interventions can be provided by the health-care provider, such as a course providing information about their condition. Others will be for the patient to source.

4.3.1.4 Step 4: support the patient to implement their plan

Together, the patient and the health professional need to assess how the patient is progressing with their plan through regular reviews or check ins. It may be appropriate to include family members and carers in these discussions. These reviews may be part of the patient's routine consultation with their family doctor or a nurse. Specific tasks for the health professional in these reviews may include *(82)*:

- finding out whether educational interventions such as courses or workshops have addressed the patient's goals and, if not, what other support, information or training they need;

Box 7. Henrik's story, part 3: the next 3 months — identifying Henrik's goals and devising a plan

Henrik goes to see the nurse several times. He is feeling better because he can talk to the nurse about his worries about his health and he feels he is being listened to.

He also starts talking to his wife about his diet, as she is the main cook in their family and is keen to cook food that will be better for her husband and all the family.

Henrik and the nurse discuss together Henrik's plan to improve his health and well-being.

Henrik decides that his first goal is to find out more about his diabetes and how he should look after himself. Henrik's nurse suggests that he can attend a 6-week course on type 2 diabetes that is run at his local health centre.

Henrik decides his second goal is to increase his exercise and he will go to the gym three times each week.

- providing support and encouragement to help the patient to persist with their plan – this is particularly the case for patients making lifestyle changes such as losing weight or stopping smoking;

- assessing the patient's emotional well-being and providing appropriate support if needed;

- monitoring biological measures such as blood pressure, peak flow, blood sugar and weight, and checking whether the patient is correctly monitoring these measures themselves and whether they need further skills training to do so; and

- checking treatment adherence and tolerance to medication.

Lastly, if the patient is not progressing with their plan, there is a risk that they may feel a sense of failure and lose confidence in their ability to self-manage their condition. The health professional has an important role in providing reassurance, assessing the circumstances and reviewing the goals with the patient. This may involve changing the goals or breaking them down into smaller steps that are more achievable so that the patient retains a sense of efficacy and success and persists with their plan.

> **"**
>
> *I only really got a grip on myself when I lost the sight in one eye 3 years ago. Now I feel more in control. My sensor, linked to Bluetooth, has changed everything. Its alerts keep me safe even while I sleep, I have a pen and I carry needles. Everything is portable. I scan all the time, and obsess about food, the calories and carbohydrates and the timing of meals. My blood sugar is now down to 7.4 after a lifetime of double figures!*
>
> **Living with diabetes: Matt, aged 52 years, gardener**
>
> **"**

4.3.1.5 Step 5: review progress and adapt to changing circumstances

During the patient's lifetime, changing circumstances such as the death of a spouse, retirement and development of other conditions, as well as changes to treatment options, necessitate a review of the patient's ability to self-manage their condition (Box 8); they may require additional therapeutic patient educational interventions.

Box 8. Henrik's story, part 4: 4 years after his diagnosis, everything changes

Henrik's wife has a stroke. He is devastated and has to take time off work to care for his wife. His diet deteriorates as he is now the main cook and relies on takeaways. He does not have time to go to the gym. His weight starts to increase and his blood sugar goes above his target level. He becomes depressed.

Henrik goes to see the nurse. She spends time discussing with Henrik his changing circumstances and asks Henrik what matters most to him at the moment. Henrik explains that it's keeping healthy so he can care for his wife.

Together, Henrik and the nurse put together a new plan that reflects his changed circumstances. As part of the plan, the nurse suggests that Henrik gets psychological support to help with depression and offers him a cookery course so that he can prepare healthier food for both himself and his wife.

Henrik adapts to new circumstances

Henrik finds new ways to incorporate exercise into his life, including walking to work rather than driving. He enjoys cooking healthy food. Slowly, his weight decreases, his depression lifts and his diabetes is better controlled.

4.3.2 Delivering educational interventions

The second component of therapeutic patient education is delivering educational interventions. These will predominantly be information sharing and skills training but may also include interventions to support lifestyle change or other interventions that are important to improve clinical outcomes. They may also be part of a broader programme of self-management support interventions such as coaching.

The intervention can be delivered in a clinic visit alongside goal-setting and action-planning activities or provided as a separate intervention, for example in groups (see section 4.3.2.2).

Health-care providers of therapeutic patient education services will need to decide what will be the educational content of the service and how they are going to deliver it.

4.3.2.1 What should be the educational content?

Although each patient will have an individual plan adapted to their needs, many patients (and

potentially their carers) will have similar gaps in their knowledge and skills competencies; therefore, health-care providers can develop educational services that can be used for most patients with the same chronic condition (Box 9).

The content of an educational programme that addresses information and skills training can be derived from the general patient competency profile (see section 4.2). Profiles will have specific competencies relevant to a particular condition

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Box 9. Henrik's story, part 5: gaining knowledge and skills

Henrik attends a 6-week evening course for people with type 2 diabetes. He finds it very informative and learns how to monitor his blood sugar and how to keep it within his target range. He is also comforted by the fact that there are other people attending the course who are in a similar position to him. He finds discussing how to tackle certain problems with his peers very helpful.

He attends the cookery course, which he enjoys.

Henrik's confidence in managing his diabetes grows. He knows how to measure his blood sugar and understands how to manage his medication and diet.

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and common competencies that may be found in patient competency profiles across several conditions. For example, a profile for an adult living with type 2 diabetes and using oral medication will describe the competencies of knowledge and skills related to self-monitoring and medication adherence for diabetes, and in these respects the profile will differ from a profile for a patient living with ischaemic heart disease. However, there will be some common competencies in both patient profiles, for example, those related to diet and physical activity, as well as confidence.

The concept of common and specific competencies for people living with chronic conditions can be helpful for health-care providers in thinking about offering therapeutic patient education to groups of patients with a range of different conditions as it may be possible to combine educational content that is relevant to patients with different conditions.

An example of this is the Chronic Disease Management Program *(83)*, which was originally developed at Stanford University and has been adapted and delivered in many countries. It addresses common themes such as how to manage fatigue and pain, as well as self-efficacy.

These kinds of courses will need to be supplemented with condition-specific knowledge and skills to acquire the specific competencies

needed to address each patient's condition, such as COPD, type 1 diabetes or heart failure. An example is the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) programme in the United Kingdom, which is offered to all patients who have recently been diagnosed with type 2 diabetes.

Health-care providers should also consider how frequently educational interventions should be provided, the amount of information they offer in each session and the importance of repeating information to support learning. More intensive educational activities may have a particular role for patients living with complex medical events (such as home dialysis for severe chronic kidney disease) who need specific training to support them to self-manage clinical tasks.

4.3.2.2 How should services be delivered?
There are multiple ways to offer therapeutic patient education services. Information sharing and skills training can be delivered as part of a clinical visit or dedicated support session, in an inpatient setting, as a telephone call or online. There are also options for self-guided interventions using apps on smart phones or specific devices.

The available technology might be best suited to particular kinds of intervention, for example information sharing, supporting motivation, medication adherence and self-monitoring *(3)*.

A variety of health professionals can provide therapeutic patient education, including physicians, nurses, pharmacists, physiotherapists, occupational therapists, psychologists, dietitian/nutritionists and health-care assistants.

Therapeutic patient education services can be delivered in a number of settings such as hospital (inpatient and outpatient care), long-term centre/nursing home care, community-based care and primary care.

An important decision is whether services are to be offered to individuals or as group sessions. One-to-one education provided at a clinical visit or as an inpatient may be appropriate if the patient does not want to join a group session or if group sessions are not accessible or available. If a clinical visit is used to provide education, then it is important that the health professional has access to appropriate resources (see section 4.3.3).

Group sessions are an effective way to provide structured education programmes for patients *(3)*. They can be designed to cover specific topics, as well as providing opportunities for patients to suggest subjects for discussion. The benefit of these models is that they can encourage peer support and provide opportunities for patients to learn from each other's experiences; disadvantages are that some patients may find that the course content does not address their needs or that they dislike learning in a group. Examples of group sessions include programmes for people living with diabetes (Case studies 1 and 2).

Case study 1. Ten-day therapeutic patient education courses, Tajikistan

In Dushanbe, people with diabetes can register with a dedicated diabetes centre, and twice a year will be invited to spend 10 days on a diabetes management course. The centre opened in 2020 and is designed to help not only people with type 1 or type 2 diabetes but also people living with obesity who want to prevent diabetes. It serves over 1000 children and adults and has seven part-time staff, including doctors, nurses, a psychologist, a physiotherapist and a cook. Its comprehensive programme on diabetes management involves working in both classroom groups and peer support groups. It provides information and knowledge on diabetes but also practical training, cooking courses and dietary advice, physiotherapy and rehabilitation, and hydrotherapy. The centre is equipped to offer physical activity support.

Source: Dr Asomuddin Giyoszoda, Director, Modern School of Diabetes, Dushanbe, Tajikistan, personal communication, 21 October 2022 (reproduced with permission).

Case study 2. Let patients decide, Albania

A project run by the Albanian Diabetes Association involved 50 patients living with diabetes who met for 2 hour per month over a 6-month course facilitated by a diabetes specialist and a nurse. The meetings were free, varied in size (including one to one) and were held in different towns. The patients themselves chose the topics for their next meeting. In all, 94% of the patients completed the programme. The overall satisfaction with their treatment improved from 35% to 56% after the intervention.

Source: Toti et al. *(84)* (reproduced with permission).

Online/virtual groups can provide accessible education as either a stand-alone or hybrid version (that is, integrated with face-to-face sessions). In the United Kingdom, the MyDES-MOND *(85)* app can be used on mobile phones and offers a wide range of resources and interactive tools to support people living with type 2 diabetes to become self-managing.

It may be possible to give patients a menu of options of how they want to learn, for example, online or in a face-to-face group. In some health

systems, it may only be possible to offer educational interventions as part of the patient's consultation with their family doctor or clinic nurse. In these circumstances, it will be important to ensure that the clinician has adequate time to deliver therapeutic patient education services as part of routine care.

Policy-makers and health-care providers will need to take account of several factors when deciding on the exact local model of delivery. Access, cost and availability of staff will all influence decisions on how to set up a service, as will the available evidence on which model is most effective.

However, it is important to be aware that all interventions are not equally effective for all conditions nor produce the same outcomes *(3,4)*. For example, self-management support for people living with COPD has been shown to have an impact on quality of life but no significant impact on acute episodes or visits to a doctor *(86)*, whereas self-management support for patients with heart failure shows a reduction in hospital admissions and mortality *(87)*. The evidence suggests that, for therapeutic patient education interventions, biological outcomes or mental health-related quality of life are influenced by the kind of chronic condition, who delivers the intervention and the technique used, but that these factors do not affect the patient's adherence or knowledge *(2)*.

Readers are directed to the Cochrane Library *(17)* or the European Union's COMPAR-EU platform *(18)*; the latter provides a useful resource for comparing the effectiveness and cost–effectiveness of different delivery methods of self-management support interventions for four common chronic conditions.

4.3.3 Resources
Many written and electronic information or educational tools such as leaflets, infographics, apps and videos can provide information or reinforce education programmes.

Information should be appropriate for each patient's needs and preferences and available at a suitable literacy level (for example, using plain language, avoiding jargon, or using pictures and symbols) *(88)*.

Health professionals should be aware that information developed for a group of patients (for example, a leaflet with dietary advice for patients living with diabetes), although useful, may be too rigid for an individual patient's needs and circumstances. It should be available in varied and accessible formats to meet specific patient needs, for example customized materials developed for people with learning disabilities or those with visual impairment.

Health professionals need to be skilled in assessing the quality of online information, technological devices and platforms and should be able to support patients to navigate and judge what is likely to be useful and evidence informed. The Organization for the Review of Health and Care Apps (ORCHA) is a digital accreditation platform that is available in 14 different languages *(89)*. The ORCHA library has over 17 000 apps that have been systematically assessed and evaluated, and can provide a valuable resource for health professionals and patients wishing to assess the suitability of particular apps or technology used in health care.

4.3.3.1 Peer-to-peer information through social media platforms
Social media platforms are useful for people who have recently developed a chronic condition, for example to find other people living with the same condition. However, there are risks of unregulated sources of information for both people with chronic conditions and health professionals. There are many accounts of inaccurate, misleading or dangerous information being shared on unregulated social media accounts.

Both health professionals and people with chronic conditions need to be trained to identify accurate information, for example by using hallmarks of trustworthy sources such as validation by a recognized and trusted body (Case study 3).

The WHO Regional Office for Europe has developed a new Toolkit for tackling misinformation on noncommunicable diseases *(91)*, which makes recommendations on collaborative action to better protect people from misinformation.

4.3.3.2 Community assets
Community assets are important resources to support self-management that patients can be directed to. They can include physical environments such as green spaces and leisure facilities such as sports centres, as well as community

Case study 3. The European Lung Foundation's quick response for information during the COVID-19 pandemic

The European Lung Foundation's COVID-19 and lung disease Q&A was organized within a couple of weeks of the start of the COVID-19 pandemic (due to complaints from respiratory physicians and general practitioners, who were flooded with questions) and quickly exceeded 1 million visits *(90)*.

groups, social activities, friends and peers. They can provide important social and emotional support for people living with chronic conditions.

Health professionals should be aware of and encourage use of community assets through signposting or, in some countries, the use of social prescribing (Case study 4).[2]

Case study 4. Self-help group, United Kingdom

Tessa runs a self-help Breathe Easy patient support group for over 200 people with respiratory conditions, and their carers and families, for sharing information, meeting monthly and hosting expert talks *(92)*. This benefits both patients and health-care staff.

Source: Local patient coordinator, Asthma + Lung UK Support Group, personal communication, 22 July 2022 (reproduced with permission).

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[2] Social prescribing is where a health professional issues a prescription for a specific activity (such as a walking group) or refers the individual to an intermediary, such as a link worker, with whom a package of support services can be constructed *(46)*.

5

TRAINING HEALTH PROFESSIONALS TO DELIVER THERAPEUTIC PATIENT EDUCATION INTERVENTIONS

Training in the principles and practice of self-management support and therapeutic patient education should be widely available to all cadres of health professionals. It can be offered throughout a health professional's career, including at undergraduate and postgraduate levels, and as part of continuous professional development.

This chapter provides guidance on developing and delivering training programmes in self-management support and therapeutic patient education for health professionals.

5.1 WHO SHOULD BE TRAINED IN THERAPEUTIC PATIENT EDUCATION?

Any health professional who regularly works with patients living with chronic conditions can benefit from training in the principles of self-management support and therapeutic patient education.

All cadres of health professionals can be trained to deliver effective therapeutic patient education *(2)*; this includes general or specialist medical practitioners, nursing professionals, pharmacists, dietitians and nutritionists, psychologists, physiotherapists, health associate professionals, or other personal care workers in health services working with people living with chronic conditions.

Embedding an understanding of therapeutic patient education at an early stage of training can have long-term benefits, such as more person-centred care and health-care providers who focus on empowering patients and caregivers in self-management.

Therapeutic patient education is a powerful idea. It has to be built into your daily routines [and] how you treat each patient, depending on what staffing you have and what expectations you and the patient have. With the backup from our Ministry of Health and other institutions, who are very supportive, we hope that therapeutic patient education can remain a central part of medical education, and one which will be repeated during the health professionals' careers – not just a one-off. It is too important for that.

Professor Mehmet Ungan, Professor of Family Medicine in Türkiye, former President of the World Organization of Family Doctors

Policy-makers may consider making training in the essential elements of therapeutic patient education mandatory for health professionals undertaking core undergraduate training programmes (Case study 5). Further training can be made available for health professionals post qualification and thereafter as part of continual professional development.

Case study 5. Embedding the principles of therapeutic patient education into core training for doctors and nurses, Germany

Germany's National Catalogue of Competence-based Learning Objectives in Medicine, the core curriculum that drives medical training, emphasizes the principles of therapeutic patient education *(93,94)*.

For doctors and nurses, patient education is the standard approach.

For 15 years we have had a model course of study. Great importance is attached to patient contacts from the beginning. It includes compulsory training on doctor–patient communication, on patients recounting their own history, communication of diagnosis, shared decision-making, and motivational interviewing.

Professor Karin Lange, Head of Medical Psychology Unit, Hannover Medical School, Hannover, Germany, personal communication, 26 July 2022 (reproduced with permission).

5.2 THE EDUCATIONAL APPROACH

Effective education for health professionals should draw on evidence-informed practice and build on principles of adult learning (see Chapter 3). The WHO and Jhpiego guide, Effective teaching: a guide for educating health-care providers *(74)*, is a useful resource with practical guidance on designing and delivering training

> 66
> *The gulf between doctors and patients can be vast. Until the clinicians are aware of what the patient is experiencing, they're not going to progress with their care with empathy or understanding.*
>
> **Living with COPD: Tessa, aged 78 years, retired manager**
> 99

programmes for health professionals. Readers may also find helpful the evidence-informed recommendations in the WHO guidelines, Transforming and scaling up health professionals' education and training *(75)*.

The principles of co-design (see Chapter 7) by patients and health professionals can be used in the design, delivery and evaluation of training courses.

Evidence suggests that programmes based on **active learning**, which are problem based, focus on the needs and problems of the patient and use simulation *(75)* are more likely to lead to deep learning for students and learners (Box 10).

It is important that training for health professionals draws on a broad range of disciplines, such as educational theory, health-care communication, psychology (clinical, health and educational),

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Box 10. What is active learning?

Active learning is an approach to instruction that actively engages students and learners with course material through discussion, problem-solving, case studies, role play and other methods. Its aim is to enable students to have deep rather than surface learning and to be able to apply and transfer their learning from one topic to another.

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sociology (health care and educational) and health literacy.

During their training, health professionals themselves may experience barriers to delivering therapeutic education. These may be because of their own knowledge, competencies or motivation, or related to their structural support or resources *(95)*. Steps can be taken to support health professionals to address these barriers both through training and by addressing health system barriers at policy and operational level.

If feasible, it is beneficial to take a multidisciplinary approach to training in which all members of a team or workforce group are trained together. This approach can:

- create a common understanding of self-management support and core tools and techniques;

- create a common language and culture;

- develop a critical mass of trained practitioners within a team or service in order to put the

skills into practice across a service or organization;

- improve the ease with which self-management support can be tested and adopted; and

- enable practitioners to support one another throughout their training and later when using the skills in practice *(46)*.

5.3 DEVELOPING A COURSE IN SELF-MANAGEMENT SUPPORT AND THERAPEUTIC PATIENT EDUCATION FOR HEALTH PROFESSIONALS

The **content** (sometimes referred to as the curriculum) of an educational programme for health professionals in therapeutic patient education and self-management support is built around **health professional competency profiles.**

Fig. 4 shows how health professional competencies are used to generate course learning

Fig. 4. Course development based on health professional competency profile
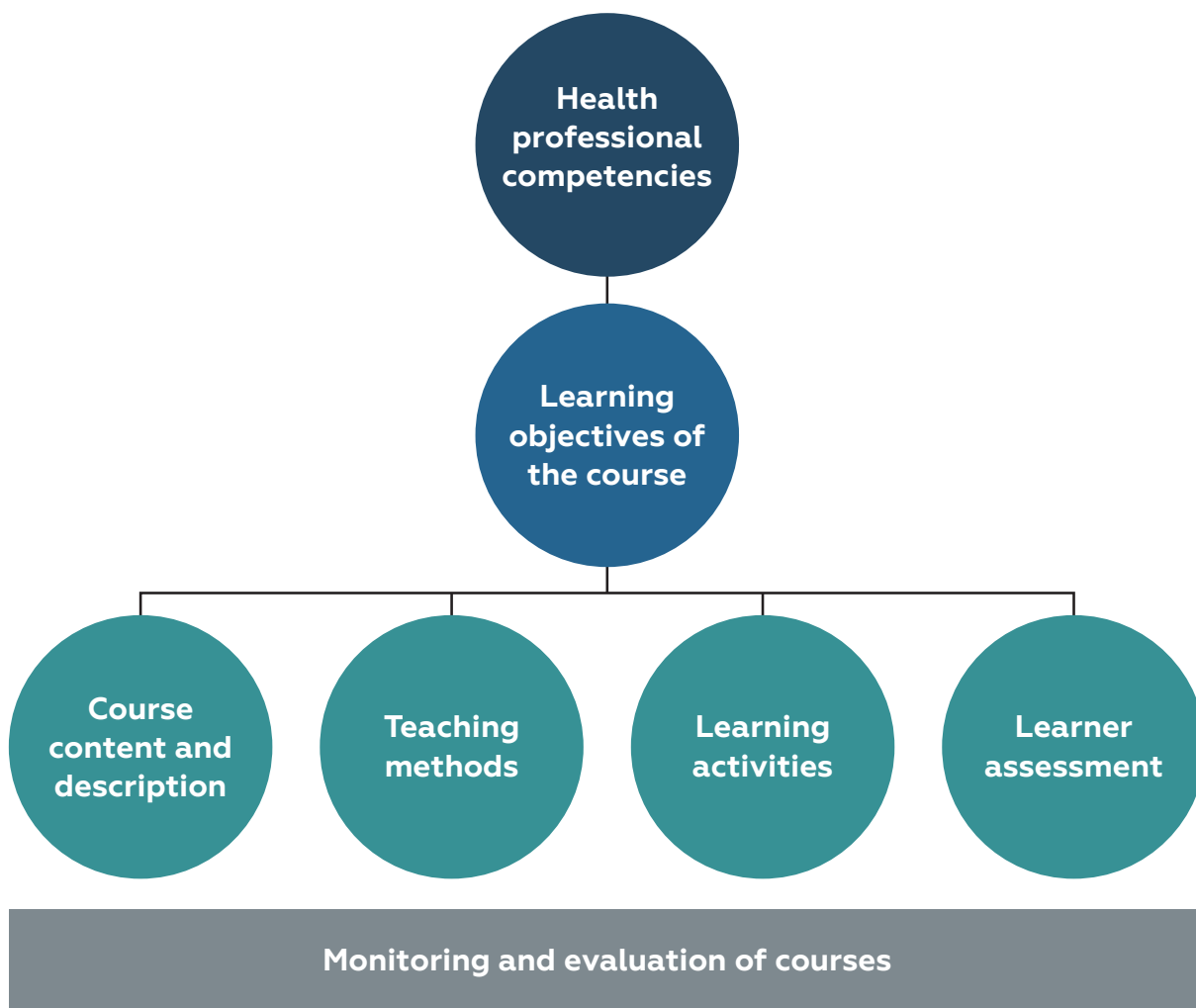
Source: adapted from WHO and Jhpiego *(74)*.

objectives, course content, teaching methods, learning activities and learner assessment.

A health professional competency profile for therapeutic patient education will include a set of competencies that all health professionals will need, regardless of what chronic conditions their patients may have, as well as specific competencies that address a particular chronic condition.

For example, educators in France have produced a competency framework for professionals providing therapeutic patient education *(96)*.

The framework considers the different activities that health professionals need to undertake, such as supporting the patient to analyse their situation, identifying their needs and supporting the patient and their carers to develop, implement and evaluate a plan. For each activity, the framework indicates the competencies that

health professionals will need, broken down into technical, teaching (pedagogic) and relationship, and organizational competencies.

Train4Health *(97)* is a European project that is developing an educational package to train health professionals in behaviour change support for people living with chronic conditions. It includes the development of a health professional competency profile, learning outcomes and course content *(98,99)*. Readers are directed to the Train4Health website *(97)* for further information on course development.

Table 7 is an extract showing competency statements that have been developed as part of the Train4Health project. These relate to the common competencies that all health professionals need to support self-management for a patient, regardless of the chronic condition the patient is living with.

Table 7. Competency statements for training health professionals in behaviour change for self-management support

Category	Statement
Behaviour change competencies in self-management of chronic disease	
BC1	Knowledge of health behaviour and health beliefs
BC2	Knowledge of appropriate behaviour change models/theories
BC3	Knowledge of relevant behaviour change techniques
BC4	Knowledge of clinical features of chronic diseases and target behaviours for their self-management
BC5	Ability to identify self-management needs in relation to target behaviour(s) relevant for the chronic disease(s)
BC6	Ability to engage and empower individuals with chronic diseases in self-management
BC7	Ability to foster and maintain a good intervention alliance with individuals
BC8	Ability to identify opportunities and barriers (determinants) to implementing change in the target behaviour
BC9	Ability to work in partnership to prioritize target behaviours to develop an intervention plan
BC10	Ability to identify and select behaviour change techniques that are tailored to behavioural determinants (opportunities and barriers) in developing an intervention plan
BC11	Ability to select behaviour change techniques that are appropriate to the length of the intervention (brief or long term)
BC12	Ability to apply behaviour change techniques and implement the intervention plan, adapting and tailoring as required
BC13	Ability to plan for follow-up and maintenance when the target behaviour has been achieved
BC14	Ability to provide access to appropriate information and educational materials tailored to individual needs
Foundational competencies for behaviour change in self-management of chronic disease	
F1	Knowledge of the roles of other professionals in the local health system
F2	Ability to maintain effective interprofessional relationships
F3	Ability to provide interventions that are person centred and consider the context (e.g. culture, family, local health system)
F4	Ability to screen for readiness for behaviour change
F5	Knowledge of foundational aspects of effective communication
F6	Ability to communicate effectively in partnership with people and families
F7	Ability to communicate effectively with others (e.g. health-care providers, administrators)
F8	Ability to engage and partner with people individually and in groups
F9	Ability to explore and manage expectations of individuals and groups
F10	Knowledge of professional and ethical guidelines
F11	Ability to demonstrate professional behaviour
F12	Ability to reflect, self-evaluate and continuously develop these competencies

BC: behaviour change; F: foundational.
Source: Cadogan et al. *(98)*. Reproduced without changes under CC BY 4.0 licence (https://creativecommons.org/licenses/by/4.0/).

The health professional competency profile is used to generate **learning outcomes**, which provide an overview of the knowledge, skills and attitudes needed by a student or learner *(100)*. The learning outcomes can cover topics such as knowledge of the condition and its complications and management; communication skills; theories and models of motivation, learning and behaviour change; and digital and health literacy.

Again, common learning outcomes usually cover topics that are relevant to all health professionals supporting patients with any chronic condition, so these may need to be supplemented with specific learning outcomes related to a particular chronic condition.

Teaching methods that follow the principles of adult learning (see Chapter 3) allow students to practise integrating their knowledge, skills and attitudes in classroom sessions that simulate consultations or clinics.

Practice may include group teaching methods such as case studies, role play, clinical simulations and supervised clinical practice. Training can include direct practical experience with patients (patient-based education) as an important part of learning.

Live online teaching, as well as the use of e-learning teaching resources and methods where available, can make high-quality training programmes more widely accessible to health professionals *(75)*.

The Train4Health website *(97)* has a number of training materials, including e-books, open online courses and simulations on behaviour change to support self-management.

5.4 ROLLING OUT TRAINING FOR HEALTH PROFESSIONALS

The principles of therapeutic patient education are relevant in most health-care settings, and most health professionals can benefit from some understanding of its core concepts. Therefore, courses in therapeutic patient education can be part of the lifelong training for many health professionals.

To achieve this aim, senior leaders and policy-makers may consider ways to offer training in a wide range of organizations and settings. This may be facilitated by the appointment and training of **training programme coordinators** to oversee the development and delivery of therapeutic patient education courses for health professionals.

The roles of training programme coordinators can include *(1)*:

- promoting, designing, implementing and evaluating programmes of therapeutic patient education;

- designing educational methods and tools;

- training educators of patients; and

- contributing to research in therapeutic patient education where appropriate.

Countries, subnational regions or organizations that wish to expand access to therapeutic patient education training programmes may consider using a **training of trainers** model of cascade learning *(101)*. This approach focuses on preparing instructors to present information effectively, respond to participant questions and lead activities that reinforce learning *(102)*. This approach can help to embed the principles of therapeutic patient education into practice across the workforce, as well as making it more accessible *(103)*.

It can be beneficial to offer interdisciplinary or interprofessional training *(75)* at different levels, such as basic, intermediate and advanced training courses (Case studies 6 and 7). Basic courses can be as short as 2 days, which makes them more accessible to a wide range of staff. Policy-makers and senior leaders may wish to consider whether intermediate and/or advanced training in therapeutic patient education should be mandatory for professionals such as nurses and doctors in specialty training focused on patients with chronic conditions, such as cardiology, endocrinology, nephrology, primary care and respiratory medicine.

Case study 6. Different levels of training for educators delivering the DESMOND programme, United Kingdom

The DESMOND programme of self-management support for people living with diabetes includes three training levels for educators *(104)*:

- **core training:** a 1-day course on the philosophy, theories and behaviours that underpin all modules as a first step in educator training;

- **module-specific training:** a 1-day course that introduces educators to the curriculum and resources they will need to deliver a chosen module to patients; and

- **lay educator support:** for lay personnel or non-registered health-care professional team members, a course offers additional support prior to attending the 2 days of training for the Newly Diagnosed and Foundation module.

Case study 7. Certificate and diploma of Advanced Studies in Therapeutic Patient Education, Switzerland

The Faculty of Medicine of the University of Geneva has offered a Continuing Education Certificate and a Continuing Education Diploma in therapeutic patient education since 1998 *(105)*. These meet the expectations of the Swiss Ministry of Health (Federal Office of Public Health) in terms of training professionals in self-management. The training has two integrated steps that offer professionals the opportunity to improve their skills to (i) support the capacities and skills of patients to strengthen their power to act on their health (Continuing Education Certificate) and (ii) support therapeutic patient educators to design and develop therapeutic patient education activities with and for patients (Continuing Education Diploma). Training is interactive and individually supervised, with a wide range of disciplines (doctors, nurses, psychologists, pedagogues and art therapists), experts and patient trainers participating in the curriculum.

Organizations that focus on care for patients living with specific chronic conditions may consider running refresher courses, regular updates as part of team meetings, and core training in therapeutic patient education as part of induction programmes for new staff (Case study 8).

Case study 8. Different levels of therapeutic patient education training, Portugal

In Portugal, the Portuguese Diabetes Association (*Associação Protectora dos Diabéticos de Portugal*) developed a certified training programme for health professionals *(106)* that includes therapeutic patient education principles at different levels. All of the courses may be provided as face-to-face learning, e-learning or blended learning according to preferences and the available resources.

- **Basic courses** on diabetes (2 days) are aimed at health professionals with no previous experience in diabetes. Together with the fundamentals of diabetes care, the course defines therapeutic patient education and includes practical examples of its use in regular consultations and the role of multidisciplinary teams.

- **Intermediate courses** (2–5 days) develop specific areas of intervention in diabetes care, and therapeutic patient education concepts are developed in relation to nutrition, physical activity and pharmacological options. Specific courses on motivational interviewing and digital resources are offered at this level.

- **Advanced courses** (3–5 days) include training in communication processes, including the use of adequate information in different settings.

A psycho-educational course is also offered as a dedicated 5-day programme for intensive training in these issues.

Source: Professor João Filipe Raposo, Medical Director, Portuguese Diabetes Association, Lisbon, Portugal (reproduced with permission).

6

HEALTH SYSTEM BARRIERS AND OPPORTUNITIES

Supporting patients living with chronic conditions to be self-managing requires a health system that rewards and integrates person-centred care into the way it designs, funds and delivers services, and potentially changes the culture of the way health services are delivered.

This chapter identifies factors in the health system that can act as facilitators or barriers to delivering therapeutic patient education services and ways to overcome these (Box 11).

6.1 POLICY AND STRATEGY

Policy-makers can facilitate the adoption of self-management support and therapeutic patient education services by ensuring that they are part of any policy, strategy and processes of care addressing a chronic condition such as cardiovascular diseases, diabetes or respiratory disease. This may be relevant not just for policy-makers in ministries of health but also for those working in other government areas such as social welfare.

Within a ministry of health, it may be helpful to check whether self-management support is promoted across all chronic conditions or limited to a single condition such as diabetes. This may occur if the ministry is organized in vertical disease-specific programmes. Sharing learning and resources across disease-specific programmes may encourage the rollout of self-management support across a health system.

Other policies or approaches in a ministry in charge of health or other government ministry can also play a part in facilitating or hindering the rollout of self-management support and therapeutic patient education programmes. For example, policies that address health financing,

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Box 11. What kinds of therapeutic patient education programme are likely to succeed?

Large-scale initiatives suggest that self-management support programmes that are most likely to succeed:

- are promoted by policy, thus ensuring meaningful adoption (and ideally provision of resources and reimbursement of costs) by health services;

- provide training programmes for professionals; and

- focus on structured self-management education for patients in the context of overall disease management and are sufficiently flexible to address local, cultural and personal variation.

Source: Taylor et al. *(4)*.

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workforce and professional training and quality improvement may all be relevant. In some countries, a ministry in charge of education may be responsible for undergraduate education for health professionals and, therefore, may need to be involved in any changes to course content. The specific impact of these policy areas is discussed in more detail later in this chapter and in Chapter 7.

Policy leaders working across these agendas should ensure that aims and priorities are aligned across different areas and ministries in order to successfully embed therapeutic patient education into routine clinical care.

Engaging people with lived experience of chronic conditions to act as advocates in policy or strategy development may provide an important lever to bring about change by highlighting their

needs related to self-management support (Case study 9).

A national person-centred guided self-management programme that includes therapeutic patient education is more effective in achieving improved health outcomes than conventional treatment guidelines alone *(108)*. Examples of this kind of approach can be found across Europe, such as the Diabetes Management Programme in Germany *(109)* or the National Asthma Programme in Finland *(110)*.

Strategies to support self-management through therapeutic patient education can also contribute to other strategic aims such as patient empowerment and raising the levels of health literacy *(69)*. They may also achieve broader health goals such as promoting digital health, active citizenship and meaningful engagement

of people living with chronic conditions *(111),* and addressing health inequalities.

The promotion of digital health for therapeutic patient education can have benefits across the health system, and governments and academic bodies may wish to support more implementation research programmes on developing and evaluating new technologies for therapeutic patient education. However, digitalization of health does entail a risk of increasing health inequalities and inequities because of the varying levels of digital health literacy *(112)*.

Apart from demonstrating the benefits to people with chronic conditions, senior leaders can advocate for therapeutic patient education as a policy priority by highlighting evidence that it can reduce service utilization in primary and secondary care and, potentially, save costs for the health system in the long term (Box 12).

6.2 LEGAL AND REGULATORY FRAMEWORKS

Policy-makers can deploy a range of legal and regulatory mechanisms to facilitate access to high-quality therapeutic patient education, along with training in therapeutic patient education for health professionals.

Regulatory frameworks may also play a part in determining which health professionals can offer therapeutic patient education. For example, in some countries nurses may be unable to offer therapeutic patient education because this activity is not explicitly covered in regulations that describe a nurse's role, or health insurance funds will not fund therapeutic patient education that is provided by a nurse. Policy-makers may need to address these kinds of barrier in order to support the expansion of self-management support across a health system.

Box 12. Reducing service utilization

Studies have shown that services led by specialist respiratory nurses reduce the average length of hospital stay for patients with COPD by 2.53 days and the average readmission rate by 4.5 per month *(113)*.

Exemplar studies have shown that interventions led by specialist respiratory nurses in primary care prevent hospitalization and are safe and cost-effective for patients with chronic lung disease *(114)*.

Interventions led by specialist respiratory nurses and physiotherapists have reduced emergency room admissions and the need for hospitalization *(115)*.

Specifications of the services to be delivered by a health-care provider can be used by government, commissioning agencies or insurance systems to ensure that health-care providers include therapeutic patient education as part of the management plan for patients with chronic conditions (Case study 10).

Specifications can be linked to quality systems (see Chapter 7) to ensure that the therapeutic patient education service is evidence informed and of a high quality. For example, in England (United Kingdom) health-care providers are required to deliver patient education services that meet national quality standards as defined, assessed and accredited by the independent Quality Institute for Self-management Education and Training *(118)*.

Similarly, accreditation systems for training programmes for health professionals offered by universities or colleges can be used to make sure that the principles of therapeutic patient education are integrated into training programmes for health-care providers (Case study 11).

Using regulatory frameworks to embed therapeutic patient education into a health system can be complex as it may require the integration

of several different workstreams. However, once done, it can deliver significant benefits in facilitating the use of therapeutic patient education within a health system (Case study 12).

Case study 12. Regulatory progress, Georgia

Since the early 2000s, the health system in Georgia has undergone numerous transformations and reforms. Most health-care services are provided by the private sector. Continuing professional development is a not mandatory for all medical professionals but applies to selected disciplines only. The country is facing health workforce challenges, especially in rural primary health care. There is a need for a framework for training health-care providers in therapeutic patient education, quality indicators and a shift towards performance-based payments. There is hope that this will come soon. Preparations for a large-scale reform of primary health care were launched in 2021 and implementation should start in 2024. The plans include integrating priority NCDs into primary health care with add-on capitation payments and introducing quality indicators for primary health-care services. The reform will also include preventive services, patient education and improved access to continuing professional development and education opportunities.

Source: Dr Nato Shengelia, General Practitioner Trainer, National Family Medicine Training Centre, Tbilisi, Georgia, personal communications, 21 July and 17 August 2022 (reproduced with permission).

6.3 HEALTH FINANCING

6.3.1 Financing therapeutic patient education services

An evaluation of self-management support and therapeutic patient education services identified a key barrier to success as insufficient ongoing funding or other resources (including time) to enable complex interventions to be sustained *(4)*.

Financing for therapeutic patient education can be viewed within the context of broader provider payments. In many countries, health financing arrangements may hinder transformative agendas, first, through significant underfunding of health systems, in particular for prevention and health promotion, and secondly, through failure to align incentives to deliver comprehensive person-centred care. Consequently, individual service delivery undervalues health prevention and self-management, reinforces specialist and hospital orientation of care provision, and promotes episodic rather than continuous care.

Both factors can lead to inadequate or absent funding for self-management support and therapeutic patient education. Therefore, addressing the funding gaps will require working through the provider payment system, which may operate in several ways. For example, in many countries, primary health care receives

funding as a capitation payment and it is up to providers to decide on spending priorities.

Another common system is that secondary care providers are paid for on a fee-for-service basis, which may not incentivize investment in therapeutic patient education services.

Therefore, policy-makers may need to consider how to fund therapeutic patient education in the context of their provider payment system in relation to:

- level of funding: for example, by increasing funding in order to achieve an adequate level of human resources in the service to support therapeutic patient education (Case study 13); and

- incentives: health-care providers are incentivized to prioritize therapeutic patient education in their care practice; this can be done in several ways such as pay-for coordination, pay-for performance or the use of bundles of care[3] – these approaches can be linked to the introduction of quality standards or specifications (discussed in Chapter 7) and offer a way to incrementally change health systems (Case study 14).

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[3] See the WHO Regional Office for Europe report, Health systems respond to noncommunicable diseases: time for ambition *(122)*, Chapter 12, for a more detailed discussion of these approaches.

6.3.2 Financing training programmes for health professionals in provision of therapeutic patient education

Training programmes for health professionals can be funded from various sources, including fees for participants or directly from ministry of health funds, pharmaceutical companies or nongovernmental organizations. The programmes can be supplemented by educational resources for health professionals such as e-platforms, websites and apps, which may be provided by nongovernmental organizations free or at reduced cost.

6.4 HUMAN RESOURCES

Time is always tight for clinicians and nurses. But when you educate patients well, you don't need more time because they have fewer complications, less morbidity and even a reduction in mortality.

Professor Karin Lange, Head of the Medical Psychology Unit, Hannover Medical School, Hannover, Germany

The evidence indicates that a range of health professionals can deliver effective self-management support and therapeutic patient education *(2)*. In addition, some generic chronic disease management programmes, such as the Stanford model, can be delivered by lay workers *(83)*.

Although many in the workforce deliver therapeutic patient education as part of a broader role, some countries have created a dedicated role of educator, whose main remit is to deliver therapeutic patient education for a particular condition, for example diabetes.[4] Although the role is most well developed in diabetes care, there are educators for asthma and other conditions.[5] Often, the educator's role is not only to support self-management in patients but also to train their colleagues and be a resource expert in their field.

Creating an adequate and sustainable workforce to deliver therapeutic patient education can be challenging for policy-makers since frequent staff turnover can lead to skills being lost (Box 13) *(4)*.

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[4] For example, the International Diabetes Federation's School of Diabetes provides training for health professionals to become diabetes educators *(124)*.
[5] For example, the Association of Asthma Educators runs certification courses for asthma educators *(125)*.

Box 13. Creating an enabling workforce

Professional training in supporting self-management, collaborative multidisciplinary working, with good communication and referral systems between professionals, and the involving [of] staff members in the design of interventions are potentially important ingredients of implementing self-management support.

Source: Taylor et al. *(4)*.

Staff who may be well positioned to provide therapeutic patient education, such as specialist nurses, may be excluded from such activities because of regulations or entrenched positions by other health-care disciplines. For example, a 2021 survey by the International Coalition of Respiratory Nurses confirmed a wide global variation in general nursing education and respiratory nursing education, with many countries lacking any formal educational programmes to provide nurses with the skills to provide enhanced quality respiratory care *(126)*.

In September 2022 for the first time, the International Coalition of Respiratory Nurses presented a session at the European Respiratory Society Congress on the need to develop a standardized curriculum for respiratory nurses (127).

Respiratory specialist nurses are a key part of the allied respiratory professional community, and they are involved in almost all care programmes. They have an important role in patient education, the enhancement of patient self-management and the management of care.

Years ago, we nurses were not expected or allowed to talk to the patient or their families about their diagnosis, disease or treatment, but nowadays patients want to know what is happening and why, and how to manage their disease. Treatment and technology are developing very fast, *and nurses are taking on a wide range of competencies, but they do not get the ongoing education provided to doctors and their training rarely covers the need for therapeutic patient education. What we need is a standardized curriculum, and that is what the International Coalition of Respiratory Nurses is campaigning for now across Europe.*

Andreja Šajnić, Croatian nurse, President of the International Coalition of Respiratory Nurses

National and regional government can promote health workforce development for therapeutic patient education by revising:

- **workforce regulations**, including job roles and responsibilities, standard operating procedures and service package descriptions for multidisciplinary team care with a strengthened role for nurses, educators and other non-health professionals; and

- **educational strategies** and introducing accredited educational programmes in therapeutic patient education for different health and allied professionals.

For example, a national government can ensure that the principles of therapeutic patient education are included in core curricula for medical and nursing undergraduates and for other members of multidisciplinary teams (Case study 15).

Case study 15. Embedding principles to support therapeutic patient education into the core curriculum for medical students, United Kingdom

The 2018 Core Curriculum for Communication in United Kingdom Undergraduate Medical Education *(128,129)* is published by the United Kingdom Council for Clinical Communication in Undergraduate Medical Education, which represents all United Kingdom medical schools. The Core Curriculum specifically highlights the domain of health behaviour change, which includes the skills required to support people in behaviour change and to manage their long-term conditions.

7

OPERATIONAL DELIVERY

Building and sustaining effective therapeutic patient education services requires strong leadership, working with people with lived experience of chronic conditions, and a focus on quality, evaluation and equality in access to services.

This chapter discusses some of the practical issues to consider when either implementing or improving a therapeutic patient education service.

7.1 LEADERSHIP, COORDINATION AND MANAGEMENT

An effective, sustainable therapeutic patient education service requires strong leadership. This may include policy-makers in national or regional government, senior administrators, clinicians and representatives of people living with chronic conditions; the last group can play an important role through stimulating public debate and prompting the redesign of services.

Leaders can advocate for person-centred care, self-management support and therapeutic patient education. Leaders who can work across a wide range of stakeholders to gain their support can play an important role in starting and sustaining a programme of action. The evidence shows that strong leadership will be required to integrate therapeutic patient education into routine clinical care *(4)*.

Policy-makers can encourage and support leadership across the health system by setting up a network of leaders among health-care providers and training institutions in order to build knowledge and understanding of therapeutic patient education and share experiences about successfully implementing or improving local programmes and preventing inequalities in processes of care (Box 14).

Box 14. The importance of leadership

[S]trategies for achieving the necessary organisational change to implement effective self-management support … [include] strong clinical leadership and commitment at the highest level to ensure that self-management support was prioritised, involving stakeholders to ensure that professionals are motivated and "bought in" to the process of change, training to ensure all staff have appropriate skills, availability of resources to enable ongoing delivery of self-management programmes, and regular oversight and evaluation to sustain the programme.

Source: Taylor et al. *(4)*.

At a local level, the leader's role may include building relationships with existing services, embedding therapeutic patient education into routine clinical practice across a health-care provider or clinical specialty, sharing up-to-date knowledge of the discipline, training colleagues, encouraging the establishment of multi- and interdisciplinary teams for patients with chronic conditions, and acting as a conduit to community groups who can provide additional information and support for people with chronic conditions and co-design local services.

Both disease-specific patient groups and professional associations such as national associations of specialist nurses or physicians can play a crucial role in providing leadership in this area.

7.2 FACILITATORS OF IMPLEMENTING A SUCCESSFUL THERAPEUTIC PATIENT EDUCATION SERVICE

A review of the implementation of self-management to support interventions identified several lessons and facilitators that can guide the design and delivery of an effective therapeutic patient education service. These are set out below *(4)*.

Early engagement with the health workforce and senior leaders is important for the successful design and implementation of a therapeutic patient education service. Greater success is also associated with organizations in which senior leaders support health professionals to promote therapeutic patient education (Box 15).

Both collaboration among key stakeholders (which can support health professionals to integrate new behaviour into practice) and the use of plan–do–study–act (PDSA) cycles appear to promote success. It is also important to promote effective communication and deliver training for health professionals in multidisciplinary teams.

Effective patient engagement in co-designing therapeutic patient education service is a critical facilitator (section 7.2.1). For example, a team approach involving the community has been essential to the success of projects in deprived, minority communities. It is also important to consider how patients will be engaged, considering the context- and patient-specific barriers to participation in therapeutic patient education interventions.

It is also important to monitor and evaluate service implementation, for example, by incorporating frequent reviews of how self-management support interventions are provided in order to ensure intervention fidelity, that is, that interventions are designed and delivered as intended. Many studies have identified the commitment of policy leaders and health-care providers to ongoing evaluation as a key facilitator of success.

7.2.1 Co-design of therapeutic patient education services and training programmes for health-care providers

Co-design is when an organization and its stakeholders are involved in designing or rethinking a service. The central feature of any co-design process recognizes people as experts of their own experience *(130)*.

Principles of co-design involving both patients and health professionals should be adopted at an early stage and used to guide the process of planning, design and implementation.

This approach is applicable both to the design of therapeutic patient education services and to training programmes for health professionals. Co-design means involving both people living with a condition (and their families and carers) and health professionals in the design phase. This can be achieved, for example, by creating working groups composed of both patients and health professionals (Case study 16). The evidence indicates that people living with chronic conditions would like to play an active role in coordinating their disease management and choosing their therapeutic orientations and treatments *(131)*.

The European Lung Foundation works with an international network of patients and patient organizations to involve patients in improving lung health and advancing the diagnosis, treatment and care of respiratory diseases *(132)*. (The Foundation's website provides information in English, French, German, Greek, Italian, Polish, Portuguese, Russian and Spanish.) The Foundation is patient led: it considers patients as equal partners with clinicians and helps to equip them with knowledge from lived experiences. Through the network, patients can play an active part in setting guidelines. For example, four patients joined clinicians and methodologists in 2021 for the rigorous process of developing the European Respiratory Society's clinical practice guidelines on the treatment of sarcoidosis *(133,134)*. The patients were instrumental in ensuring that fatigue was included as one of the seven key issues covered by the evidence-informed guidelines.

The benefits of co-design include creating better services that are more likely to be responsive to patients' needs, create the right conditions for engagement, facilitate openness and trust, and, ultimately, be effective (Box 16) *(135)*.

Box 16. The value of co-design of services

Positive outcomes for patients and health professionals involved in co-design of services include:

- increased confidence and engagement

- new and stronger social connections

- improved access to information

- stronger leadership and convening skills

- greater knowledge and expertise on a particular issue and/or the co-design process.

Source: Man et al. *(135)*.

7.2.2 Steps in starting or improving a therapeutic patient education service

For policy-makers and senior leaders, the first step in starting or improving an existing therapeutic patient education service is establishing a group that can drive the process of change. Membership of the leadership group will depend on the area of interest and whether the focus is national, regional or local. The group will need influential leaders who can work across disciplines and can command resources.

The first task of the leadership group is to establish or identify an existing stakeholder group comprising patients and other key stakeholders to support the process of change. An early step is to undertake a situational and gap analysis. This information can be used to develop a plan for improvement, followed by the design and implementation of new or revised services. These steps are discussed in detail in Fig. 5.

Although the figure describes the process of getting started as linear, with one step following another, in reality the steps may need to be revisited several times to develop a sustainable service. The process also may incorporate recognized design methodologies such as PDSA cycles.[6]

7.2.2.1 Step 1: establish a stakeholder group

The leadership group should establish a stakeholder group with whom they can work using the principles of co-design. This will include people and patients living with chronic conditions, as well as other stakeholders.

Members could include:

- patients living with the chronic condition, and their carers and families to represent users of the service;

[6] Examples of using PDSA cycles are available from WHO *(136)* and the Institute for Healthcare Improvement *(137)*.

- people living with the chronic condition and community groups to represent those people with the condition who may not use services;

- organizations that are responsible for providing, commissioning and/or paying for services for people living with chronic conditions (including insurers);

- leaders of relevant professional groups such as family doctors, physicians, nurses, physiotherapists, pharmacists, public health clinicians and policy-makers; and

- health-care educators and regulators of undergraduate and postgraduate health-care training for courses in therapeutic patient education.

Fig. 5. Steps in starting or improving a therapeutic patient education service

Once the group is established, it is important to specify its role and whether it takes decisions or provides advice. The group's role could include refining the scope of the situational analysis, providing advice about how to collect information, ensuring that the voices of people with lived experiences are heard in the analysis, providing insight into the findings of the analysis,

agreeing areas for improvement, and adding input to the design and oversight of any implementation plan.

7.2.2.2 Step 2: decide the scope of the situational analysis

Across the WHO European Region, the picture of therapeutic patient education is diverse and complex, so it is important at the outset to agree the scope of the situational analysis.

When considering the scope, it is important to define the population of interest in terms of geography or setting (people who live in an area or attend a particular health facility), by age and by condition.

Some examples of types of scope are given below.

- The senior cardiologist in a hospital in a large town wants to undertake a situational analysis in order to understand what therapeutic patient education is provided to patients with heart failure who attend the hospital.

- The medical director of a polyclinic wants to understand what therapeutic patient education is provided to people with chronic conditions (specifically, people with cardiovascular diseases, diabetes and respiratory disease) who attend the polyclinic.

- A policy-maker working in a national government and who is responsible for respiratory disease wants to find out what therapeutic patient education is provided to working people below the age of 60 years with pulmonary fibrosis in the country.

7.2.2.3 Step 3: collect information about current provision and evidence of what works

The type and amount of information collected will depend on the scope, resources and time available to carry out the analysis. If the analysis is too broad or complex, it may take too long and lose impetus. Table 8 gives suggestions about the kind of information that could be collected.

Table 8. Information to be collected as part of a situational analysis

Type of information	Description
Evidence of what works	Information on previous co-design projects, best buys and evaluations and results of any pilot project in own country and in countries with similar health systems; for examples, see the COMPAR-EU platform *(18)*
Population and community	Voices of people with lived experiences: what people with chronic conditions and their carers and families think about the support they receive to self-manage their condition. This should include both patients who attend health-care providers and people with chronic conditions who do not Questions should include the barriers and facilitators to accessing support Description of the number of people with chronic conditions who are likely to benefit from therapeutic patient education Additional information may include demographics, levels of health literacy and community assets that can support people with chronic conditions

Table 8. contd

Type of information	Description
Model of delivery	If therapeutic patient education is available, it should be described in terms of: • who provides it? – identify the organizations responsible for providing it • what is provided? – a description of the content of therapeutic patient education • how is it provided and funded? – as part of existing consultations or groups, etc. • which professional groups are involved in its provision and is there multi- and interdisciplinary working? • when is it provided? – e.g. at diagnosis or later in the patient's lifetime • how frequently is it provided?
Equity	Information on whether all patients have equal access to therapeutic patient education – are any particular groups disadvantaged by age, gender, socioeconomic factors or ethnicity? Families and carers should be included in this analysis
Quality	Information on staff training, whether the interventions on offer are based on the best evidence Whether the service is operating to any quality standards or specification, and whether evaluations/audits of the offered services have been carried out
Resources	Information on current expenditure and dedicated workforce Description of any additional resources such as online platforms, apps or dedicated resources that are available to both patients and staff

Methods for data collection will vary according to the scope of the situational analysis. Some suggestions on how information may be collected are given below (as categorized in Table 8).

• Qualitative information from patients/people living with chronic conditions, their carers and families: information may be collected via questionnaires, interviews or focus groups. This can provide data on the population, community, quality and equity.

• Qualitative information from stakeholders and health-care providers: information may be collected via questionnaires, interviews or focus groups. This might provide data on quality, equity and resources and evidence of what works.

• Quantitative information collected from health-care providers: for example, the health-care provider might be able to provide information on how many patients living with chronic conditions are offered some form of therapeutic patient education.

7.2.2.4 Step 4: identify gaps in provision

The next stage in the analysis is to draw up a list of gaps in provision. The categories shown in Table 9 can be used to structure the analysis.

Table 9. Examples of possible gaps in provision

Category	Examples of possible gaps in provision
Population and community	People with chronic conditions (and their carers and families) feel that their needs are not listened to and/or addressed
	Community assets are available but underutilized
Model of delivery	Not enough provision is available for the population
	The programme on offer is not provided in an effective manner
Equity	Disadvantaged groups in the community cannot access therapeutic patient education
	There is not enough support for carers of people with chronic conditions
Quality	The therapeutic patient education on offer does not follow best practice
	Staff who offer therapeutic patient education do not receive regular training or updates after their basic training
Resources	There is inadequate time for staff to offer therapeutic patient education as part of the routine consultation
	Insurers will not fund therapeutic patient education programmes

7.2.2.5 Step 5: agree areas for improvement

The leadership and stakeholder group may wish to consider several options to address the existing gaps in provision. Factors that may influence their decision about which should be prioritized include the potential benefits, the speed and ease of implementation, the available resources, any regulatory or legal barriers, and engagement of the workforce.

7.2.2.6 Step 6: develop, plan and design a new or revised service

Planning and design can take considerable time – this is the stage where co-design is crucial (Box 17). During the design and implementation phase, visiting existing projects that have been successfully implemented in other subnational regions or facilities can be very helpful in understanding the likely challenges and potential solutions. It is also useful to consider how successful projects in other facilities, regions or countries can be adapted to the local circumstances. It may be useful to test out ideas in several small-scale projects or pilots and evaluate these before moving on to full-scale implementation. PDSA cycles may be very useful at the design stage.

Larger projects will need to consider the integration and phasing of different areas for improvement such as staff training, restructuring services and financing of therapeutic patient education.

7.2.2.7 Step 7: implement changes

Methods for implementation will vary according to the scale of change and available resources. A stepwise approach to starting or improving services may be best.

Scaling up successful pilots or small projects is also a useful approach to implementation. Extending services to new facilities or organiza-

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Box 17. A collaborative approach to design can support implementation

Successful programmes have used PDSA cycles and similar collaborative approaches to harness and build on professional/organisational motivation in order to achieve the desired service redesign.

Source: Taylor et al. *(4)*.

tions will require a preparatory phase of engaging with the local workforce and other key stakeholders and may also require adapting the service to new contexts or settings.

Implementation research may be useful to assess the scale-up of therapeutic patient education interventions and their integration into health systems. Implementation research may not only help to clarify barriers and facilitators in rolling out new programmes but can also support the reiterative refinement needed for successful adaptation (for example, the use of PDSA cycles during the implementation phase *(138)*).

7.3 DELIVERING A QUALITY SERVICE

To be both effective and cost-effective, therapeutic patient education services must be of a sufficient quality that can be sustained over time. In addition, an important aim of therapeutic patient education and self-management programmes is to drive up the quality of care for patients living with chronic conditions by actively involving patients and supporting them to become experts in their own care.

Programme leaders and policy-makers should work together to establish processes to continually assess and promote the quality of the services they provide. This may be referred to as a quality improvement or a quality assurance system. In addition, the services may be evaluated to determine their outcome.

Depending on a country or subnational health system and legal and regulatory framework, a quality improvement system can be developed at national, regional, organizational (for example, led by health-care providers, commissioners or insurers) or local facility level.

A focus on quality is needed for both therapeutic patient education services and training programmes for health professionals.

7.3.1 Quality improvement systems

There are several different approaches to implementing a quality improvement system, and the best approach will depend on the context and available resources; however, the principles are the same for all (Fig. 6) *(139)*.

Fig. 6. Principles of a quality improvement system

- Set (and reset) quality standards
- Measure performance against standards
- Take action to improve quality
- Measure performance against standards
- When performance matches quality standards, reset quality standards to drive up quality
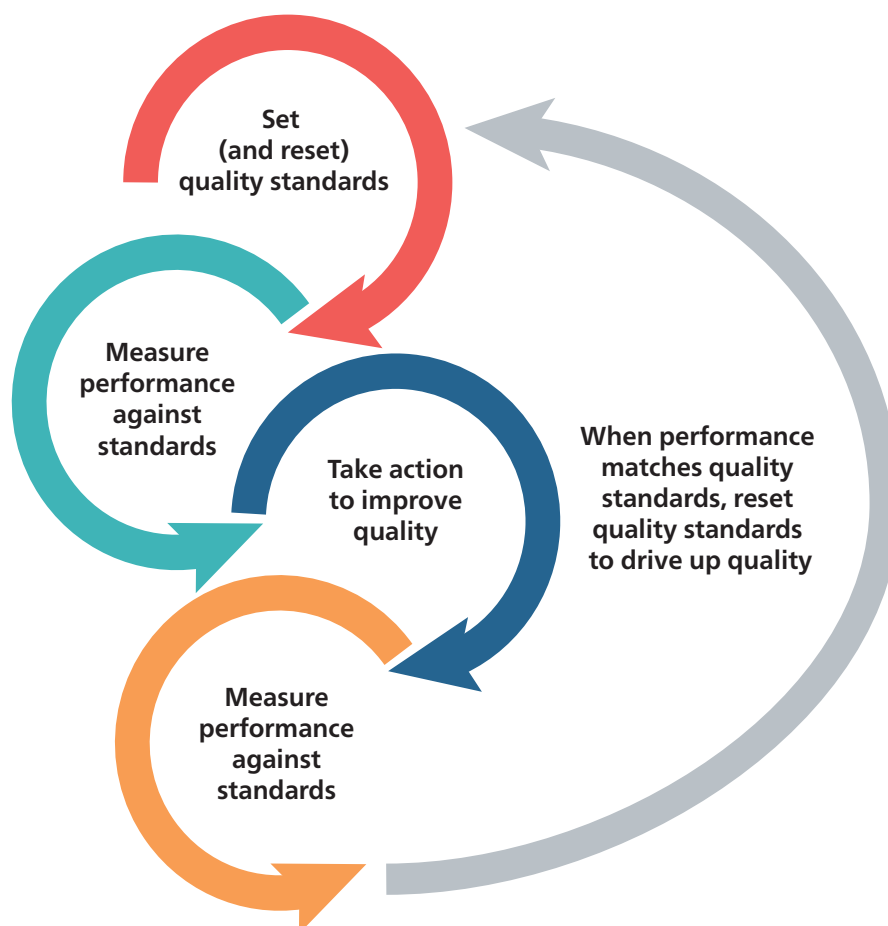
The first step is to set **quality standards**. These are processes that can be measured and are known to be important in maintaining the quality of a service. Involving patients (and their carers and families) who are using the service in setting the quality standards (and assessing performance) is crucial to identify what is important to patients.

Examples of quality standards for a therapeutic patient education programme and training programmes for health professionals could include:

- all staff offering therapeutic patient education should have attended an accredited training course in the last 3 years;

- the health-care provider conducts a yearly survey of patients with heart failure to find out their views on the patient educational group;

- all patients with diabetes should be offered an appointment to attend a one-to-one session with a specialist nurse within 6 months of diagnosis;

- interdisciplinary teams meet at least once a month;

- the basic training programme should be updated every year to ensure that it reflects best practice; and

- students completing the intermediate training programme should demonstrate proficiency in the relevant clinical communication skills, as assessed by a recognized test.

The second step is to measure performance against the quality standards. This may be done by asking a health-care provider or health professionals to complete a questionnaire each year; it can also include a patient survey. In some cases, information can be derived from health information systems or databases.

The third step is to take action to improve quality. This step is crucial but is at times neglected because it requires resources and time. Leaders must ensure that action is taken if indicated. Ways to improve the quality of a service include providing additional staff training, working with patients to co-design services, establishing interdisciplinary team meetings to discuss

individual patient's needs, service improvements, and the use of tools, apps and online platforms for staff and patients to improve the quality of a service.

After action has been taken to improve quality, performance should be remeasured to check that improvement has been achieved. Once quality standards are consistently being met, then it may be appropriate to reset standards to further drive up quality.

Common methods to implement a quality improvement system include accreditation systems (see Chapter 6), commissioning specifications or audits. For example, 10 quality standards were produced as part of the Swiss strategy to improve self-management support (Fig. 7) *(140)*.

In England (United Kingdom), the Quality Institute for Self-management Education and Training *(118)* has developed standards that it uses to accredit services that provide patient education on chronic conditions. The standards cover themes such as management, programme delivery and continual performance improvement (Case study 17). Commissioners can only commission services that are accredited to ensure that health-care providers are offering high-quality services.

7.3.2 Evaluation

Therapeutic patient education services and training programmes for health professionals should be evaluated to assess that they are effective, efficient, equitable and achieving the desired outcomes. For example, if the desired outcome is a sustained improvement in quality of life and health outcomes for patients living with asthma who attend a 3-week course, then an evaluation could ask patients to regularly record their peak flow and complete a validated questionnaire on their quality of life and asthma control (appropriate measures are discussed below) before and after the course for an agreed period such as 6 months. However, if the evaluation for the same desired outcomes only compares a participant's knowledge before and after the course, it will be unable to demonstrate whether the course is delivering on its stated aims. Ideally, the evaluation should be built into the programme at the outset before implementation (Case study 18). Ongoing evaluation was found to be a key facilitator in maintaining effective, high-quality services *(4)*.

Fig. 7. Quality standards for self-management support services, Switzerland

| SQ1. Programmes tailored to needs | QS2. Partnerships with those affected | SQ3. Involvement of relatives | QS4. Evidence-based programmes | SQ5. Quality standardization |
| SQ6. Good organization and coordination at all levels | SQ7. Sustainable programmes | SQ8. Equal opportunities | SQ9. Promotion of results and transparency | SQ10. Security and data protection |

Source: adapted from Kessler *(140)* (reproduced with permission).

Case study 17. Standards for accreditation of patient education services, England (United Kingdom)

Aims, ethos and design

a) The provider has a written statement that describes the person-centred ethos of the programme. This is shared with all people within the provider, commissioners and participants.

b) The programme has documented aims and a clearly defined target population, and is based on educational theories and a sound evidence base. The programme must have a defined desired positive impact on outcomes for the participants in at least one of: knowledge, self-efficacy, bio-medical measures, health beliefs, health-related behaviours or well-being.

c) The programme is designed to ensure that participants are supported in setting their own goals and where appropriate develop their own action plans.

d) Health-care information contained in the programme is current and reliable, including information for treatments, medicines and devices.

Source: Quality Institute for Self-management Education and Training *(118)*.

Key performance indicators can be developed to measure changes in the structure, process and outcome of services. The views of the people delivering and using the services should also be sought and incorporated.

There are established validated measures that can be used to evaluate services. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are self-administered questionnaires to measure

patients' views of their health status. Disease-specific measures have been developed, which can be used to evaluate the effectiveness of services, as well as generic measures that assess quality of life and well-being. Examples include measures for diabetes care *(142)* and respiratory disease *(143)*, as well as the WHO Five Well-being Index (WHO-5), which can be used as a measure of psychological well-being *(144)*.

Tools are also available that can measure how confident an individual is to self-manage their chronic condition and, as such, can be helpful in evaluating the success of structured self-management programmes, including therapeutic patient education services *(65,145)*.

Case study 19 is an example of an evaluation of training programmes for health-care professionals.

7.4 ADDRESSING INEQUALITIES

Policy-makers and senior leaders should be aware of how health inequalities may affect a person's risk of developing a chronic condition and their ability to minimize complications from their condition. For example, people from disadvantaged, underprivileged or ethnic minority groups are likely to have higher rates of diabetes; for those who develop diabetes, uptake rates are lower for diabetic retinopathy screening *(146)*. The International Diabetes Federation has highlighted the importance of ensuring the rights of people with diabetes to be offered retinopathy screening.

There is also a potential to heighten inequalities if interventions such as therapeutic patient education are not offered in a way that recognizes different socioeconomic contexts.

For example, interventions that do not acknowledge differences in education attainment and digital literacy and health literacy may not benefit population groups who do not meet the implicitly assumed levels *(147)*.

Applying behavioural and cultural insights for health *(148)* may help policy-makers and senior leaders to understand how social, cultural, political, psychological or economic factors may affect an individual's wish or ability to take up offers of therapeutic patient education services. Insights refer to the knowledge derived from the social sciences and health humanities that can help in understanding the drivers and barriers to participation. The insights are often context dependent and can be used in the design,

implementation and evaluation of health policies to ensure that they are effective, acceptable and equitable.

An individual's decision on whether to engage with therapeutic patient education may be influenced by factors that impede their access or by their level of health literacy.

7.4.1 Improving access to therapeutic patient education services

Policy-makers and senior leaders can consider access from the patient's perspective as patient characteristics may affect access. For example, age, disability, gender, religion and cultural characteristics may all affect a patient's access to a service (Box 18).

> **"**
>
> *I hated having diabetes. I was angry and I fought against it. Diabetes has formed my personality, my moods, attitude, career choices, outlook on life. My parents had a very hard time with me. I resisted having any jabs until I was 13, and thoroughly resented being different. I couldn't go away on school trips, I was caged at home because I had to be there where all the insulin and other gear had to be stored and administered. I went into freefall and gave up on school work. In my teenage years I was wild, completely in denial. I would ignore any restrictions and go out with my mates with no injections, then I'd collapse. And do it all over again.*
>
> **Living with diabetes: Matt, aged 52 years, gardener**
>
> **"**

Box 18. Gender inequalities in self-management support

Some studies show that men feel less comfortable participating in self-management support if it is viewed as incongruous with valued aspects of their identity [*(24)*]. Research into specific health issues reveals that men with rheumatoid arthritis, for example, find information-giving sessions, rather than a discussion group, to be more acceptable in providing support to enhance self-management [*(149)*]. Men find self-management support more attractive when activities are perceived to challenge masculine ideals associated with independence, stoicism and control, when it is perceived as action-oriented, has a clear purpose and offers personally meaningful information and practical strategies that can be integrated into daily life [*(24)*].

Source: WHO Regional Office for Europe *(150)*.

Patients' ability to access therapeutic patient education services can be affected by the location, timing and delivery method of the service. For example, offering therapeutic patient education services only during the daytime may deter working people from attending, or patients on low incomes or without transport may not be able to attend if they have far to travel for a session with a specialist nurse.

Some disadvantaged groups may be unaware of what services are available. Therefore, comprehensive recruitment strategies should be used, including raising awareness among professionals, voluntary groups, local community or social groups (Case study 20) *(46)*.

7.4.2 Increasing health literacy

Levels of health literacy, including e-health or digital health literacy *(151)*, may affect an individual's ability to self-manage their condition.

Low health literacy can be a barrier to accessing and using health information and, therefore, to engaging with healthy life choices and the appropriate use of health-care services *(47,48)*.

Individuals need a sufficient level of health literacy *(152)* to enable them to address their health needs and effectively utilize health-care services. For people with chronic conditions, the demands and complexity of their condition may mean that their level of health literacy is insufficient to address their health needs *(153)*. Both a health system and an individual approach may help to mitigate this situation.

Fig. 8 shows that low health literacy can be addressed by *(47,153)*:

- improving individual- and population-level health literacy through education (for example, in schools and public health education campaigns) and training;

- compensating for low health literacy by adjusting communication in consultations with patients and adapting educational strategies; and

- ensuring that organizations provide health information and resources that are available and accessible using different formats and approaches to meet the information needs of the people they serve.

Fig. 8. Addressing low health literacy


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│   ┌────────────┐        ╭───────────╮        ┌────────────┐       │
│   │ Skills and │───────▶│  Health   │◀───────│ Demands and│       │
│   │ abilities  │        │  literacy │        │ complexity │       │
│   └────────────┘        ╰───────────╯        └────────────┘       │
│                                                                   │
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| Improve individual and population health through education and training | Compensate for low health literacy by adapting communication and facilitating understanding | Make sure organizations provide health information & resources that are available and accessible |
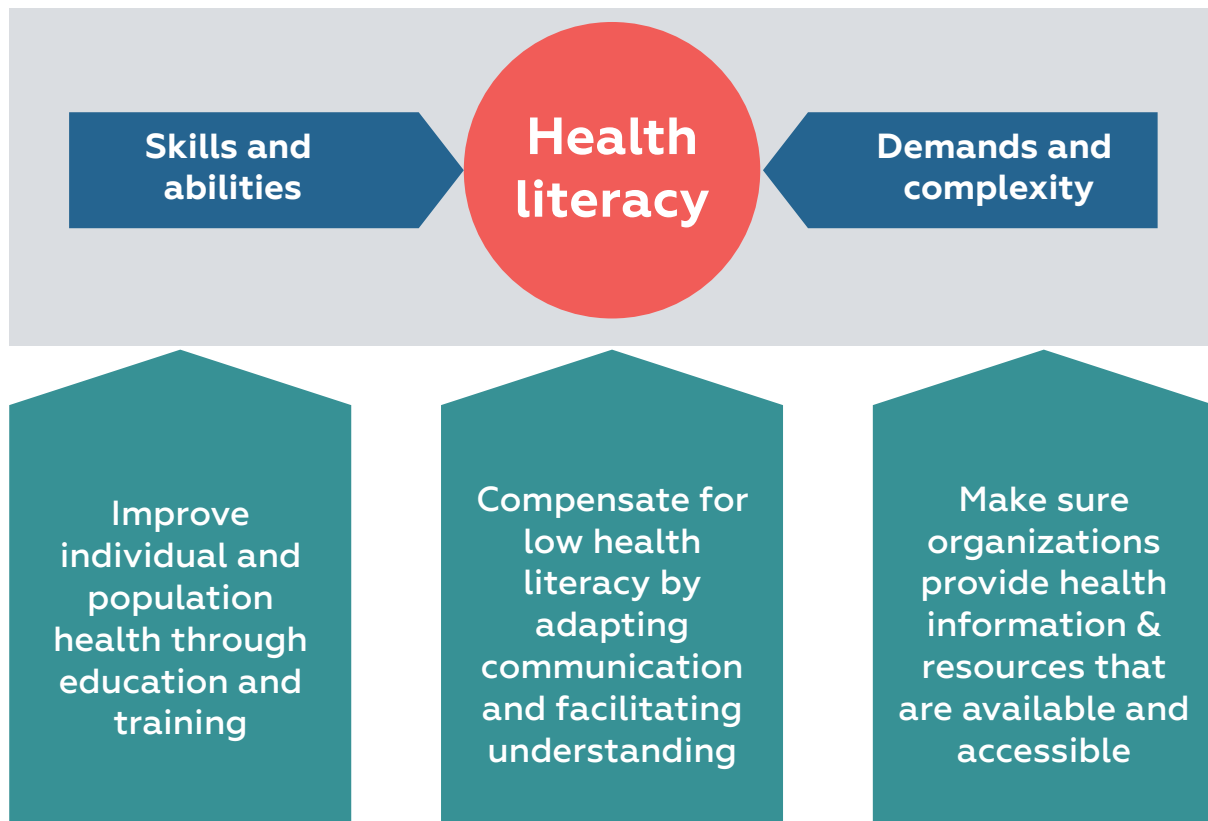
Source: adapted from World Health Organization *(153)*.

8
CONCLUSION

The purpose of this guide is to equip policy-makers and health professionals across the WHO European Region to provide better access to effective therapeutic patient education for all patients who are living with one or more chronic conditions and can benefit from this approach.

Throughout the development of the guide, people living with chronic conditions have been at the centre of the process to ensure that their views are heard so that services are built around their needs.

The guide highlights that therapeutic patient education is a complex and person-centred process involving more than simple information transfer to the patient provided by trained health professionals.

It has demonstrated how therapeutic patient education can make a real difference to the lives of people living with chronic conditions by supporting them to reduce the harmful consequences of their condition and improve their health, well-being and quality of life.

The guide makes the case that this approach to therapeutic patient education is not only beneficial for the individual and their family but, by supporting patients with chronic conditions to self-manage their care, can also reduce pressure on health services, be cost-effective and benefit the wider society.

The guide provides a roadmap for policy-makers and health professionals who are planning to set up or improve their therapeutic patient education services. It explains the background and core principles of therapeutic patient education and provides a step-by-step description of how to deliver effective therapeutic patient education services. This is illustrated with patient stories so that the reader can gain an understanding of what this means in practice.

Transforming services so that therapeutic patient education is part of routine care for patients living with chronic conditions is a complex and long-term aim for a health system. An important component of this change is training health professionals in the principles and practice of therapeutic patient education. The guide provides practical advice to policy-makers and health professionals about how they may embed this approach into their workforce through developing and implementing training programmes for health professionals in self-management support and therapeutic patient education.

Supporting patients to be self-managing requires a health system that integrates person-centred care into the way it designs and delivers services and, potentially, changes the culture of the way that health services are delivered, for example by expanding the role of nurses. In recognition of the challenges of making these sorts of changes to a health system, a chapter is devoted to discussing the barriers and facilitators policy-makers and health professionals may face and offering potential solutions.

Lastly, the guide provides some practical suggestions on how to start or improve existing services by tackling common issues such as quality and inequalities.

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