

Chapter 3

Person-Centred Care Implementation: Design and Evaluation Considerations



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Abstract The Gothenburg model of Person-Centred Care (PCC) is an evidence-based intervention shown to improve care and health outcomes while maintaining cost. Other health systems could benefit from its sustainable implementation. The WE-CARE implementation framework, adapted by COSTCares, provides a base set of enablers and outcomes recommended for the design and evaluation of PCC. The methodology is extended using implementation science to systematically address contextual factors at different levels. Evidence-based frameworks, such as the Consolidated Framework for Implementation Research (CFIR), for example, and hybrid effectiveness-implementation study designs can be used. Additional enablers to consider when designing and evaluating PCC implementation strategies are discussed. The outcomes of quality of care and cost can be addressed using a Value for Money (VfM) framework. Various VfM methods and analysis models can be incorporated into PCC implementation research design in order to influence policy makers and health system decision makers towards the sustainable uptake of PCC.

Keywords Person-centred care · Implementation science · Value for Money frameworks

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3.1 Introduction

Demographic changes and the rise of chronic diseases have led to increased demand for healthcare and are some of the many challenges currently facing health and social care systems. Viable solutions that maintain or decrease cost while improving quality of care are required. Person-centred care (PCC) has been identified as a possible intervention to improve care and maintain or reduce healthcare costs, especially for patients with chronic and long-term conditions [15]. This chapter addresses evaluation and design considerations for the sustainable implementation of PCC. First, the intervention and an implementation framework of enablers and outcomes will be presented. Then additional enablers will be detailed, along with evidence-based considerations from implementation science regarding assessment of contextual factors and study designs for PCC implementation. Finally, tools and methodologies to assess the cost-effectiveness aspects of the outcomes using a Value for Money framework will be described.

3.2 The PCC Intervention

The Gothenburg model of PCC incorporates an ethos that recognizes the person behind the patient presenting with a disease [24]. It has a basis in the ethical perspective of care provider as healer who assists identification of the patient's strengths and resources to facilitate healing when facing a diagnosis that threatens the self [28]. PCC uses the illness narrative as the foundation for collaborative, equalitarian relationships between care providers and the patient/person expert [5]. Furthermore, PCC endorses and promotes egalitarian principles [34].

In practice, the Gothenburg model of PCC involves three “routines” to help care providers systematically and consistently implement PCC. These routines, or pillars, help providers put the person before the disease in their interactions with patients in the context of their hectic, day-to-day schedules. According to Ekman and colleagues [11], the three routines are as follows:

1. **Initiate the partnership:** The providers invite the patient to relate a narrative account of his/her experience with the disease or condition. The patient provides a personal account of his/her illness, symptoms, and impact on everyday life. The person's beliefs, feelings, and preferences are expressed and heard by the providers via the narrative. The person's resources and strengths are identified and assessed. These facets are then leveraged to enhance self-management.
2. **Working the partnership:** The provider-person interactions and patient narrative are used as a basis for care planning. The patient joins the care team as an expert in his/her own life. Through discussion, all the providers and the person—and caregivers, as appropriate—engage in deliberative shared-decision making (see details in Chap. 5). Consensus is reached on care goals and all possible

options are assessed in this care team to ensure selection according to patient values, beliefs, preferences, values, lifestyle, and health issues.

3. **Safeguarding the partnership:** Through documentation, the providers validate the patient's preferences, values, and beliefs and involvement as an expert member of the care team. The PCC process, including the patient narrative and care plan, is documented for the care team. The care team meets regularly to review progress and required adaptations. In this way, continuity of PCC is ensured.

3.3 COSTCares PCC Implementation Framework

Although PCC is implemented at the micro-level by care providers, PCC is also implemented in the meso- (e.g., organizational) and macro- (e.g., policy and financing) levels of service delivery within a health system. PCC implementation involves education of health professionals, as well as constant communication and collaboration among health workers and patients [15]. Because PCC often requires a change in current processes of patient care and involves teams of professionals, PCC may affect many aspects of care—functional (e.g., support functions like financial management), organizational (e.g., networks), professional (e.g., alliances of professionals) and clinical (e.g., processes). At the system level, horizontal (across the same level of care provision) and vertical (primary-secondary-tertiary care) integration may be needed. The degree of PCC integration may also differ depending on context, ranging from separate linked structures, to coordination of care, to full integration of PCC. Clear goal definition and examination of implementation context is important before determining how PCC might be sustainably implemented and assessed [3].

The European Commission (EC)–funded WE-CARE consortium developed a model positing five critical macro-level enablers for sustainable PCC leading to quality of care and cost containment as outcomes [12]. The enablers include information technology, quality measures, infrastructure, incentive systems and contracting strategies. COSTCares, COST Action 15,222, was a follow-on EC project, which extended this framework by adding an additional enabler: cultural change [21]. These enablers overlap and interact. They are hypothesized to help to drive the uptake, adoption, and maintenance of PCC and therefore influence the two outcomes of quality of care and cost containment. Each of these enablers and outcomes, at minimum, should be considered when designing and evaluating implementation strategies.

Examination of additional enablers of PCC implementation may be warranted. For instance, a review of integrated care experiences in Europe by a European Commission Expert Group on Health Systems Performance [3] identified macro- and meso-level factors influencing successful implementation that likely apply to PCC implementation. The WE-CARE enablers were included (e.g., organizational change, financing and incentives, information communication technology infrastructure and solutions, and monitoring/evaluation system), and the following other factors were

important: Political support and commitment, Governance, Stakeholder engagement, Leadership, Collaboration and trust, and Workforce education and training.

Santana and colleagues [29] propose valuable a general conceptual framework or roadmap to guide systems and organizations in PCC provision and evaluation and quality of care improvement in general. The roadmap is based on the Donabedian model domains of structure, process and outcome. The emphasis is on the structure, or health system domain as it provides the context of care delivery. The most important constructs in this domain are the PCC culture in the continuum of care, the educational programs of health workers, a supportive environment, the development of supportive health technologies, the monitoring and measurement of PCC performance, and feedback from patients. Process constructs in the model include communication and interaction between the patients and providers of care, respectful and compassionate care, and including patients as partners in care. Outcome constructs in the model relate to the results from the integration of PCC care across the health and social care system, impact on health and social care professionals and patients, and the value of PCC implementation [29].

3.4 Implementation Science Frameworks to Examine Contextual Factors

The field of implementation science was developed to address the research-to-practice gap. Implementation science is defined as “The scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care” [10]. While clinical research addresses the “what”, implementation research addresses the “how”. Nilsen [25] offers a schematic to organize the theoretical approaches used by implementation science. Each approach is categorized based on function and include:

1. to describe or guide the process of translating research into practice (e.g., via process models);
2. to understand or explain what influences implementation outcomes, for example via determinant frameworks, classic theories, or implementation theories; or
3. to evaluate implementation, using evaluation frameworks.

One of many comprehensive models that can be used for all three functions is the Consolidated Framework for Implementation Research (CFIR; [8]). It consists of five domains, including the intervention itself with adaptations, outer setting, inner setting, characteristics of the individuals involved, and the implementation process. Each domain consists of various constructs. There is a website (<https://cfirguide.org/>) with supporting materials, including a detailed description of each construct, a qualitative codebook with operational definitions and inclusion and exclusion criteria

for each mutually exclusive construct, and quantitative measures as they become available.

Another practice resource for implementation, which cites the CFIR and other valuable frameworks for design and evaluation is ImpRes—Implementation Science Research Development Tool which can be found at: <https://impsci.tracs.unc.edu/wp-content/uploads/ImpRes-Guide.pdf> [16].

In the field of implementation science, the intervention is studied separately from the implementation strategies used to facilitate its sustainable uptake. Implementation study designs examine intervention-implementation effectiveness in real-life conditions. This is in contrast to pharmacological research, in which the gold standard to determine drug effectiveness is the randomized controlled trial. In implementation research, hybrid effectiveness-implementation designs assess both the clinical effectiveness of an intervention and its implementation. Context of intervention implementation (e.g., enablers) are considered a priori. Curran and colleagues [7] proposed three general groups of hybrid effectiveness-implementation designs, which differ depending on whether the intervention or the implementation is the primary focus:

1. Hybrid Effectiveness-Implementation Type I—Intervention primary: Examines the effects of an intervention on relevant outcomes while observing and gathering information on implementation;
2. Hybrid Effectiveness-Implementation Type II—Both the intervention and its implementation are primary: Simultaneously examines the intervention and implementation strategies; and
3. Hybrid Effectiveness-Implementation Type III—Implementation primary: Examines the effects of an implementation strategy on an intervention while observing and gathering information on the intervention’s impact on relevant outcomes.

Lane-Fall and colleagues [19] offer a visual representation of intervention and hybrid effectiveness-implementation designs in the form of a decision tree. They call it the “subway line of translational research”. The first question to determine which line one should take is if the intervention has shown efficacy. If not, efficacy research into the intervention, such as laboratory studies, are required. If the answer is yes, the next question is if the intervention has shown effectiveness in different contexts. If not, effectiveness research, such as randomized controlled trials, is warranted. If effectiveness is not fully demonstrated, hybrid effectiveness-implementation trials are considered valuable. If an intervention has shown effectiveness, hybrid effectiveness-implementation trials are also used, with a focus on implementation. Three study designs are proposed in order of advancing complexity: quantitative–qualitative (mixed) methods studies to better understand the role of contextual factors on intervention outcomes, designing implementation strategies, and finally testing and evaluating the effectiveness of different implementation strategies. A final stop that was not addressed by Lane-Fall et al. [19] would be the optimization of successful

implementation strategies. This stepwise process and use of hybrid effectiveness-implementation research designs helps to understand the role of context in intervention outcomes. This knowledge is not only useful to ensure the best possible outcomes in a specific setting, but it also facilitates the adaptation and transfer of interventions to other settings and/or the scaling-up of interventions to new, larger settings.

3.5 Examination and Evaluation of PCC in Context: Additional Considerations

Many conceptual frameworks for implementation evaluation are available, but it is important to develop practical guidelines for implementation. In this respect, logic models are an effective tool for intervention design, implementation, and evaluation.

A logic model is a visual representation of a theory of action or program logic, or program theory. It provides a simplified picture of the relationships between the intervention inputs (resources, strategies, activities) and the desired outcomes of the program. As part of COSTCares Working Group 3, Lloyd and colleagues [21] used program theory to create if-then statements to hypothesize how the different enablers might interact to facilitate PCC intervention adoption in order to generate the goals of cost containment and better quality of care. Each enabler was considered on micro, meso and/or macro levels. In brief, conclusions are offered regarding recommendations for PCC evaluation in practice [21]. For instance:

1. Health outcomes measures should be relevant to patients and their families, as well as health care workers and decision makers. Health outcomes measures should include the patient experience and the markers of quality.
2. The main areas of implementation evaluation of PCC from patient point of view are functional ability, care experience, self-efficacy and cost of care.
3. Pre- and post-intervention/implementation data collection points are important.
4. Continuous monitoring, with feedback to stakeholders involved, and over a long follow-up period is key.
5. It is crucial that the evaluation measures reflect PCC goals and results regarding goal achievement. These measures must be accurate, objective and verifiable, and indicative of real performance.
6. A minimum data set of PCC-related indicators should be compounded. These may be composed of routinely collected data, questionnaire data and qualitative data, as well as results of outcomes concerning health, quality and cost.

Santana and colleagues [30] concur that the definition of PCC quality indicators is not clear and there is a lack of current indicators available to assess implementation in the care setting.

The selection of appropriate indicators to measure enablers, the PCC intervention, and outcomes requires careful thought. There are several criteria that can be used to

determine which indicators might be most appropriate. The European Commission Expert Group on Health System Performance recommend that the most feasible indicators be chosen, for instance those that are already in use with logistics in place (such as existing datasets) for data collection [3]. The Organisation for Economic Co-operation and Development (OECD) Health Care Quality Indicators Project suggest the following criteria for the selection of indicators: validity, reliability, relevance, action ability, feasibility, and comparability [4]. Raleigh and colleagues [27] add to this list: accuracy, meaningfulness, and avoidance of perverse incentives. These last criteria are particularly important in the evaluation of PCC.

The following aspects must be operationalized when undertaking the implementation of PCC in a health system. What are the main aims of PCC? What are the desired outcomes of PCC? What are the time frames over which the outcomes could be achieved? What are the best possible outcomes? What might be some unintended effects? What is the scope of implementation? What setting or settings will be addressed? Will there be inter-sectorial collaboration (e.g., between the health sector, social/community care sector, education sector)? How can the impact be measured? To what extent can a given measure meet the indicator criteria defined above? What data are already available that might be relevant? What are the pros and cons of those readily available indicators? What are the options for new and innovative ways to collect indicator data?

New indicators of PCC may need to be developed that evaluate structure (e.g., assessment of the basic conditions and system levers needed for transformation), process (e.g., focusing on the areas where there are more barriers), and outcomes (especially concerning the patient experience). All indicators must support evidence-based investment and the impact of every change must be monitored and evaluated comprehensively from different perspectives—for instance by patients, family/caregivers, health and care workers, administrators [3]. Since the impact of PCC on outcomes may only become apparent in the longer-term, an emphasis on shorter-term intermediate outcomes and process indicators is warranted. However, measurement of longer-term outcomes (especially health outcomes) is needed in order to collect potentially convincing evidence as to cost-effectiveness.

Gyllensten and colleagues [15] support the development of a core outcome set for PCC evaluation. The set of outcomes should include economic, clinical, humanistic, and unintended outcomes, as well as measures of patient experiences with healthcare services. Given the importance of the cost containment and quality of care outcomes to the PCC Implementation Framework, the rest of this chapter is dedicated to these considerations.

3.6 Value for Money and Economic Evaluation Tools

Value for money (VfM) and economic evaluation tools have been central to health policy decisions, accountability, healthcare delivery and healthcare systems [22, 26, 32]. Economic evaluation helps identify the more relevant alternatives, allows

different analysis viewpoints, raises quantification over the informal assessment, and increases explicitness and accountability in decision-making [9, 14].

Governments are increasingly required to strategically manage scarce resources by investing in services that provide the best health outcomes [33]. The rapid diffusion of health technologies brings increased challenges to provide high quality and innovative care to meet population health needs most effectively while managing constrained healthcare budgets and safeguarding equity, access and choice [2, 22, 26, 33]. As argued by Drummond et al. [9], whatever the context or specific decision, a common question is posed: Are we satisfied that the additional health care resources (required to make the procedure, service, or programme available to those who could benefit from it) should be spent in this way rather than some other ways?

Another important reason for the importance of VfM and economic evaluation relates to accountability assuring that taxpayers and founders money is being spent wisely, and reassuring healthcare users and other stakeholders that their claims and interests on the health system are being treated fairly and consistently [13, 18, 32, 33].

VfM includes the three E's in its assessments [13]:

1. Economy (minimizing the cost of inputs, while bearing in mind quality),
2. Efficiency (achieving the best rate of conversion of inputs into outputs, while taking in mind quality), and
3. Effectiveness (achieving the best possible result for the level of investment, while maintaining in mind equity).
4. A fourth E was added to considerer Equity, ensuring that benefits are distributed fairly [17].

Figure 3.1 presents VfM main framework, their components and the relations between the four E's.

According to Smith [32], several components of VfM need to be considered when developing any VfM measure: eventual outcomes of interest, intermediate outputs and activities, inputs, possible external constraints on achieving VfM, and whether a long or short time horizon is being adopted. Outcomes are the valued outputs that usually are grouped on four broad categories: health gains, the patient experience, inequalities, and the broader social and economic benefits of health services.

Fleming [13] identifies six main methods that can be used to assess VfM: Cost-Effectiveness Analysis (CE analysis), Cost-Utility Analysis (CU analysis), Cost-Benefit Analysis, Social Return on Investment (SROI), Rank correlation of cost versus impact, and Basic Efficiency Resource Analysis (BER analysis). Table 3.1 presents a brief description of each method associated with VfM and when each should be applied.

The purpose of economic evaluation is to inform decisions. It deals with both inputs and outputs (costs and consequences) of alternative courses of action and is concerned with choices. Decision-makers face the problem of scarce resources (people, time, facilities, equipment and knowledge) and since the effects of choosing one course of action over another will not only have effects on health but also on health care resources as well as other effects outside health care, informing health

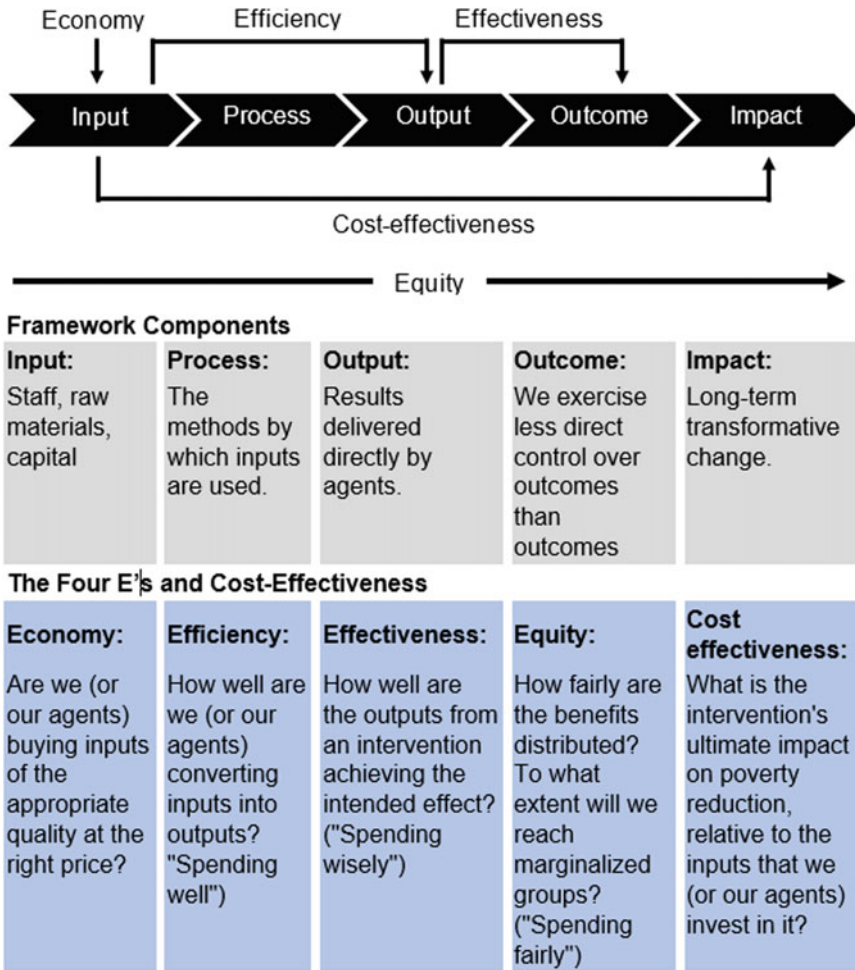


Fig. 3.1 Value for Money framework (Adapted from [18])

care decisions requires consideration of costs and benefits. Table 3.2 synthesizes additional information about five types of studies analyzing costs.

The costs involved in PCC implementation must be calculated, and all of the previous methods can be used to determine the return of investment or the value for money for private or public financing of PCC.

Table 3.1 Methods for evaluating VfM (Adapted from [13])

Method	Brief description of the method	When to apply the method
Cost-effectiveness analysis	The evaluation of two or more alternatives, based on the relative costs and outcomes (effects), in reaching a particular goal. This method can be used when comparing programs that aim to achieve the same goal	Comparing programmes that aim to achieve the same goal
Cost-utility analysis	The evaluation of two or more alternatives by comparing their costs to their utility or value (a measure of effectiveness developed from the preferences of individuals)	Used where monetizing outcomes is not possible or appropriate Most commonly used in health through quality adjusted life years (QALY). The QALY allows the comparison of medical interventions by the number of years that they extend life
Cost-benefit analysis	The evaluation of alternatives by identifying the costs and benefits of each alternative in money terms and adjusting for time	Used to identify if a course of action is worthwhile in an absolute sense—whether the costs outweigh the benefits—and allows for comparison among alternatives that do not share the same objective or the same sector
Social return on investment	Measures social, environmental and economic costs and benefits	Used when comparing programmes with different goals or in different sectors
Rank correlation of cost versus impact	Allows for the relative measurement of VfM across a portfolio of initiatives	Used to rank and correlate costs and impact of different programmes or initiatives
Basic efficiency resource analysis	Provides a framework for evaluating complex programmes by comparing impact to resources and offering a relative perspective on performance where units analyzed are judged in comparison to other peer units	Used to examine the relative value on a four-quadrant graph based on costs and impacts

3.7 Inform Decisions and Justify the Value—Inputs and Outputs

Most of the methods presented previously are concerned with choices when comparing costs and consequences (economic, clinic and humanistic outcomes). For instance, the ECHO model [6] incorporates costs, economic outcomes, and interrelationships with the clinical and humanistic outcomes. The same arguments are used

Table 3.2 Economic evaluation using costs (Adapted from [9])

Type of study	Costs measurement	Consequences	
		Identification	Measurement
Cost analysis	Monetary units	Not considered. The consequences are common to all considered alternatives	
Cost-effectiveness analysis	Monetary units	Single effect of interest, common to both alternatives, but achieved to different degrees	Natural units (e.g. life-years gained, disability days saved, blood pressure reduction, levels of LDL/HDL, etc.)
Cost-utility analysis	Monetary units	Single or multiple effects, not necessarily common to both alternatives	Healthy years, typically measured as QALYs (quality-adjusted life-years)
Cost-benefit analysis	Monetary units	Single or multiple effects, not necessarily common to both alternatives	Monetary units

by others when discussing VfM in healthcare [13, 22, 32, 33] or healthcare economic evaluation [9, 14]. That is why these models are valuable to use in the evaluation of PCC implementation. Some specific considerations regarding the costs involved and the consequences of PCC implementation are described below.

3.7.1 Costs

VfM and the economic evaluation literature can give an essential contribution to identifying the main costs involved in PCC implementation. For example, Gold et al. [14], more focused on a cost-effectiveness analysis, identifies costs related with changes in the use of healthcare resources, changes in the use of non-healthcare resources, changes in the use of informal caregiver time and changes in the use of patient time (for treatment). Similarly, Drummond et al. [9], in a broader perspective of economic evaluation involving costs and different types of analysis, identifies health sector costs, other sector costs, patient/family costs, and productivity losses. Table 3.3 provides a high-level overview of these two models.

According to Gold et al. [14], direct health care costs include all types of resource use, including the consumption of professional, family, volunteer, or patient time and the costs of tests, drugs, supplies, healthcare personnel, and medical facilities. Non-direct health care costs include the additional costs related with the intervention, such as those for childcare (for a parent attending a treatment), the increase of costs required by a dietary prescription, and the costs of transportation to and from the health facilities, they also include the time family, or time volunteers spend providing

Table 3.3 Cost components

Costs [14]	Costs [9]
Changes in the use of healthcare resources	Health sector costs
Changes in use of non-healthcare resources	Other sector costs
Changes in the use of informal caregiver time	Patient/family costs
Changes in the use of patient time (for treatment)	Productivity losses

home care. Patient time costs include the time a person spends seeking care or participating in or undergoing intervention or treatment. Relevant time costs include travel and waiting time as well the time receiving treatment.

Drummond et al. [9] indicate that health sector costs can be variable (such as the time of health professionals or supplies) and fixed or overhead costs (such as light, heat, rent, or capital costs). The other sector costs refer to consumed resources from other public agencies or the voluntary sector. Person/family costs refer to any out-of-pocket expenses incurred by patients or family members as well as the value of any resources that they contribute to the treatment process. Productivity costs include (1) the costs associated with lost or impaired ability to work or to engage in leisure activities due to morbidity and (2) lost economic productivity due to death.

According to the metrics framework described by Lloyd and colleagues (2020) from the COSTCares Working Group 3, it is possible to calculate some of the leading direct healthcare costs involved with administrative data extraction for PCC monitoring and evaluation. The calculation of other costs (mainly direct non-healthcare costs, patient times costs and productivity costs) requires the use of different tools and data sources to get the accurate values (or the closest approximations possible) to be considered in the evaluation analysis [21].

3.7.2 *Valuing Healthcare and Health Effects*

The prime objective of healthcare is to improve health, and different categories of goals and outcomes can be identified in this respect. According to Smith [32], responsiveness to patients' needs, addressing inequalities, and broader economic objectives are the leading healthcare goals. Many treatments offer broader social and economic benefits to patients, families and society. Other authors, like Cheng et al. [6], focus on economic outcomes and their interrelationships with the clinical and humanistic outcomes.

Drummond et al. [9] sustain that the literature on economic evaluations contains studies using several types of outcome measures: clinical outcomes, quality of life measures, and generic measures of health gain like Quality-adjusted life years

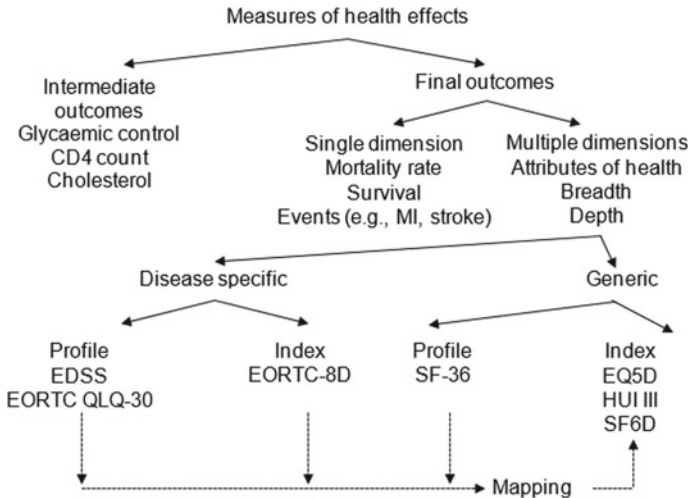


Fig. 3.2 A taxonomy of measures of health effects (Adapted from [9])

(QALYs), the Disability-Adjusted Life-Year (DALY), Short Form-36 (SF-36 Quality of Life measure), EQ5D (a family of instruments to describe and value health from EuroQol), and SF6D (Short-Form Six-Dimension, a health index designed for calculating QALYs). A taxonomy of the alternative measures of health effect is given in Fig. 3.2.

Clinical outcomes are the most common health outcome category to be considered in clinical trials and observational studies. They would be captured in hybrid implementation-effectiveness designs. Some economic evaluations use these outcomes, as reported in the relevant study of the PCC intervention, as the measure of health gain.

Humanistic outcomes are outcomes based on a patient’s perspective (e.g. patient-reported scales that indicate pain level, degree of functioning). In this category, there are health-related quality of life (HRQoL) and the range of measures collectively described as patient-reported outcomes (PROs). Patient-reported outcomes (PROs), or patient-reported outcomes measures (PROMs), are information provided by the patient about their symptoms, quality of life, adherence, or overall satisfaction [23]. PROs refer to patient ratings about several outcomes, including health status, health-related quality of life, symptoms, functioning, satisfaction with care, and treatment satisfaction. The patient can also report about their health behaviors, including adherence and well-being habits.

Generic PRO questionnaires are measurement instruments designed to be used across different subgroups of individuals and contain common domains that are relevant to almost all populations. Examples of a generic PRO measure are the Sickness Impact Profile (SIP) or SF-36 that measures general health perception, pain, physical functioning, role functioning, social functioning, mental health and vitality. An instrument that assesses a more restricted set of domains is the Index

of Activities of Daily Living, which measures independence in performing basic functioning.

Patient-reported experience measures (PREMs) are tools and instruments that report patient satisfaction scores with health service. They are generic tools that are often used to capture the overall patient experience of health care. PREMs are often used on the broader population and in non-specific settings such as an outpatient department. Patient experience tools, for example, may be used to monitor patient feedback and focus on the general experience, such as customer service rather than an experience related to a specific disease. These instruments or tools have revealed positive associations between patient satisfaction and safety. They are a reliable measure of how well a hospital or other health entities can provide good quality service from a patient perspective. Therefore, they are well-suited for use in PCC implementation evaluation.

Time devoted to collecting PROs and PREMs turns into invested time that can benefit the person receiving care and the organization that can allocate resources more optimally. Assessing the severity of symptoms, informing treatment decisions, tracking outcomes, prioritize patient-provider discussions, monitoring general health and well-being, and connecting providers to patient-generated health data are PROs and represent different ways of creating value [20].

The International Consortium for Health Outcomes Measurement (ICHOM) collaborates with patients and healthcare professionals to define and measure patient-reported outcomes to improve quality of care and value. The ICHOM website (<https://www.ichom.org>) is a valuable resource, as it is possible to find several standardized outcomes, measurement tools and time points and risk adjustment factors for a given condition that could be used in PCC implementation evaluation. The Patient-Reported Outcomes Measurement Information System (PROMIS; <https://www.healthmeasures.net>), the Outcome Measures in Rheumatology (OMERACT; <https://omeract.org>) and the Consensus-based Standards for the Selection of Health Measurement (COSMIN; <https://www.cosmin.nl>) are other useful references for these kinds of patient-reported instruments.

A more recent source of data is patient-reported information (PRI) proposed by Baldwin et al. [1]. According to those authors, PRIs take up the PRO tool and reinforce the patient perspective. This new perspective is related to social networking that enables patients to publish and receive communications very quickly. Many stakeholders, including patients, are using these media to find new ways to make sense of diseases, to find and discuss treatments, and to give support to patients and their caregivers.

According to Schlesinger et al. [31], PRI pinpoints the limits of traditional measurement techniques to incorporate narrative components into the evaluation and can be used to improve clinical practice. Those authors identify four forms of PRIs:

1. patient-reported outcomes measuring self-assessed physical and mental well-being,
2. surveys of patient experience with clinicians and staff,

3. narrative accounts describing encounters with clinicians in patients own words, and
4. complaints/grievances signalling patients distress when treatment or outcomes fall short of expectations.

The narrative aspects of PRIs align well with PCC, and more research is needed to uncover the value of these data sources for PCC implementation evaluations in the future.

3.8 Conclusion

In summary, the Gothenburg model of PCC is an evidence-based intervention shown to improve care and health outcomes while maintaining cost. Other health systems could benefit from its sustainable implementation. The WE-CARE implementation framework, adapted by COSTcares Working Group 3, provides a base set of enablers and outcomes recommended for the design and evaluation of PCC. These core enablers of information technology, quality measures, infrastructure, incentive systems, contracting strategies, and cultural change may need to be broadened, depending on the health system. Political support and commitment, governance, stakeholder engagement, leadership, collaboration and trust, and workforce education and training are additional enablers that warrant consideration for sustainable implementation of PCC. Contextual factors, and the interaction of enablers, must be examined. Implementation science offers evidence-based frameworks to systematically evaluate factors that will influence successful uptake of PCC. Regarding the outcomes of quality of care and costs, a Value for Money framework, along with associated cost-effectiveness methods and analysis models, are other important aspects of PCC evaluation and design. PROs, PROMs, PREMs, and especially PRIs should be considered as means to capture the perspective of the patient as a person, which is at the center of PCC. In conclusion, comprehensive assessments of PCC, enablers, and outcomes should be incorporated into PCC implementation design in order to influence policy makers and health system decision makers towards the sustainable uptake of PCC.

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