



Work Package 4

Development of an analytical framework to perform a comprehensive evaluation of integrated care programmes for multi-morbidity using Multi-Criteria Decision Analysis

Deliverable report 1

Outcomes and indicators in integrated care for persons with multi-morbidity

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Date

January 31, 2017

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 634288. The content of this report reflects only the SELFIE groups' views and the European Commission is not liable for any use that may be made of the information contained herein.



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Executive summary

Preface

This chapter constitutes the executive summary of the deliverable of Work Package (WP) 4 of the SELFIE project. In this WP we developed the methods to perform comprehensive evaluations of integrated care programmes for multi-morbidity using Multi-Criteria Decision Analysis (MCDA). The WP leader is the Institute of Health Policy & Management from Erasmus University Rotterdam in the Netherlands and the WP co-leader is the University of Bergen (UiB) in Norway.

The chapter is structured as follows. First, an overview of the SELFIE project is provided and an introduction to WP4 is given. Next, a summary of the two WP4 deliverable reports is given. In the first deliverable report we give an overview of the outcomes that will be included in the MCDA and we describe the methods used to identify and select them. The second deliverable report starts with a description of MCDA methods in general, followed by the MCDA methods that will be applied in SELFIE. At the end of this chapter we describe how this work feeds into the next WP in which the comprehensive evaluations will actually be carried out.

Introduction to SELFIE and WP4

The EU Horizon2020-funded SELFIE ('Sustainable Integrated Care Models for Multi-Morbidity: Delivery, Financing and Performance') project aims to improve person-centred care for persons with multi-morbidity by providing evidence on the impact of promising integrated chronic care (ICC) programmes and supporting financing/payment schemes on health- and well-being, experience with care, and cost outcomes (i.e., the Triple Aim). This four year research project is divided into nine work packages (WP) conducted by eight European partners: The Netherlands (coordinator), Austria, Croatia, Germany, Hungary, Norway, Spain, and the UK. SELFIE distinguishes itself from other research projects on integrated care and/or multi-morbidity by aiming to not only identify and describe promising integrated care programmes for multi-morbidity, but to evaluate them using an innovative approach: Multi-Criteria Decision Analyses (MCDA). MCDA is an umbrella term for a set of methods that aid decision-making when this is based on more than one criterion, whereby the relative impact that all criteria have on the decision-making process is made explicit. MCDA thus aims to improve transparency, accountability, and acceptability of the decision-making process by explicitly defining aims, or criteria.

In WP1 we first developed a conceptual framework to guide the further descriptive and evaluative work on integrated care for multi-morbidity in SELFIE. This conceptual framework includes six key components centred around the holistic understanding of an individual with multi-morbidity: (1) Service delivery (2) Leadership and governance, (3) Workforce, (4) Financing, (5) Technologies and medical products (6) Information and research. Subsequently, in WP1 and WP2, 17 promising integrated care programmes for persons with multi-morbidity were identified in the countries of the SELFIE consortium (2-3 per country) and extensively described, using both document analyses and interviews. This resulted in 17 'thick descriptions' that are being compared across countries (see also the executive summaries of [WP1](#) and [WP2](#)). Preparations for the empirical evaluations using an MCDA framework were made in WP4.

Integrated care programmes are complex interventions consisting of a mixed package of interacting patient-, provider-, and organisational-oriented interventions that are tailored to the context in which they are introduced and continuously improved as more experience is gained. They do not only aim to maximise health but also to improve well-being, experience of care and reduce costs. Therefore, traditional evaluation frameworks such as cost-utility analysis in which costs per Quality Adjusted Life Years (QALY) are calculated, were deemed insufficient. In contrast, using MCDA has the purpose of ensuring that these evaluations are broad enough to incorporate the wide range of different outcomes of these programmes.

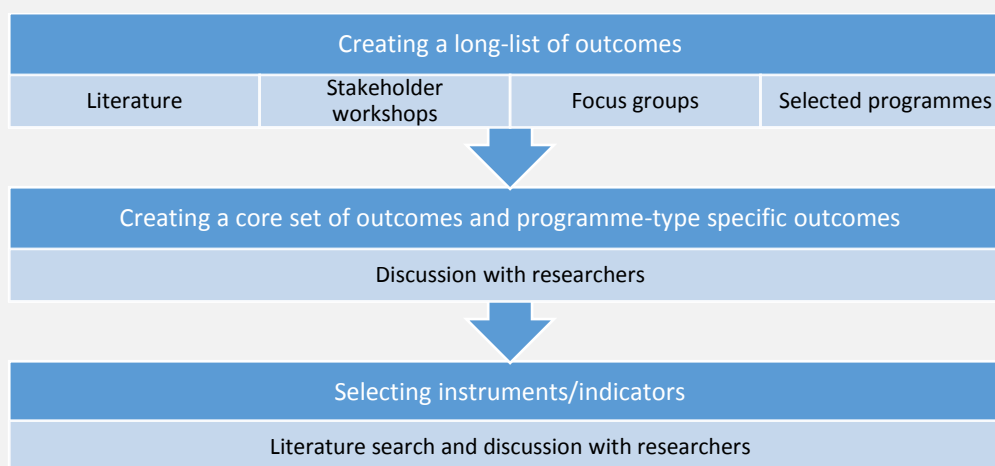
The work done in WP4 is divided into two deliverables (i.e., two reports). In the first report we defined a set of outcomes for which we will **measure performance** of the promising integrated care programmes and for which we will **elicit weights**. In the second report, we created an MCDA evaluation framework by selecting an MCDA method, constructing study designs to measure the performance of the 17 promising programmes, and preparing for the weight-elicitation study whereby the **importance** of the various outcomes will be determined. With this MCDA framework we will, in WP5, conduct 17 comprehensive evaluations in which integrated care programmes are compared to usual care or a control group.

The results of the two deliverables will be summarised below.

WP4 Deliverable Report 1: Selecting and defining outcomes for the evaluation

In the first deliverable report of WP4, entitled “*Outcomes and indicators in integrated care for persons with multi-morbidity*”, we selected and defined a set of outcomes that are specifically relevant for the empirical evaluation of integrated care programmes for persons with multi-morbidity. Secondly, we selected instruments or indicators to measure these outcomes. A great number of outcomes and instruments exist to measure integrated care, and we witnessed a tremendous growth in new types of measures such as patient reported outcomes (PROMs) and patient reported experience measures (PREMs). Although multiple criteria, or outcomes, can be incorporated in an MCDA, feasibility in collecting performance information on these and the need to avoid cognitive overload for respondents in the weight-elicitation study forced us to select the most relevant ones. **Figure I** provides an overview of the steps in this selection process.

Figure I: Steps to develop the list of outcomes measures and indicators included in the MCDA: a core set and a programme-type specific set



We used four main sources to create an initial ‘long-list’ of outcome measures: (1) literature review, (2) stakeholder workshops, (3) focus groups in individuals with multi-morbidity, and (3) a review of outcomes currently used in the 17 programmes selected for evaluation in SELFIE.

Key (grey) **literature** was used to explore innovative definitions and measures of health and integrated care. We focused in particular on outcomes to measure integrated care according to the Triple Aim (health- and well-being, experience of care, and costs). In scientific literature, we identified outcomes that were measured in integrated care programmes specifically targeting individuals with multi-morbidity.

Alongside the literature review, each country in the SELFIE consortium organised a **workshop with national stakeholders** that represented five stakeholder groups, the 5Ps: Patients, Partners (i.e., informal caregivers), Professionals, Payers, and Policy makers. During these workshops the stakeholders were asked to name and define what would make them reimburse, participate in, offer, or implement an integrated care programme for multi-morbidity. The outcomes that resulted from these workshops were added to those found in the literature.

In order to zoom into and learn more about the importance of person-centred integrated care for individuals with multi-morbidity, each country in the SELFIE consortium organised a **focus group**. In total 58 individuals with multi-morbidity attended these focus groups, in which they discussed what it means to them to be in 'good health' and how they define a good care process. Outcomes mentioned in the focus groups were again added to the list of candidate outcomes.

Lastly, we reviewed the 17 **promising integrated care programmes** included as case studies in SELFIE as a source of information on possible outcomes: what are the goals of these programmes, what are they already measuring, and what do they find important to measure?

An abundance of outcomes was obtained from these four sources, many with large conceptual overlap. We clustered the outcomes into higher-level concepts and categorised them into the Triple Aim. There was considerable agreement between the outcomes mentioned by the various stakeholders. There was general consensus that we should focus on patient-reported outcome measures and patient-reported experience measured to extend the frequently used structural indicators or indicators of the adherence to

programme-components that are extracted from routine organisational and system-level databases. Furthermore, an overarching theme was that evaluations of integrated care for multi-morbidity should go beyond traditional clinical health outcomes, and should focus more broadly on well-being. Further, it was felt that in the selection process the outcomes that were frequently mentioned by the persons with multi-morbidity in the focus groups should be leading. The group of persons with multi-morbidity is in and of itself complex and varied; they deal with many different health- and social problems that may interact with one-another. For these reason, in SELFIE, we incorporate **‘social relationships and participation’**, **‘enjoyment of life’** and **‘resilience’** as health- and well-being outcomes alongside the more traditional outcomes of **‘physical functioning’** and **‘psychological well-being’** as these apply to persons with all different types of disease- and problem-combinations. Persons with multi-morbidity often deal with care providers from different sectors, with a high risk of fragmentation and repetition. Thus we identified **‘person-centeredness’** and **‘continuity of care’** as the two key elements of experience of care that should be included in evaluations. Moreover, we also include **‘total health- and social care costs’** in SELFIE, to capture the care utilisation in different sectors.

The above mentioned outcomes were also selected because they were found relevant and applicable across all 17 integrated care programmes. The discussion of these outcomes amongst the SELFIE researchers revealed the need to add important programme-specific outcomes to the MCDA. This resulted in the decision to construct a) a core set of outcomes to be included in all 17 programme evaluations, and b) programme-type specific outcomes. Defining outcomes that are relevant across multiple programmes is important because one of the SELFIE aims is to develop a reusable MCDA, where criteria-weights can be used again by others who want to monitor different integrated care programmes, facilitated by an online tool.

To keep the weight elicitation study feasible, the 17 integrated care programmes were categorised into four types of programmes: population health management programmes, programmes targeting frail elderly, palliative care and oncological programmes, and programmes targeting persons with problems in multiple life domains. For each type of programme a list of outcomes was defined. The core set of outcomes includes the eight

mentioned above; they are presented and defined in **Table I**. An overview of the core set and the programme-type specific outcomes are presented in **Table II**. Both the core set of outcomes and the programme-type specific outcomes will be included in the MCDA. This implies that we will elicit weights for both of them.

The outcomes in **Tables I** and **II** were defined at a conceptual level in order to allow the use of different instruments or indicators to measure a particular outcome-concept. The reason that we permit the use of different instruments and indicators to measure a particular concept is that some programmes have already been measuring certain outcomes for years, and this retrospective data is of great value. In the cases when data collection still needs to be set up, we make recommendations for instruments or indicators that best operationalise the outcomes in SELFIE.

Table I: *Core set of outcomes*

Health / well-being
Physical functioning <i>"Acceptable physical health and being able to do daily activities without needing assistance"</i>
Psychological well-being <i>"Absence of stress, worrying, listlessness, anxiety, and feeling down"</i>
Social relationships & participation <i>"Having meaningful connections with others as desired"</i>
Enjoyment of life <i>"Having pleasure and happiness in life"</i>
Resilience <i>"The ability to recover from or adjust to difficulties and to restore ones equilibrium"</i>
Experience with care
Person-centeredness <i>"Care that care matches an individual's needs, capabilities and preferences and jointly making informed decisions"</i>
Continuity of care <i>"Good collaboration, smooth transitions between caregivers, and no waste of time"</i>
Costs
Total health and social care costs <i>"Total health and social care costs per participant"</i>

Table II: Overview of core set and programme-type specific outcomes in SELFIE

Outcomes for integrated care for persons with multi-morbidity					
	Core set outcomes	Programme-type specific outcomes			
		<i>Population health management</i>	<i>Frail elderly</i>	<i>Palliative and oncology</i>	<i>Problems in multiple life domains</i>
Health & well-being	Physical functioning	Activation & engagement	Autonomy	Mortality	Self-sufficiency
	Psychological well-being			Pain and other symptoms	
	Social participation/relationships				
	Resilience				
	Enjoyment of life				
Experience	Person-centeredness		Burden of medication	Compassionate care	
	Continuity of care		Burden of informal caregiving	Timely access to care	
				Preferred place of death	
				Burden of informal caregiving	
Costs	Total health- and social care costs	Ambulatory care sensitive hospital admissions	Living at home		Justice costs
		Hospital re-admissions	Falls leading to hospital admissions		

WP4 Deliverable Report 2: Creating an MCDA evaluation framework

In the **WP4 Deliverable Report 2**, entitled “*MCDA framework*”, the reason why MCDA was chosen as the evaluative framework in SELFIE is explained. As described above, this broad evaluation framework allows for multiple outcomes (in MCDA-terms ‘criteria’) to be included in the evaluation, and weighs these from specific perspectives. There are different MCDA methods, which can broadly be divided into the value-based, outranking, and goal- or reference point methods. Each is briefly described below.

In **value-based methods**, the aim is to assign values to alternatives and construct a value function. In SELFIE the alternatives are the integrated care programme and its comparator. In the commonly used value-based method Multi-Attribute Utility Theory (MAUT), a single overall value is created. The performance of each alternative, on all criteria, is determined. Separately, the importance of the criteria needs to be determined. For each alternative, the weighted performance on each criterion is aggregated into an overall value score. This overall value score is compared between the integrated care programme and its comparator.

In **outranking methods**, pairwise comparisons are made of the performance of all alternatives on all criteria. In the simplest case, if we compare the performance of alternatives on all criteria and one alternative scores better on all, then this is the preferred alternative. In less simple cases, patterns of dominance between alternatives are studied to reach a decision about the preferred alternative. For this method the performance of alternatives on criteria needs to be known, as well as the weights for these criteria.

In **goal or reference point methods**, alternative care programmes are compared by calculating the weighted deviations from a priori set goals. This method requires a specification of desirable levels of performance for each criterion.

Given that in SELFIE we aim to compare each integrated care programme to its comparator and not to rank all 17 programmes, and considering the theoretical foundations of all

methods, we have opted for MAUT methods to be applied in the MCDA. The seven steps commonly undertaken in MCDAs, and MAUT specifically, are as follows:

1. Establish the decision-context
2. Identify and structure criteria
3. Determine performance on criteria
4. Weight-elicitation
5. Creating a global score
6. Sensitivity analyses
7. Examine results

The work done in earlier SELFIE WPs has helped us understand and establish the **decision-context** of integrated care for multi-morbidity (step 1). For most of the 17 case studies in SELFIE, the decision pertains to reimbursement, continuation, extension, and/or wider implementation of the integrated care programme. Step 2 was described in **WP4 Deliverable Report 1** *“Outcomes and indicators in integrated care for persons with multi-morbidity”*.

To determine the performance on the criteria, step 3, empirical evaluations for all 17 promising programmes are being set up. In order to be able to attribute effects to the intervention, performance will be repeatedly assessed in both the integrated care group as well as a comparator group. Each SELFIE partner selected the most appropriate study design for their evaluation and started working on a study protocol to make this explicit.

There are different methods to elicit weights (step 4), including: direct ranking, visual analogue scales, point allocation, analytical hierarchy process, swing weighting, and **discrete choice experiments** (DCE). In a DCE, choice sets with scenarios are presented to stakeholders. The scenarios consist of various alternatives (e.g., care programmes) that systematically differ on performance criteria (i.e., outcomes, attributes). Stakeholders are asked which scenario they prefer. Hereafter, weights for each criterion can be statistically derived on the basis of the likelihood that one scenario, with specific criteria performance, is preferred over another. The stakeholders are forced to make trade-offs in criteria and take the full range of potential performance into account. DCE was selected as the method to elicit weights, in all eight SELFIE partner countries, from the 5P perspectives. Due to the

number of different outcomes/criteria, it is not possible to conduct a DCE for the core set and the programme-type specific outcomes. For this reason, a DCE will only be used to elicit weights for the core set of outcomes.

The perceived 'next-best' method, **swing weighting**, will be used to elicit weights for the programme-type specific outcomes. Swing weighting is also a trade-off weighting method, in which the relative importance is determined on the basis of moving from the worst to best score on a scale. Specifically, the SMARTER method will be used, whereby a stakeholder is asked to pretend there is an alternative (e.g., care programme) that has the lowest possible scores on all criteria. The stakeholder then ranks which criteria would be selected first to swing from the worst to the best level. This is subsequently done for the remaining criteria. These ranks are then turned into weights using, for example, the rank ordered centroid method.

Table III illustrates the type of information that will be obtained in the MCDA. This includes the (standardised) performance scores of two alternative care programmes (e.g., integrated vs. usual) on a number of criteria, the weights of these criteria from the viewpoint of different stakeholder groups (S1 and S2), and the weighted aggregation. In the simplified example, in **Table III** the aggregated weight for resilience is calculated by multiplying the criteria weight of stakeholder 1 (0.30) or stakeholder 2 (0.15) with the standardised performance (0.74 for the integrated care programme and 0.67 for the usual care). When these weighted performance scores are summed across all criteria the overall value of a programme is obtained (step 5 of the MCDA).

Table III: SELFIE example of information needed for an MCDA of integrated care programmes for multi-morbidity

		Weight		Care alternatives		Weighted aggregation			
		S1	S2	Integrated	Usual	Integrated	S2	Integrated	Usual
Triple Aim	Criteria			Standardised performance*					
Improved health	Resilience	.30	.20	0.74	0.67	0.22	0.15	0.20	0.13
	Physical functioning	.20	.15	0.68	0.73	0.14	0.10	0.15	0.11
Improved experience	Person-centeredness	.15	.05	0.80	0.60	0.12	0.04	0.09	0.03
	Continuity of care	.25	.05	0.77	0.63	0.19	0.04	0.16	0.03
Reduced costs	Health care costs	.05	.30	0.28	0.30	0.01	0.08	0.02	0.09
	Social care costs	.05	.25	0.24	0.34	0.01	0.06	0.02	0.09
		Sum				0.69	0.47	0.64	0.48

Note: Aggregation on the basis of Multi-Attribute Utility Theory (MAUT). *Standardised performance based on relative standardisation. S1 = Stakeholder 1 (e.g., patient), S2 = Stakeholder 2 (e.g., payer).

In step 6, sensitivity analyses will be done. This will include subgroup analyses, such as per gender, educational level or types of morbidities. Furthermore, we will conduct deterministic analyses, whereby certain criteria are excluded, as well as probabilistic analyses, in which uncertainty in weights and performance is modelled simultaneously. In step 7, the results will be examined. This will be done by the SELFIE researchers, but will also involve reflecting and interpreting the findings with representatives from the 5Ps in international and national stakeholder workshops.

In the **WP4 Deliverable Report 2** we extensively describe the background of MCDA methods, the seven steps undertaken in MAUT, MCDA and weight-elicitation choices in SELFIE, possible study designs, the weight-elicitation procedure, and the draft study designs to measure the performance of the 17 programmes.

Next steps

In the next phase of SELFIE research, each SELFIE partner will start data collection from the five defined stakeholders (5Ps) for the weight-elicitation. Parallel to this, the study designs for the empirical evaluations will be made definite and data collection in all 17 promising integrated care programmes will begin. Subsequently, the performances of the promising programmes on the (core) set of outcomes and the weights from the various stakeholders will be brought together in the proposed SELFIE framework, resulting in MCDAs of 17 promising integrated programmes for persons with multi-morbidity

In order to allow findings from the SELFIE study to be shared with others, an online MCDA tool will be developed that will allow others to also apply the criteria weights from the 5Ps to their own programme performance. The tool will stay available after the SELFIE research project has ended.

1. This report in the context of SELFIE

SELFIE is a Horizon2020 EU project that will contribute to the current state of knowledge of integrated chronic care (ICC) for persons with multi-morbidity and provide applicable policy advice. We aim to generate evidence on the impact of promising ICC programmes and supporting financing/payment schemes on health and well-being outcomes, experience, and costs. Specific ICC programmes for multi-morbidity will be empirically evaluated using multi-criteria decision analyses (MCDA). The definitions of multi-morbidity and ICC in the SELFIE project can be found in **Box 1**.

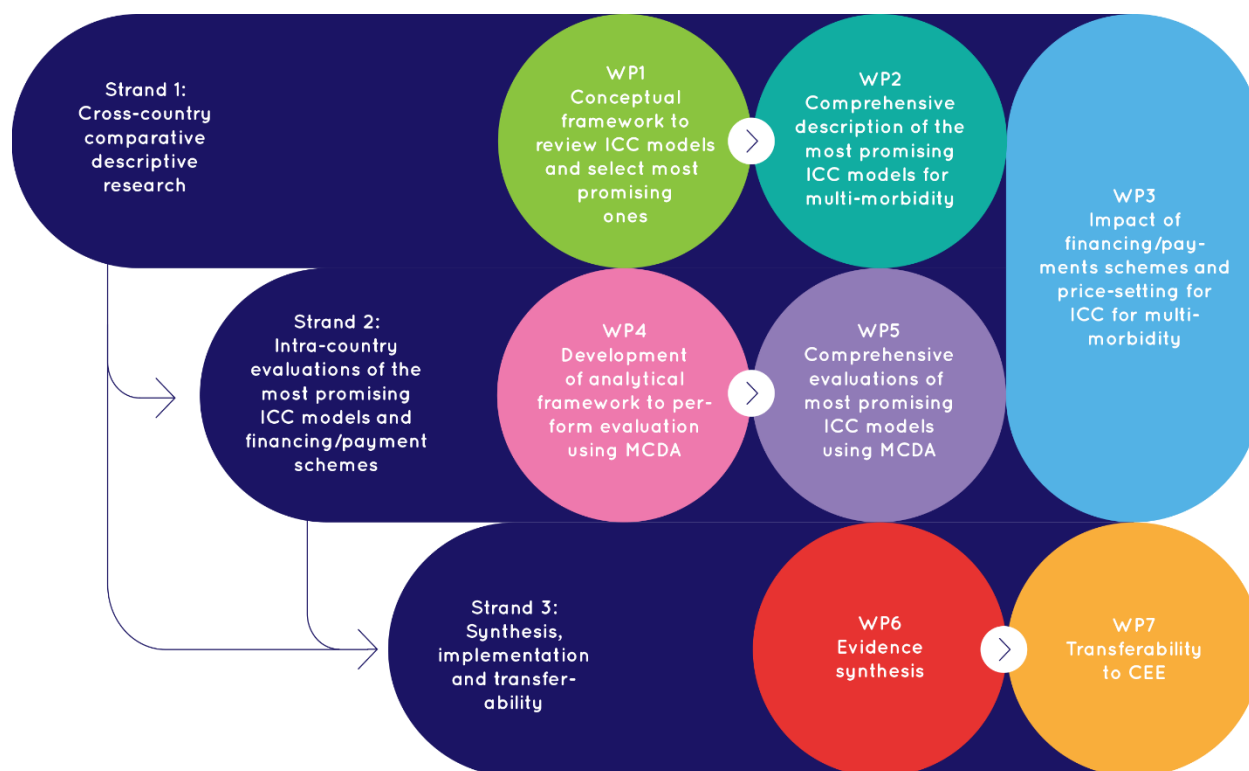
Box 1: *Definitions of multi-morbidity and integrated chronic care in SELFIE*

Multi-morbidity in the context of SELFIE refers to multiple (i.e., at least two) chronic conditions, physical or mental, occurring in one person at the same time, where one is not just a known complication of the other.

Integrated chronic care (ICC) in the context of SELFIE refers to structured efforts to provide coordinated, pro-active, person-centred, multidisciplinary care by two or more communicating and collaborating care providers that may work at the same organisation or different organisations, either within the healthcare or across the health care, social care, or community care sector (including informal care).

In SELFIE three research strands are distinguished, with 9 work packages, 7 of which are content based (WP8: Communication and dissemination, WP9: Management):

Figure 1: SELFIE strands of research and work package (WP) overview (click to see overview on the SELFIE website)



In WP1 a conceptual framework for integrated care for multi-morbidity was developed. Furthermore, promising integrated care programmes for multi-morbidity in each of the SELFIE partner countries were identified, and 17 were selected (2-3 per partner) (see **Appendix 1** for an overview of these programmes). In WP2 these 17 programmes were described on the basis of the framework developed in WP1, using both document analyses and interviews. This resulted in 17 ‘thick descriptions’ that are being compared across countries. In WP3 the impact of different financing and payment schemes is being investigated. This WP makes use of the descriptive research on this topic in WP2 and the empirical evaluations in WP5, but it also investigates the impact of different funding and payment schemes, independent of the 17 programmes. Hence, WP3 overlaps strand 1 (descriptive, cross-country) and 2 (evaluative, intra-country).

The aim of WP4 is to develop an analytical framework to perform comprehensive evaluations of the 17 programmes using Multi-Criteria Decision Analysis (MCDA); the work in WP4 forms the theoretical basis and preparation of the actual empirical evaluation in WP5.

Throughout the SELFIE project five groups of stakeholders are repeatedly involved to reflect on findings and advice on how to move forward and interpret findings, the **5Ps**:

1. **Patients; persons with multi-morbidity**
2. **Partners; informal caregivers**
3. **Professionals**
4. **Payers**
5. **Policy makers**

The Dutch EUR team leads WP4, the Norwegian UiB team leads WP5 – they are also one-another's co-leaders in these WPs. The teams collaborate closely, as the work in WP4 feeds directly into WP5. WP4 started on February 1st, 2016 and ends February 1st, 2017. WP5 started on September 1st, 2016 and ends September 1st, 2018.

In WP4 we aim to develop an analytical framework and have two main deliverables:

- i. Outcomes report – due month 17 (Jan 2017 – submit before Feb 1st 2017)
- ii. MCDA framework report – due month 17 (Jan 2017 – submit before Feb 1st 2017)

This is the first deliverable report, on the outcomes that will be used in the MCDA Framework. These reports correspond to the tasks set out in the grant agreement, the current report addresses tasks 2 and 3 of WP4:

1. To select the MCDA method to be applied;
2. **To select, define, develop and prepare the collection of outcomes, including indicators specifically relevant to the evaluation of integrated care programme for persons with multi-morbidity;**
3. **To develop methods to collect healthcare utilisation and other cost categories that will be included in the evaluation;**
4. To determine the importance of the various outcomes and indicators from the perspective of the 5 stakeholder groups;
5. To construct study designs and select statistical techniques to ensure causal inference between the integrated care programmes and outcomes.

In the remainder of this report a general introduction to measuring outcomes of integrated care programmes is given (**Chapter 2**). Hereafter, we describe the methods used to identify and select the outcomes that will be used in the MCDA (**Chapter 3 and 4**). Subsequently, in **Chapter 5**, we describe the core set of outcomes that will be used across all 17 programmes in SELFIE as well as the programme-type specific outcome measures. In **Chapter 6**, we present the instruments and indicators that we recommend to use for the measurement of the core set of outcomes and the programme-type specific outcomes. The entire SELFIE questionnaire is presented in **Appendix 4**.

2. Introduction outcome and indicators

Health care providers, policy makers and payers are increasingly challenged to demonstrate the added value of new treatments and services delivered, with value defined as the additional outcomes relative to the additional costs in comparison with the standard of care or usual care.¹ Systematic outcome measurement is the “sine qua non” of value improvement.² That is because outcome measurement plays an important role in highlighting problems, identifying trends, and contributing to the process of priority-setting, policy formulation and evaluation, and monitoring of progress.³ However, it is a challenge to value the benefits of complex interventions such as integrated care (ICC).⁴ These programmes do not only aim to maximise health, but they also aim to improve the experience of care and reduce costs (i.e., the Triple Aim).^{5,6} Further adding to this complexity is the mixed package of interacting patient-, provider-, and organisational-oriented interventions that are tailored to the context in which they are introduced and continuously improved as more experience is gained.⁷ The extent to which the Triple Aim is achieved is impacted by the behaviour of those providing, receiving, funding and managing the programme.

In SELFIE, we aim to generate evidence on the impact of promising ICC programmes on all three of the Triple Aims: health and well-being outcomes, patient experience, and costs. We will be conducting an MCDA in which we combine the performance of the 17 integrated care programmes on the Triple Aim with the weights that various stakeholders assign to the importance of the different outcomes to measure these aims. However, there is a great number of instruments and indicators existing to measure the Triple Aim⁸⁻¹⁰ and we witness a tremendous growth in new types of measures such as patient reported outcomes (PROMs) and patient reported experience measures (PREMs).¹¹ In SELFIE we need to define a set of outcomes for which we will measure performance and elicit weights. It is not feasible nor relevant to measure all possible outcome measures in the 17 integrated care programmes. As will be explained in the methods chapter, we have opted to define a core set of outcomes that are most relevant for people with multi-morbidity across the 17 programmes and to define additional lists of programme-type specific outcomes. Together, these are the outcomes that will be included in the MCDA. In addition, each integrated care

programme that is evaluated in SELFIE will measure outcomes that are considered relevant for that particular programme. These outcomes will be included in the (cost-) effectiveness analyses of the programme but not in the MCDA. For the outcomes to be used in the MCDA we developed a list of instruments/indicators to measure these outcomes.

It is important to note that outcomes can be measured and reported at various levels. In **Figure 2** we have distinguished between an individual and a system level, where the latter can for example be an organisational or a national/regional/local population level. At both levels, outcomes can be measured using either objective or subjective indicators, where the objective indicators are often extracted from medical records and administrative databases while the subjective indicators are mostly self-reported. It is argued that the true value of care is measured by the outcomes achieved,¹² not the volume of services delivered, the level of compliance to clinical guidelines or the improvement in intermediate biological indicators. Therefore, we decided to include the individual level outcomes in the SELFIE MCDAs. Specifically, health and well-being and experience outcomes at an individual and subjective level will be included and the total utilisation and costs of health and social care per participant. All of these individual-level measurements can be aggregated into indicators at the system level, as is shown in **Figure 2**.

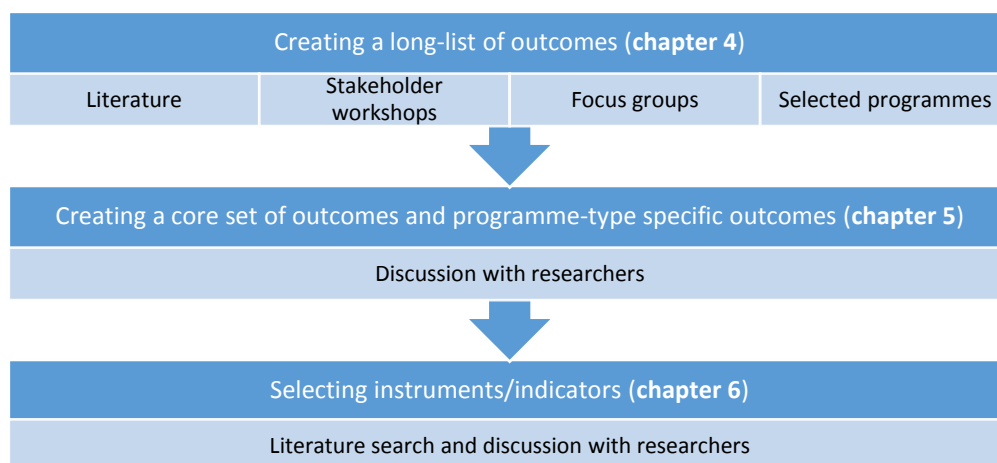
Figure 2: Examples of outcomes used to measure the performance of integrated care programmes for multi-morbidity at individual and system level

Individual level		System level	
1. Personal characteristics <ul style="list-style-type: none">• Lifestyle factors (e.g., smoking, BMI, physical activity, alcohol/drug use)• Charlson Co-morbidity Index		1. Characteristics of the target & participating population <ul style="list-style-type: none">• Size target population, % participating in programme• Lifestyle factors (e.g., % current/former/new smoker, mean BMI, mean level of physical activity, mean alcohol/drug use, mean Charlson Co-Morbidity Index)	
2. Health / well-being <div>OBJECTIVE<ul style="list-style-type: none">• Risk factors• Clinical outcomes• Events/exacerbations/falls• Mortality</div> <div>SUBJECTIVE<ul style="list-style-type: none">• PROMS on e.g., ADL, psychological well-being, self-management</div>		2. Health / well-being <div>OBJECTIVE<ul style="list-style-type: none">• Mean risk factor level• Mean clinical outcomes• Mean no events/exacerbations/falls• % with x-year survival</div> <div>SUBJECTIVE<ul style="list-style-type: none">• Mean and % with MID on PROMS on e.g., ADL, psychological well-being, self-management</div>	
3. Experience <div>OBJECTIVE<ul style="list-style-type: none">• Waiting time• Access to service y/n• Individual care plan y/n• Holistic assessment y/n• Multi-disciplinary team meeting (MDT) y/n• Died at home / place of choosing</div> <div>SUBJECTIVE<ul style="list-style-type: none">• PREMS on e.g., shared decision-making, tailored care, collaboration between professionals, continuity</div>		3. Experience <div>OBJECTIVE<ul style="list-style-type: none">• Mean waiting time• % with access to service• % with individual care plan• % with holistic assessment• % with MDT meeting• % died at home/place of choosing</div> <div>SUBJECTIVE<ul style="list-style-type: none">• Mean and % with MID on PREMS on e.g., shared decision-making, tailored care, collaboration between professionals, continuity</div>	
4. Costs <div>UTILISATION (Y/N + AMOUNT)<ul style="list-style-type: none">• Scheduled health/social care• Ambulatory-care sensitive hospital admission• Other unscheduled care• 30-day re-admission</div> <div>COST<ul style="list-style-type: none">• Development costs• Operating costs• Costs of health/social care• Cost of informal care• Productivity loss</div>		4. Costs <div>UTILISATION (MEAN/%)<ul style="list-style-type: none">• Scheduled health/social care• Ambulatory-care sensitive hospital admissions• Other unscheduled care• 30-day re-admission</div> <div>COST (TOTAL + MEAN P/PERSON)<ul style="list-style-type: none">• Development costs• Operating costs• Costs of health/social care• Costs of informal care• Productivity loss</div>	
5. Implementation <ul style="list-style-type: none">• Did person receive a certain component y/n		5. Implementation <ul style="list-style-type: none">• % of persons that received a certain component	

3. Methods to create a list of outcome measures and indicators

The development of a list of outcomes and indicators relevant for persons with multi-morbidity was performed in several steps (see **Figure 3**). First, we created a long-list of outcomes relevant for persons with multi-morbidity on the basis of four different sources, i.e., scientific and grey literature, national stakeholder meetings, focus groups with persons with multi-morbidity, and outcomes currently measured in the 17 integrated care programmes. Second, the long-list was shortened into a list of most important outcomes for which we are going to elicit weights that will be used in the MCDA. Third, we selected instruments and indicators to measure these outcomes. The methods to create a list of outcomes will be further described in **Chapter 3.1** and the methods to select instruments and indicators in **Chapter 3.2**.

Figure 3: Steps to develop the list of outcome measures and indicators included in the MCDA: a core set and a programme-type specific set



3.1. Creating a list of outcome measures

3.1.1. Creating a long-list of outcomes

The four sources used to create a long-list of outcomes, i.e., scientific and grey literature, national stakeholder meetings, focus groups with persons with multi-morbidity, and outcomes currently measured in the 17 integrated care programmes will be explained below.

Literature

The SELFIE researchers from the Erasmus University Rotterdam (the SELFIE-EUR team) started to make a list of outcomes obtained from the literature, including the scientific papers identified during the scoping review that was done to construct the SELFIE conceptual framework of integrated care in multi-morbidity and additional (grey) literature.^{13,14} The scoping review identified 14 unique integrated care programmes for multi-morbidity in the EU (n=9) and US (n=5).¹³ Additional literature included papers on the new concept of 'positive health' ^{15,16}, a review to investigate well-being outcomes¹⁷, a report on indicators of the performance of health systems, including health outcomes and quality of care from the OECD¹⁸, a report on measuring the Triple Aim from the Institute of Health Improvement (IHI)⁸, a review paper by Hendriks and colleagues on Triple Aim measures in population health management programmes⁹, a report on indicators to measure the performance of integrated care programmes from the Policy Innovation Research Unit (PIRU) of the Department of Health in England¹⁹, a report on the evidence about people-centred integrated care from the World Health Organisation (WHO)²⁰, and a review on outcomes used in practice to measure integrated care in Europe.²¹

Stakeholder workshops

Because programmes tend to measure what is easy to operationalise and easily accessible, the risk exists that they do not measure outcomes that truly matter.¹² Therefore, to complement the outcomes reported in the literature search, each of the eight countries in SELFIE held a stakeholder workshop with national representatives from the 5 P's (Patients, Partners, Professionals, Payers, and Policy makers). The stakeholders were asked to discuss

what outcomes of integrated care programmes for persons with multi-morbidity they would need to see improved in order for them to:

- Participate in the programme?
- Insure the programme?
- Offer / provide the programme?
- Implement the programme (on a larger scale)?

Focus groups

In addition, each of the eight countries organised a focus group with persons with multi-morbidity to discuss what 'good health' means to them, and how they define 'a good care process'. The focus group started with a brainstorm session on possible outcomes.

Thereafter we asked the participants to draft their own 'top-10' list of relevant outcomes.

We used a standardised format for the focus groups across the eight countries in SELFIE.

This format was developed by the SELFIE-EUR team and discussed with the organisers of the focus group in each partner country. The format and instructions can be found in **Appendix**

2. During the focus group discussions at least two researchers were present: one that explained the process and steered the discussion (moderator) and one that took notes and made observations throughout the session. Participants were recruited from different disease-related patient organisations (e.g., Lung-, Heart-, Arthritis-, Diabetes-, and Kidney-Foundations) and different general patient/client organisations. In order to ensure sufficient variation in the type of multi-morbidities of the participants (e.g., not only persons with cancer or COPD and a comorbidity), we asked each patient organisation to suggest one or two persons with multiple chronic conditions for participation in the focus group. We did not invite patients who were participating in one of the 17 promising integrated care programmes selected for further evaluation in the SELFIE project. To minimise the risk of last minute cancelation, all participants received a written confirmation of the invitation for the focus group (by email or by post), including an information and consent form.

Furthermore, the participants received a reminder (by phone or by email) one or two days before the focus group. All participants provided informed consent before participating in the focus group discussion. The travel expenses of the participants were reimbursed in all

focus groups and, based on the national norm, the participants received a remuneration for their contribution. All focus groups were conducted in the national language, but the final reports were translated into English.

Promising integrated care programmes

In the last step, we analysed what is currently measured in the 17 promising integrated care programmes for multi-morbidity that were selected in WP1. This last step was conducted to see if relevant (programme-type specific) outcomes were missing in the list of outcomes from the literature, national workshops, and focus groups.

The sum of these four sources (literature, national stakeholder workshops, focus groups, and promising integrated care programmes selected in WP1) resulted in a long-list of outcomes. This long-list of outcomes was grouped according to the **Triple Aim**^{5,6}:

- Improving population health and well-being;
- Improving experience of care;
- Reducing costs.

3.1.2. Reducing to a core set and programme-type specific outcomes

The number of outcomes than can be included in the core set is limited because the chosen weight-elicitation method, i.e., a Discrete Choice Experiment, should avoid cognitive overload when presenting the two programmes between which respondents have to choose. Therefore, the long-list was shortened into a list of most important outcomes for which we are going to elicit weights that will be used in the MCDA. This core set of outcomes had to fulfil the following **conditions**:

- Cover the Triple Aim: 1) improving population health/well-being and 2) patient experience, and 3) reducing cost (growth);
- Measurable at an individual level using PROMS and PREMS (this only applies to the first and second of the three aims);
- Relevant for multi-morbidity in different contexts and population groups;
- Relevant for each of the 5Ps;

- Relevant across the 17 integrated care programmes;
- The intervention effect (i.e., the impact of a programme on the outcome) in newly enrolled patients is likely to start occurring within the SELFIE evaluation period (6-18 months);
- The outcomes are not redundant, meaning that they are all necessary and not superfluous (e.g., one outcome does not overlap much with another outcome);
- Preference independence, i.e., the weight on one outcome can be elicited independently from the performance score on another outcome;
- Feasible to measure performance.

A draft of the core set of outcomes was created by the SELFIE-EUR team. These outcomes were defined at a conceptual level in order to allow the use of different instruments or indicators to measure a particular outcome-concept. The reason behind this choice is that some of the 17 programmes have already been collecting data for years. It would be infeasible and of less value to ask these programmes to start measuring new and different indicators then they have been using for many years. It was felt that the advantage of having a longer follow-up and continue historical analyses with the same indicators outweighed the disadvantage of having to map the existing indicators to the outcome-concepts that we are including in the MCDA.

The researchers from the SELFIE team from the University in Bergen provided feedback on the draft core set of outcomes. Thereafter, this adapted draft core set was presented to and discussed with each of the eight partners in SELFIE at the SELFIE Steering Committee Meeting in October 2016. This led to a second revision of the core set that was discussed with the SELFIE partners over email and during teleconferences until consensus was reached.

During discussion with the SELFIE partners, the draft core set of outcomes was also discussed with researchers from related projects, namely Sustainable tailored integrated care for older people in Europe (Horizon2020 project SUSTAIN)²², Advancing Care Coordination and Telehealth deployment at Scale (Horizon2020 project ACT@Scale)²³, and

The Older Persons and Informal Caregivers Survey Minimum DataSet (Topics-MDS)²⁴. We discussed the reasons behind the choice of outcomes in these projects, options to standardise the outcome measurement across the projects and explored opportunities for collaboration.

On the basis of discussions held at the SELFIE Steering Committee Meeting in 2016, our review of the outcomes already measured in the 17 programmes (source 4 mentioned above), and the limited number of outcomes that can be included in a weight elicitation method, it was decided that, besides the core set of outcomes, we would define additional programme-type specific outcomes. For that reason we grouped the 17 integrated care programmes selected for further empirical evaluation in SELFIE into 4 groups, i.e., population health management programmes, frail elderly programmes, palliative care / oncology programmes, and programmes targeting persons with problems in multiple life domains. These programme-type specific additional outcomes were also discussed among the SELFIE partners until consensus was reached. During this process of discussion the outcomes that were most frequently mentioned by the persons with multi-morbidity in the focus groups were leading.

Both the core set of outcomes and the programme-type specific outcomes will be included in the MCDA. This implies that we will elicit weights for both of them. In addition, each integrated care programme that is evaluated in SELFIE will measure outcomes that are considered relevant for that particular programme. These outcomes will be included in the (cost-) effectiveness analyses of the programme but not in the MCDA.

The results from the literature, programme outcomes, stakeholder workshops, and focus groups are described in **Chapter 4**. The final core- and programme-specific sets of outcomes are presented in **Chapter 5**.

3.2. Selecting instruments and indicators

After the identification of the relevant outcomes, a list of instruments and indicators to measure these outcomes was developed. The search strategy, selection process and selection criteria that were used to create this list will be explained below.

Identification strategy

1. First, we performed a PubMed search for recent systematic review papers and papers describing the development and validation of instruments measuring the outcomes-concept at stake;
2. Second, we screened the papers included in the scoping review that we did to develop the conceptual framework of integrated care in multi-morbidity to identify the instruments and indicators used in these papers.

The draft set of instruments and indicators was discussed with researchers from related projects, namely Horizon2020 project SUSTAIN²², Horizon2020 project ACT@Scale²³, and Topics-MDS²⁴. We discussed the reasons behind the choice of instruments and options to standardise the outcome measures.

Selection strategy

To reduce the number of candidate instruments or indicators measure an outcome, we choose instruments and indicators that had a positive review or were recommended in the review papers. When recommendations were lacking we made a top-3-5 list of instruments that were most closely related to the outcomes-concept as we defined it, starting with the most recently developed instruments. This judgment is inevitably subjective. Instruments could only be selected when they met the above mentioned conditions for inclusion in the core set. Moreover, we performed a quick scan of the (psychometric) properties of an instrument. Finally, we assessed if there were any major concerns regarding the feasibility (e.g., duration to complete the instrument) and availability of the instrument (e.g., excessive license costs).

To summarise, the final selection of instruments was mainly driven by:

- **Conceptual agreement** between the instrument and the outcomes-concept that we were aiming to measure in the SELFIE programmes;
- **Feasibility and availability** considerations regarding the duration of completion, the number of languages in which a questionnaire was translated and the availability for free;
- **Methodological quality** of the instrument relating to the reliability, validity and responsiveness to change.

4. Long-list of outcome measures

As explained in the previous chapter we used four sources of information to inform our choice of outcome measures in the core set of the SELFIE project. The results from these four sources will be described in this chapter. We conclude by presenting the long-list of candidate outcomes.

4.1. Literature

The first source is a review of the literature. The results of this review will be summarised below, starting from a very broad perspective discussing what health is and how it should be measured, narrowing down the perspective to outcomes related to integrated care in general, and the Triple Aim specifically, and concluding with the presentation of outcomes measured in integrated care programmes for persons with multi-morbidity.

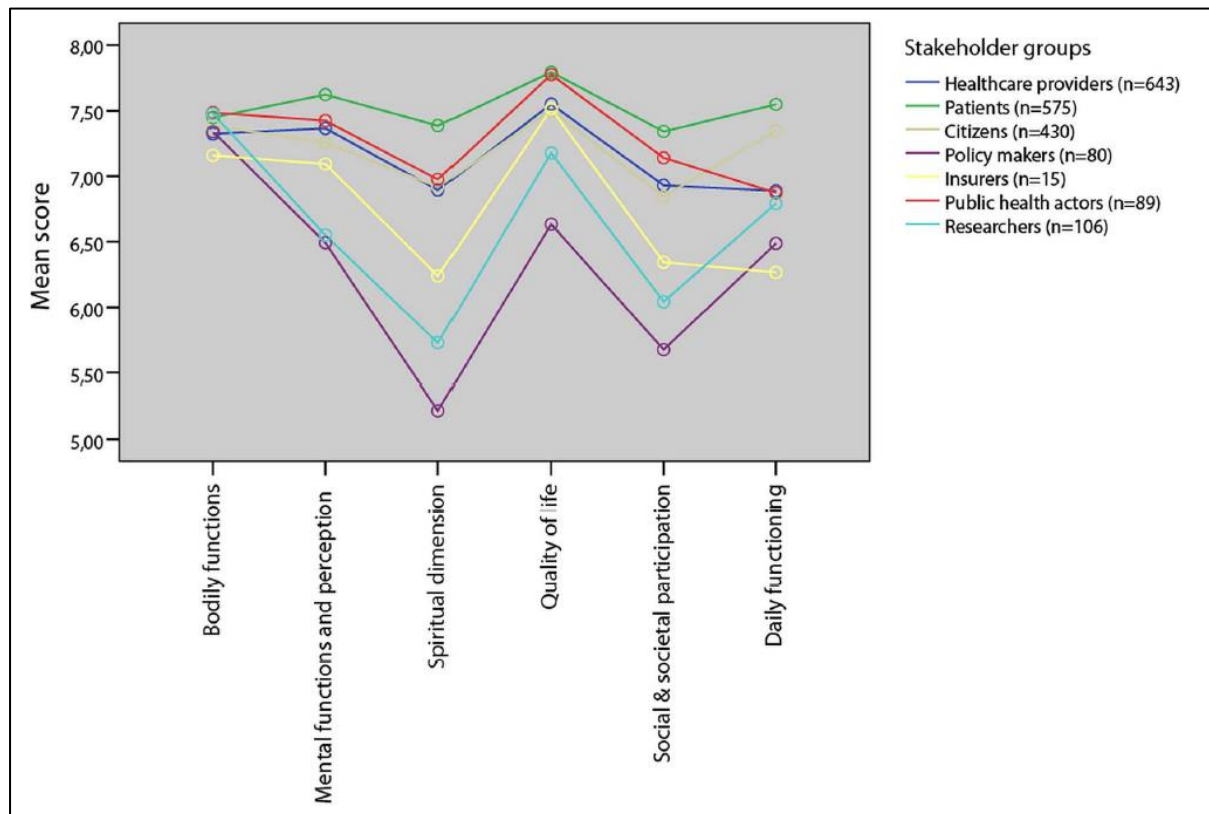
4.1.1. Definition and measures of health

In 1948, the WHO defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”²⁵ But this definition has been both applauded and criticised over the past 69 years. As populations’ age and the pattern of illness changes, aging with one or more chronic illnesses has become the norm. In this situation, the WHO definition may even be counterproductive. This is because the word “complete” in the definition declares all people with one or more chronic diseases ill and ignores the possibilities to function with fulfilment and a feeling of well-being despite having a chronic disease or disability.¹⁵ As a response, Machteld Huber and colleagues proposed to change the definition of health into “the ability to adapt and to self-manage, in the face of social, physical and emotional challenges.”¹⁵ This new definition seems to be appreciated by various stakeholder groups in health care (patients with a chronic condition, health care providers, policymakers, insurers, public health actors, citizens, and researchers), because it emphasises that people are more than their illness and because of its focus on their strengths rather than their weaknesses.¹⁶ Although this definition has also been criticised, primarily for that not everybody is capable of self-management, it is interesting to explore the consequences it would have for the type of outcomes that we should measure. In a qualitative study Huber and colleagues searched for indicators to measure the new concept of health. In this study 556 health indicators were identified by seven stakeholder groups (i.e., patients with a chronic condition, health care providers, policymakers, insurers, public health actors, citizens, and researchers).¹⁶ These outcomes were categorised into 6 groups containing 32 underlying outcomes:

1. **Bodily functions** (medical facts, medical observations, physical observations, complaints and pain, energy);
2. **Mental functions & perception** (cognitive functioning, emotional state, esteem/self-respect, in control/manageability, self-management, resilience, sense of coherence);
3. **Spiritual/existing dimension** (meaning/meaningfulness, striving for aims, future prospects, acceptance);
4. **Quality of life** (quality of life/well-being, enjoyment, perceived health, flourishing, zest for life, balance);
5. **Social & societal participation** (social and communicative skills, social contacts, meaningful relationships, being accepted, community involvement, meaningful work);
6. **Daily functioning** (basic ADL, instrumental ADL, ability to work, health literacy).

A follow-up quantitative study conducted by Huber and colleagues, involving 1938 participants from seven stakeholder groups (patients with a chronic condition, health care providers, policymakers, insurers, public health actors, citizens, and researchers) investigated the importance of these outcomes.¹⁶ The researchers found that chronically ill valued the outcomes as almost equally important and considered health to be a broad concept (see **Figure 4**). The other stakeholder groups gave significantly different scores for various outcome groups: they had a narrower view of health mainly based on bodily functions.

Figure 4: Mean scores per stakeholder group on a nine-point scale, indicating the importance assigned by respondents to an outcome as being part of 'health'¹⁶



The authors concluded that if we are aiming for person-centred care, we should use the broad perception of health. In order to prevent the use of the commonly used definition of health as “the absence of disease” they further propose to use the term “positive health” which is connected to the six categories of outcomes.

Linton and colleagues broadened the scope and went beyond health when systematically reviewing self-report measures of well-being.¹⁷ They found 99 measures of well-being, including in total 196 dimensions. These dimensions clustered around 6 key themes that are mentioned below:

1. **Mental well-being** (psychological, cognitive and emotional quality of life);
2. **Social well-being** (how well an individual is connected to others in their local and wider community);
3. **Activities and functioning** (behaviour and activities that characterise daily life);
4. **Physical well-being** (quality of performance of bodily functioning);
5. **Spiritual well-being** (concerned with meaning, a connection to something greater than oneself and in some cases faith in a higher power);

6. **Personal circumstances** (conditions and external pressure that an individual faces, e.g., financial security).

When comparing the dimensions of health and well-being from Huber and colleagues¹⁶ and Linton and colleagues¹⁷, there is considerable overlap (**Table 1**). Only the outcomes “quality of life” and “personal circumstances” are not covered in both, although this is probably related to the labels that have been used, because what is included in the dimension “quality of life” in Huber and colleagues¹⁶ is covered by several dimensions of Linton and colleagues.¹⁷

Table 1: *Comparison of outcomes to measure health and well-being*

Health <i>Huber and colleagues¹⁶</i>	Well-being <i>Linton and colleagues¹⁷</i>
Bodily functions	Physical well-being
Mental functions & perception	Mental well-being
Spiritual/existing dimension	Spiritual well-being
Quality of life	-
Social & societal participation	Social well-being
Daily functioning	Activities and functioning
-	Personal circumstances

Indicators of health are also frequently used in health-systems comparisons. In their 2015 report of Health at a Glance, the OECD compares the performance of health systems in OECD countries on key indicators of health. These are highly aggregated indicators including life expectancy, (infant) mortality, perceived health status and cancer incidence. The perceived health status is measured with general questions like “How is your health in general?”. Besides health, this 2015 report contains indicators of the determinants of health, workforce, health care activities, access to care, quality of care, health expenditure and financing, the pharmaceutical sector, and ageing and long-term care.¹⁸ In the context of SELFIE the quality of care indicators presented in this 2015 report are worth to have a closer look. They mostly include statistics on for example avoidable hospital admissions, prescribing in primary care, mortality following acute myocardial infarction, but also patient experience with ambulatory care. The latter is based on surveys asking about doctors spending enough time with the patient in consultation, providing easy-to-understand explanations, giving opportunity to ask questions or raise concerns, involving patient in

decisions about care and treatment. The Health Care Quality Indicator (HCQI) project of the OECD has identified measurement of patient experiences as a priority for indicator development and quality improvement.²⁶ To explore the possibilities for cross-national comparison of patient experiences, the OECD commissioned the Norwegian Knowledge Centre for the Health Services to perform a review of the use of national and international surveys to measure patient experiences. Based on this review and the outcomes of further consultation with country experts, academics in the field and key international partners, the HCQI project developed a population-based survey, and undertook the cognitive testing of the questionnaire and a pilot data collection. Patient experience indicators have been collected for international reporting. The following quality of care outcomes, are currently considered suitable for international comparison:

1. Waiting time of more than 4 weeks for getting appointment with a specialist
2. Consultation skipped due to costs
3. Medical tests, treatment or follow-up skipped due to costs
4. Prescribed medicines skipped due to costs
5. (Regular) doctor spending enough time with patients during the consultation
6. (Regular) doctor providing easy-to-understand explanations
7. (Regular) doctor giving opportunity to ask questions or raise concerns
8. (Regular) doctor involving patients in decisions about care or treatment

This list does not include specific indicators for the quality of integrated care, but this omission is recognised and likely to change in future. The following reports of the Department of Health in England¹⁹, the WHO²⁰, and a review study²¹ do focus on outcomes to measure integrated care.

4.1.2. Measures of integrated care

When we narrow down the perspective and focus on outcome measures of integrated care more specifically, there are a number of recent reports and papers worth mentioning.

The Policy Innovation Research Unit (PIRU) of the Department of Health in England published an advice on a common indicator set for the quality of integrated care measurable from existing data sources.¹⁹ The advice was primarily written to support the

Integrated Care and Support ‘Pioneers’ and the initiatives in the context of the Better Care Fund. The work should also support the outcomes measured in the three Outcomes Frameworks (OF), i.e., the NHS Outcomes Framework (NHSOF), the Public Health Outcomes Framework (PHOF), and the Adult Social Care Outcomes Framework (ASCOF). The indicators can support monitoring, assessing and improving care coordination and other dimensions of local integration; they can be used for benchmarking against peers and monitoring against national trends. The indicators were classified into six groups:

1. **Community well-being and population health** (*e.g., excess winter deaths, % of physically active and inactive adults*)
2. **Organisational processes and systems** (*e.g., delayed transfers of care from hospital, % of older people who were offered rehabilitation following hospital discharge*)
3. **Personal outcomes** (*e.g., social care related quality of life, % of older people still at home 91 days after discharge from hospital*)
4. **Resource use/balance of care** (*e.g., bed days for selected patient types, numbers receiving long-term community-based care as a % of total numbers receiving long-term care*)
5. **Service proxies for outcomes** (*e.g., emergency admissions, re-admissions for selected patient groups*)
6. **User/carer experience** (*e.g., questions from existing surveys like ‘In the last six months, have you had enough support from local services or organisations to help you manage your long-term condition’*)

The indicator set is seen as a menu, from which to choose the indicators most useful for a particular integrated care initiative, considering its aims, target population, interventions, measurement opportunities, analytical capacity, etc. There is a generic indicator list which can be supplemented by a list of indicators for specific conditions or groups of service users. These are mainly indicators for mental health and learning disabilities, and some for cardiovascular disease, cancer, and ‘other’, although the latter three are mainly intended to be illustrative of the potential uses of available data.

In 2015, the WHO published an overview of key measures and outcomes for people-centred integrated care.²⁰ They created a composite set of potential indicators that have been put forward within different countries (e.g., UK, US, New Zealand) as ways to examine the

impact of people-centred and integrated care, resulting in almost similar groups of outcome measures as reported by PIRU:

1. **System-level measures of community well-being and population health** including avoidable deaths, mental health and well-being, healthy lifestyle);
2. **Organisational processes and characteristic** e.g., access to care, care planning, care transitions, self-care support, care coordination, and medication management;
3. **Personal health outcomes for people and communities** including quality of life measures, remaining independent and self-management;
4. **Resource utilisation measures** in order to measure the reorganisation of care (toward primary care and community), e.g., hospital utilisation, residential and long-term care utilisation, primary care utilisation;
5. **Service proxies for improved health outcomes** for example avoidable hospital admissions, hospital days and patient safety;
6. **User and carer experiences** such as shared decision making, care planning, communication and information sharing and continuity of care.

The WHO reported that this list should not be seen as definitive but rather as a menu of possible options. The current heterogeneity of measures and indicators to assess person-centred and integrated care strongly suggest that indicators need to be chosen to suit local and national contexts and priorities.

In 2016, a mixed-methods design study was performed by Guézennec and colleagues to present a list of outcomes used in practice to measure integrated care in Europe.²¹ First, a review of the international literature was performed to identify outcomes and indicators of integrated care, and second, experts in the field helped in the validation process by giving feedback and comparing with existing frameworks during workshops organised by the WHO. From the literature review, 261 indicators were found including both objective indicators (e.g., number of avoidable admissions to in-patient care) and subjective indicators (e.g., % of persons reporting that they feel safe). These indicators were categorised into 7 categories:

1. **Access to care** (e.g., access to GPs, responsiveness, availability of services);
2. **Care-coordination** (e.g., presence of multidisciplinary team, communication between in and outpatient settings, avoidable readmission);

3. **Continuity of care** (e.g., continuous monitoring and follow-up, assignment of a named-person of contact, existence of needs assessment);
4. **Person-centred care** (e.g., shared decision making, support for self-management, support of informal caregivers and family);
5. **Community-based care** (e.g., range of home/community-based services available, collaboration of community-based services with other settings);
6. **User experience** (e.g., patient satisfaction, feeling safe and secure, patient/family experience of service providers);
7. **Management/organisational level** (use of data management tools, evidence-based guidelines, staff-satisfaction/perspective).

It is important to note that the outcomes reported in the reports of PIRU and WHO, and the review of Guézennec and colleagues mostly include indicators of the extent of implementation of integrated care (the objective input parameters) and indicators related to the experience of integrated care. These are mainly process-related indicators, indicating that health / well-being outcomes or costs are less frequently used in practice.

4.1.3. Measures of the Triple Aim

Many reports and papers about outcomes of integrated care include outcomes that cover the Triple Aim. From that literature, we have summarised two contributions. One from the Institute for Health Care Improvement (IHI) ⁸ which developed the Triple Aim and one recent review study from Hendrikx and colleagues on measures of the Triple Aim used in population health management programmes.⁹

The IHI, which developed the Triple Aim as a statement of purpose for health system reforms, has published a white paper with a menu of suggested measurements for the Triple Aim.⁸ The measurements are structured hierarchically with top-level population outcome measures for each dimension of the Triple Aim, and related process and outcome measures for projects that support each dimension.

The dimension **Population Health** is measured with:

- 1) health outcomes (mortality, health and functional status, and the combination of these two in healthy life expectancy);

- 2) burden of disease indicators (incidence/prevalence of major chronic conditions);
- 3) behavioural measures (e.g., smoking, physical activity) and physiological measures (e.g., body mass index, blood glucose), possibly combined into a health risk assessment score.

The dimension **Experience with care** is measured:

- 1) From an individual's perspective using standard patient experience surveys.
- 2) From a systems perspective on six aims of improvement, i.e., safety, effectiveness, timeliness, efficiency, equity and patient-centeredness.

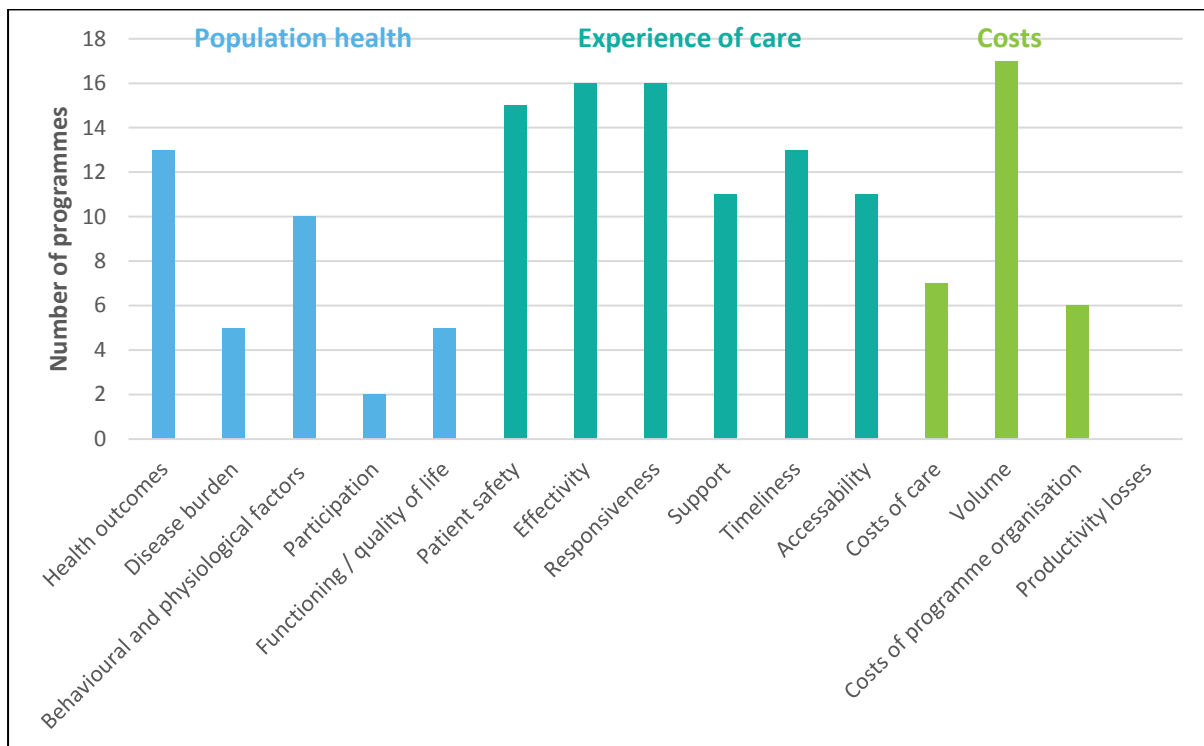
The **Cost** dimension is measured in terms of:

- 1) The total costs per member of the population per month
- 2) Hospital and emergency department utilisation rate and/or costs

These measurement recommendations were based on an underlying model of Evans and Stoddart describing the causal pathways and relationships between determinants, intermediate outcomes and health outcomes.²⁷ Programmes aiming to improve the Triple Aim are encouraged to measure downstream health outcomes, but if these are not available they can start further upstream, with surrogate measures. When measuring costs it is recommended to disaggregate them into volume and unit costs, to better understand sources of variation and change. IHI's white paper gives dozens of examples of specific instruments, indicators and data sources to measure the outcomes listed above, with a focus on population-level measures. It is a useful framework for measuring value in healthcare. The challenge for organisations and communities pursuing the Triple Aim is to integrate these measures into a continuous learning system.

In 2016, a review study conducted by Hendrikx and colleagues explored how population management programmes measure the Triple Aim in practice.⁹ The study included 20 population health management programmes and the researchers clustered the outcomes into 15 outcome groups, 5 related to population health, 6 related to experience of care, and 4 related to costs (see **Figure 5**). The results showed that outcomes were mostly related to experience of care and not all programmes measured outcomes from all three dimensions of the Triple Aim.

Figure 5: Overview of types and number of outcomes in population health management programmes in Hendrikx and colleagues, 2016⁹



The overview given above indicates that there are virtually no indicators that are specifically developed to measure the impact of integrated care in persons with multi-morbidity. This may be because it is obvious that the indicators presented above are also relevant for people with multi-morbidity; it's just that the problems they experience in domains like care coordination, continuity of care, and person-centeredness are commonly more serious than people with a single chronic disease. It may also be that the perspective of multi-morbidity has received less attention up to now.

4.1.4. Measures of integrated care programmes for multi-morbidity

It is therefore that we investigated which measures were used in integrated care programmes specifically targeting patients with multi-morbidity. These programmes were identified in the previous scoping interview that we conducted to inform the development of our conceptual framework on integrated care in multi-morbidity.^{13,14} **Table 2** and **Figure 6** gives an overview of the type of outcomes used in the evaluations of these programmes. The results showed that outcomes were mostly related to health/well-being and not all programmes measured outcomes from all three dimensions of the Triple Aim. Only one

study included the programme costs in their evaluation. We concluded that the type of outcome measures used is generally similar to studies not specifically focussing on integrated care in multi-morbidity, although perhaps generic quality of life and well-being measures are used more often.

Figure 6: Overview of types and number of outcomes in integrated care programmes for multi-morbidity as identified in the SELFIE WP1 review

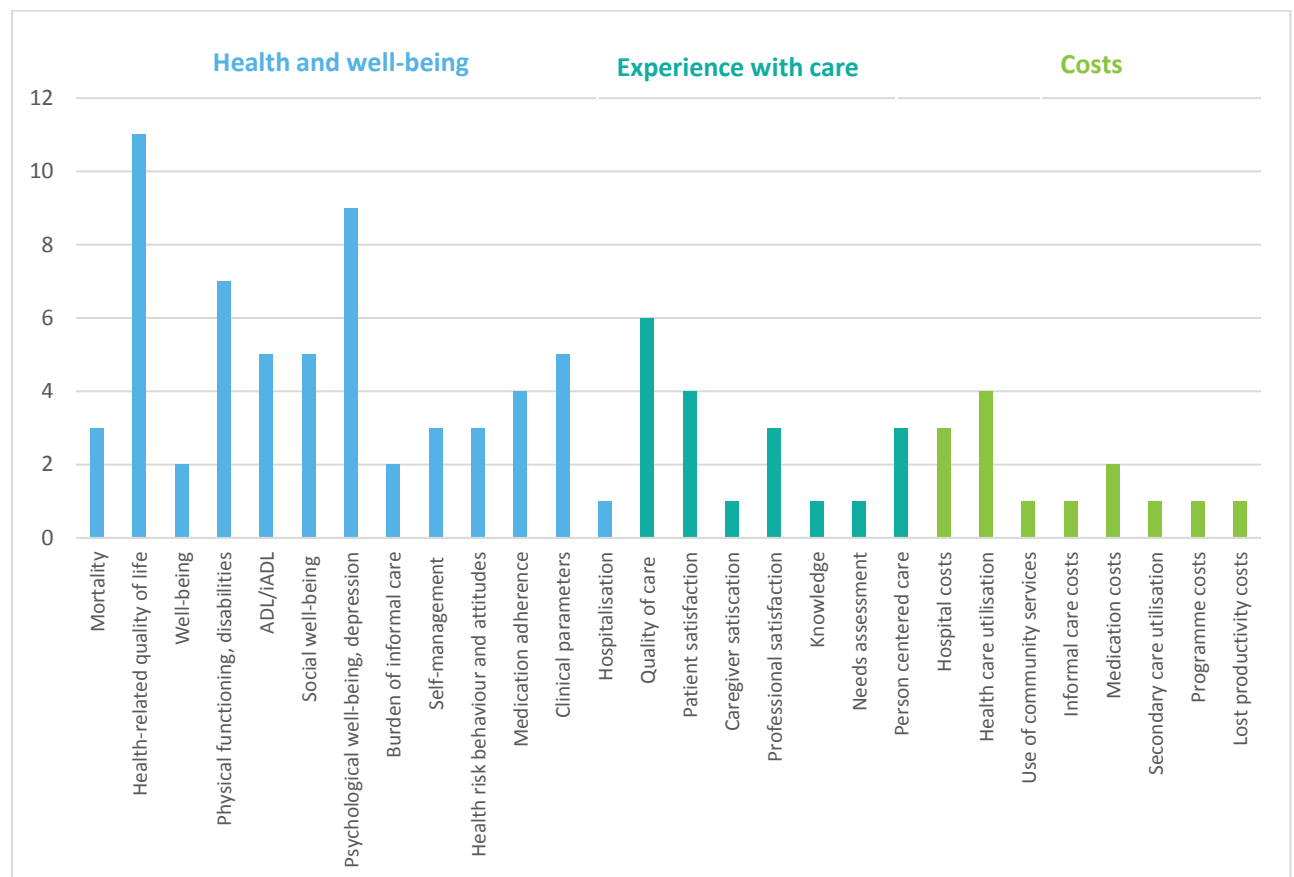


Table 2: An overview of outcomes used in implemented integrated care programmes

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
Boorsma et al. ¹ , 2011, Netherlands	RCT, <u>Frail elderly</u> : Elderly people living in residential care facilities	Multi-disciplinary integrated care intervention	<p>Health</p> <ul style="list-style-type: none"> • Health-related quality of life (Rand Health Insurance Study Questionnaire) • Quality-adjusted-life-years (QUOTE-Elderly instrument (Quality of Care from the Perspective of the Elderly)) • Mortality • Activities of daily living (Groningen Activity Restriction Scale (GARS)) <p>Experience</p> <ul style="list-style-type: none"> • Quality of care indicators (32 risk adjusted quality-of-care indicators) <p>Costs</p> <ul style="list-style-type: none"> • Hospital admissions <p>Process</p> <ul style="list-style-type: none"> • Process outcomes (Content analysis of care plans, opinion of professionals regarding the protocol obtained from interview (e.g., percentage of residents with completed assessment, the number of multidisciplinary meetings held, the number of agreed on medical, nursing and social actions))
Fabbricotti et al. ² , 2013, Netherlands	Quasi experimental design, <u>Frail elderly</u> : Frail elderly persons (>75 years) living at home with a Groningen Frailty Indicator ³ score ≥ 4	National care for the Elderly programme	<p><u>Outcome measures patients</u></p> <p>Health</p> <ul style="list-style-type: none"> • Health-related quality of life (ICEpop CAPability measure (ICECAP), EuroQol -6 Dimensions^{4,5}, Short Form 36⁶, Cantril's self-anchoring ladder) • Perceived health (Short Form 36) • Social functioning (Short Form 36) • Mental well-being (Short Form 36) • Physical functioning (Katz-15) <p>Experience</p> <ul style="list-style-type: none"> • Patient satisfaction (Consumer quality index (CQ-index), self-constructed questionnaire) <p>Costs</p> <ul style="list-style-type: none"> • Health care utilisation (Self-reported utilisation, extracted from GP files)

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
			<p>Outcome measures caregivers</p> <p>Health</p> <ul style="list-style-type: none"> Burden of informal caregiving (Objective burden informal care¹⁴, CarerQol¹⁵, Self-related burden VAS (SRB)¹⁶, Caregiver Strain index (CSI)¹⁷, Assessment of the informal care situation (ASIS), Perceived time) Health-related quality of life (Short Form 36⁶, Cantril's self-anchoring ladder) <p>Experience</p> <ul style="list-style-type: none"> Satisfaction caregiver (Consumer quality index (CQ-index), self-constructed questionnaire) <p>Costs</p> <ul style="list-style-type: none"> Use of community services (Community Service Attitude Inventory (CSAI), self-report) <p>Outcome measures health professionals</p> <p>Health</p> <ul style="list-style-type: none"> Burden of caregiving (Self-related burden VAS (SRB), self-reported objective burden) <p>Experience</p> <ul style="list-style-type: none"> Job satisfaction (Job satisfaction scale) Knowledge (Self-constructed VAS) <p>Process</p> <ul style="list-style-type: none"> Degree of integration (Self-constructed questionnaire)
Muntinga et al. ⁷ , 2012, Netherlands	Stepped-wedge cluster RCT, <u>Frail elderly</u> : Community-dwelling frail older adults >65 years experiencing one or more limitations in either physical, psychological and/or social areas	Frail older adults: care in transition	<p>Outcome measures patients</p> <p>Health</p> <ul style="list-style-type: none"> Quality of life (Short-Form 12 items (SF-12), EuroQol 5 Dimensions (EQ-5D)) ADL(KATZ) Psychological well-being (RAND-36 subscale) Social functioning (RAND-36 subscale, 1 item) Self-reported health (RAND-36 subscale, 2 items) <p>Experience</p> <ul style="list-style-type: none"> Care needs (Camberwell assessment of needs in the elderly (CANE)) Patient-reported Client-centred Care (Client-centred Care Questionnaire (CCCQ))

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
			<p>Costs</p> <ul style="list-style-type: none"> • Direct and indirect costs (Cost diaries) <p>Outcome measures caregivers</p> <p>Health</p> <ul style="list-style-type: none"> • Quality of life (SF-12) • Self-rated burden of Care (CarerQol) <p>Costs</p> <ul style="list-style-type: none"> • Direct and indirect costs (Cost diaries) <p>Process</p> <ul style="list-style-type: none"> • Level of implementation (Fidelity, Dose delivered (completeness), dose received (exposure satisfaction) measured by time registrations, tailored care plans, minutes of team meetings, focus groups with practice nurses and local stakeholders) • Interviews and focus groups • Barriers and facilitates to implementation (Interviews and focus groups) • Extend to which transition is achieved (client autonomy, coordination of care) • Timely identification of health problems and care needs (Tailored care plans, interviews, focus groups)
Van den Akker, 2014 ⁸ , Netherlands	RCT, People with multi-morbidity and polypharmacy	Polypharmacy in Limburg (PIL)	<p>Health</p> <ul style="list-style-type: none"> • Physical health (Disability of functional status (using data from the Minimal Data Set (MDS))) • Mental health • Psychosocial outcomes • Quality of life outcomes • Well-being <p>Costs</p> <ul style="list-style-type: none"> • Medication adherence • Utilisation of health services (e.g. number of prescriptions, number of hospitalisations) • Costs of medication prescriptions <p>Process</p> <ul style="list-style-type: none"> • Acceptability and feasibility of the intervention (Barriers and facilitators of the intervention according to patients, GPs, nurse practitioners and pharmacists)

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
Freund et al., 2011 ⁹ , Germany	Cluster RCT, Persons aged ≥18 with at least one of the following conditions (type 2 diabetes mellitus, COPD, chronic heart failure) and with high risk of future hospitalisation	Primary care practice-based care management for chronically ill patients (PraCMan)	<p>Health</p> <ul style="list-style-type: none"> • Mortality • Health-related quality of life (SF-12, EQ-5D) • Depression (Patient Health Questionnaire (PHQ)) • Self-management (European Selfcare Behaviour Scale (EHFScB), Self-developed instrument for COPD and diabetes)) • Physical activity (Rapid Assessment of Physical Activity (RAPA)) • ADL/iADL(Katz, Lawton iADL) • Smoking status (Self-developed items) • Clinical parameters (Case report form (e.g., blood pressure, HbA1c, number of severe hypoglycaemias, MRC dyspnoea scale, exacerbations)) <p>Experience</p> <ul style="list-style-type: none"> • Quality of care (Patient Assessment of Chronic Illness Care (PACIC)) <p>Costs</p> <ul style="list-style-type: none"> • Healthcare utilisation (Insurance claim data (ED visits, practice visits, skilled nursing home days)) • Total healthcare costs (Insurance claim data)
Schmidt et al., 2014 ¹⁰ , Germany	RCT, <u>Specific morbidity combination</u> ; Patients with severe sepsis or septic shock (ICD-10), at least two criteria of systemic inflammatory response syndrome (SIRS), at least one organ dysfunction and sufficient cognitive capacity are present.	Sepsis survivors monitoring and coordination in outpatient health care (SMOOTH)	<p>Health</p> <ul style="list-style-type: none"> • Health-related quality of life (SF-36) • Depression (Major Depression Inventory (MDI)/WHO-10, Posttraumatic Stress Scale 10) • Motoric function (Extra-short Musculoskeletal Function Assessment Questionnaire (XSMFA-D).) • Pain(Graded Chronic Pain Scale (GCPS)) • Malnutrition (Malnutrition Universal Screening Tool (MUST)) • Neurocognitive deficits (Telephone Interview of Cognitive Status (TICS-M)) • Critical illness neuropathy and myopathy (Neuropathy Symptom Score) • Activities of daily living (Daily living and instrumental activities of daily living) • Medication Adherence (Morisky Questionnaire) • Sleep (Regensburger Insomnia scale (RIS)) <p>Experience</p> <ul style="list-style-type: none"> • Quality of care (Patient Assessment of Chronic Illness Care (PACIC))

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
Muth et al. ¹¹ , 2016, Germany	Cluster RCT, Elderly multi-morbid patients with multi-medication in general practice	Prioritising multimедication in multimorbid patients (PRIMUM)	<u>Health</u> <ul style="list-style-type: none"> Medication Appropriateness (Medication Appropriateness Index (MAI)-Score) Generic health related quality of life (EQ-5D) Functional disability (WHO Disability Assessment Schedule (WHO-DAS-II)) Medication adherence (Observed adherence, self-reported adherence measured by the Morisky-Score, Medication Adherence Rating Scale (MARS)) Medication complexity (Medication Regimen Complexity Index (MRCI)) Health and illness beliefs and attitudes (Beliefs about Medicines Questionnaire (BMQ)) Pain (Characteristic Pain Intensity score, the Disability Score, and the resulting Grades of chronic pain severity) Hospitalisation Mortality
Roland et al. ¹² , 2012, UK	Multi-method evaluation, Older people at risks of emergency hospital admission	Six management demonstration sites	<u>Experience</u> <ul style="list-style-type: none"> Satisfaction with care (Patient and staff experience with care questionnaire) <u>Costs</u> <ul style="list-style-type: none"> Secondary care utilisation (Registration data (Hospital Episode Statistics))
Coventry et al. ¹³ , 2015, UK	Trial to evaluate intervention in depressive patient with physical conditions, Patients with depression and diabetes and/or heart diseases in the Northwest UK	The Collaborative Interventions for circulations and Depression Trial	<u>Health</u> <ul style="list-style-type: none"> Depression (Symptom Checklist Depression Scale (SCL-13)) Mental health and anxiety (Improving Access to Psychological Therapies (PHQ-9), Generalised Anxiety Disorder Assessment (GAD-7)) Social support (Enrichd Social Support Inventory (ESSI)) Global quality of life (WHO quality of life measure (WHOQOL-BREF)) Disease specific quality of life (Diabetes quality of life, Seattle angina questionnaire) Disability (Sheehan disability scale (SDS)) Self-management (Health education impact questionnaire (heiQ), Self-Efficacy Questionnaire (SEQ), Multimorbidity Illness Perception Scales (MULTIPLEs)) <u>Experience</u> <ul style="list-style-type: none"> Patient centeredness (Patient Assessment of Chronic Illness Care (PACIC)) Satisfaction with care (Client Satisfaction Questionnaire (CSQ))
Allen et al. ¹⁴ , 2012, USA	RCT, >60 Years with Medicaid, must have life-limiting illnesses, be nursing home	Promoting Effective Advanced Care	<u>Health</u> <ul style="list-style-type: none"> Symptom management (Memorial Symptom Assessment Scale) Quality of life/death (Quality of life at the end of life (QUAL-E)) Relationships (Meaning in life scale)

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
	eligible, have at least 2 deficits in Activities of Daily Living	for Elders (PAECE)	<ul style="list-style-type: none"> Depression and anxiety (<i>Hospital Anxiety and Depression scale</i>) <p><u>Experience</u></p> <ul style="list-style-type: none"> Decision making/care planning/continuity/communication (<i>Patient activation Measure</i>)
Meret-Hanke, 2011 ¹⁵ , UK	Quasi experimental design, <55 Years and eligible for nursing-level care	Programme of the All Inclusive Care for the Elderly (PACE)	<p><u>Health</u></p> <ul style="list-style-type: none"> Activities of Daily Living (<i>Assessment of the programme staff</i>) Cognitive impairments (<i>Assessment of the programme staff, cognitive impairment measure</i>) Health (<i>Self-reported health</i>) <p><u>Costs</u></p> <ul style="list-style-type: none"> Hospitalisation Nursing home use
Bielaszka-DuVernay, 2011 ¹⁶ , USA	RCT, Low-income elderly people, most with multiple chronic conditions	Geriatric Resources for Assessment and Care of Elders (GRACE)	<p><u>Health</u></p> <ul style="list-style-type: none"> Health related quality of life (<i>Quality of life scales</i>) <p><u>Experience</u></p> <ul style="list-style-type: none"> Satisfaction with care (<i>Physicians satisfaction with care</i>) Quality of care (<i>Quality indicators both in general medical care (flu shots, care coordination during transitions) and in geriatric specific care (evaluation of falls, treatment of depression)</i>) <p><u>Costs</u></p> <ul style="list-style-type: none"> Hospitalisation costs Programme costs

Author, Year, Country	Study design & target group	Programme name	Outcome and instrument (indicator(s))
Katon et al. ¹⁷ , 2010, USA	RCT, Patients with diabetes or coronary heart disease, or both, and blood pressure above 140/90 mm Hg, low density lipoprotein concentration >3.37 mmol/L, or glycated haemoglobin 8.5% or higher, and Patient Health Questionnaire-9 (PHQ-9) and Hopkins Symptom Checklist-20 (HSCL-20) depression scores of ≥10.	TEAMcare	<p>Health</p> <ul style="list-style-type: none"> • Depression (Patient Health Questionnaire-9 (PHQ-9) and Hopkins Symptom Checklist-20 (HSCL-20), Patient Global Rating of Change for depression) • Biomedical outcomes (Systolic blood pressure, glucose control, lipid control) • Compliance (Continuous Multiple Gaps therapy Measure (CMG)) • Self-efficacy • Health risk behaviours (Diet, physical activity, smoking, checking blood glucose and blood pressure) • Disability (Sheehan disability scale (SDS), World Health Organisation disability assessment schedule (WHODAS-2)) <p>Experience</p> <ul style="list-style-type: none"> • Satisfaction with care • Quality of care (Clinical quality of care measures, e.g. % with blood pressure <130/80)
Tanio & Chen, 2013 ¹⁸ , USA	RCT, Elderly with multiple chronic conditions	ChenMod Model	<p>Experience</p> <ul style="list-style-type: none"> • Quality of care (Various quality indicators extracted from registration data of the payer (Health care Effectiveness Data and Information set)) <p>Costs</p> <ul style="list-style-type: none"> • Hospitalisations (Various quality indicators extracted from registration data of the payer (Health care Effectiveness Data and Information set))

4.2. Stakeholder workshops

The second source of information to inform our choice of outcome measures in SELFIE were the national stakeholder workshops with representatives of the five groups of stakeholders involved in integrated care. Between February and July 2016 eight national stakeholder workshops were held in the eight participating SELFIE countries. An overview of the present stakeholders from the 5Ps at each workshops is given in **Table 3**. In total, 124 stakeholders participated in the seven workshops between February and July 2016. The number of participants ranged from 5 (England) to 29 (Croatia), with a mean number of 16 participants. From the five stakeholder groups, most participants (45%) were professionals.

Table 3: Participants of the National Workshops in the eight countries

Location	Date	Patients (N)	Partners (N)	Professionals (N)	Payers (N)	Policy makers (N)	Total number (N, %)
Hungary, Pécs and Budapest*	February 11 th and 25 th	2	3	8	5	7	25 (20%)
The Netherlands, Rotterdam	March 15 th	2	2	5	3	3	15 (12%)
Croatia, Zagreb	April 8 th	2	2	16	3	6	29 (23%)
Norway, Bergen	April 13 th	2	0	7	2**		11 (9%)
England, Manchester	April 26 th	1	0	1	0	3	5*** (4%)
Germany, Berlin	June 3 th	3	1	3	3	1	11 (9%)
Austria, Vienna	June 8 th	2	1	2	2	1	8 (7%)
Spain, Barcelona	July 11 th	1	0	12	3	4	20 (16%)

Note: * The Syreon Research Institute organised the Hungarian workshop in two separate sessions: one workshop in Pécs on 11th February 2016 and one workshop in Budapest on 25th February 2016. ** Stakeholders represented as payer and policymaker; for the public health care sector in Norway the distinction between policy makers and payers is not clear and will in general involve people from the same units (ministries/directorates and municipalities). *** There was no representative of the partner or payer perspectives in the workshop in England, as no representatives from these groups were able to attend

The stakeholders were asked to discuss what outcomes of integrated care programmes for persons with multi-morbidity would need to see improved in order for them to:

- Participate in the programme?
- Insure the programme?
- Offer / provide the programme?
- Implement the programme (on a larger scale)?

They were specifically instructed to focus on integrated care programmes for persons with multi-morbidity. The SELFIE-EUR team extracted the outcomes that were mentioned by the stakeholders from the notes of the national stakeholder workshops and grouped them according to the Triple Aim. This is presented in **Table 4**, **Table 5**, and **Table 6**. The workshop notes on the discussion of outcomes are presented in **Appendix 1**. Although this qualitative research does not allow firm conclusions, it seems that the stakeholders are more inclined to report structure and process indicators than indicators of health outcomes. Among the process indicators we see a lot of indicators related to the level of implementation of integrated care (i.e., the inputs), that can relatively easy be extracted from routine databases. When discussing costs, there was a lot of attention for the costs of complications and unplanned or avoidable care and the costs of inappropriate health care utilisation (i.e., over-utilisation). Referring back to **Figure 2**, perhaps unsurprisingly, professionals, payers, and policy makers mentioned health outcomes more in terms of the system level, whereas persons with multi-morbidity and informal caregivers mentioned more individual level outcomes. Although these outcomes are essentially the same, it is important to take note that these different stakeholders communicate differently about outcomes. Below we will report the most interesting findings from the workshop notes categorised by the Triple Aim.

4.2.1. Health

A finding that reinforces the broad MCDA framework planned in SELFIE, is that all different stakeholders focused not only on health- and well-being outcomes for the person with multi-morbidity him- or herself, but also mentioned the health and well-being of partners and families (i.e., informal caregivers). We also see in all countries that not only traditional clinical health outcomes are mentioned. Instead, a broader set of health-related outcomes is mentioned, such as well-being (Hungary), loneliness (Netherlands), coping (Norway), and self-management capabilities (UK). The complete list of health and well-being outcomes mentioned during the national stakeholder workshops is presented in **Table 4**.

Table 4: *Health and well-being outcomes mentioned during the national stakeholder workshops*

Extracted outcome	Examples of measures/indicators mentioned during workshops
Generic health-related quality of life	Health Related Quality of Life (HRQoL), utility measurement with time-trade-off scales
Mortality	Survival rate, potential life years lost, life expectancy
Disease burden	Incidence /prevalence rates, severity of diseases, functional abilities
Disease specific biomedical outcomes	Regular monitoring of key clinical parameters (e.g., HbA1c)
Life-style	Smoking rate
Physical functioning	Functional patient reported outcomes scales
Caregiver burden	Partners' and family members' quality of life, pressure on informal caregiver
General well-being	WHO well-being score
Loneliness	Loneliness
Health literacy	Patient's health literacy, clear and relevant sources of information
Self-management	Availability of patient (and partner) education and counselling in the programme, self-management capabilities, adaptability, coping, resilience, positive health
Treatment adherence	Drug adherence
Self-sufficiency	Autonomy, self-direction, empowerment
Social functioning	Level of participation

4.2.2. Experience

With regard to experience, the role of communication and more/better professional collaboration and integration was highlighted by different stakeholders in different countries. For example, in Germany persons with multi-morbidity and partners mentioned that communicating about sensitive issues is a challenge that needs to be worked on. There was a perception that the performance measurement of experience could be improved by developing an outcome that would capture this. It is interesting to note that Hungary and Croatia, the Central- and Eastern European (CEE) SELFIE partners mentioned waiting times, whereas this outcome was not mentioned by stakeholders from the other countries. The complete list of experience with care outcomes mentioned during the national stakeholder workshops is presented in **Table 5**.

Table 5: Experience of care outcomes mentioned during the national stakeholder workshops

Extracted outcome	Examples of measures/indicators mentioned during workshops
Shared information system	Availability of personalised patient information system, application of mobile/e-health solutions in managed care, electronic medical records or shared databases, flagging risk for patient in polypharmacy
Coordination of care	Availability of protocol for cooperation among professionals within the institution, existence and use of protocols, availability of clinical guidelines, care feels coordinated, leadership and team climate, involvement of interdisciplinary teams, the willingness of involved professionals for collaboration, continuous communication and different roles during the implementation and respect for and promotion of good practices clear responsibility of contact persons and ensure transparency throughout the process
Patient satisfaction with care	Patient satisfaction with staff kindness, being informed, cleanliness of the facilities, organisation, waiting time, waiting list transparency and duration
Timely access	Waiting time for treatment, diagnostics and rehabilitation
Continuity of care	Regular and predictable control visits, interactions with care providers (how often, with whom?), follow-up of patients, patient pathways
Respectful interaction between provider-patient	The number and duration of patient information events (e.g., explaining the diagnosis, listening to the patient's opinion), Relationship development between the patient and the provider
Shared-decision making	Involvement of partners in decision making, involving the network of the person with multi-morbidity
Provider satisfaction with care	Satisfaction of healthcare workers
Pro-active, prevention-oriented care	Existence of prevention and health promotion activities in the integrated care program, Active care provision
Good communication	Availability of solutions supporting communication among professionals , good communication about benefits, Lack of information and time: no time to discuss open questions, no communication on possible choices, and a "sensitive" communication on diagnoses that helps understanding and coping with the situation
Tailored care	Tailored programme to lifestyle and world of the patient, individual health goals, individual needs and expectations
Structural access	System capacities (number of care providers, health professionals, available technologies)
Knowledge and skills of care providers	Availability of required levels of competence, Learning/increased competence among patients, professionals and partners
Holistic assessment	Personal development of the patient (goal-setting), See the patient in his environment (living situation, partner), wishes, needs and individual treatment goals at the core of each health related communication.

4.2.3. Costs

Almost all countries had attention for the role of costs, resource utilisation, and economic evaluations in discussing what outcomes of integrated care are. In Hungary, with regard to costs, it was also mentioned that co-payments should be considered; this was not mentioned by stakeholders in the other countries.

It is further important to mention that different stakeholders reported different type of cost outcomes, related to the different expectations they had of integrated care. The payers reported health care costs reductions as a facilitator to insure the programme, while patients and partners (informal caregivers) reported out-of-pocket costs as barrier to participate in a programme.

The complete list of costs outcomes mentioned during the national stakeholder workshops is presented in **Table 6**.

Table 6: *Costs outcomes mentioned during the national stakeholder workshops*

Extracted outcome	Examples of measures/indicators mentioned during workshop
Costs of health care utilisation	Resource utilisation (e.g., patient visits, hospital stays, average length of stay, emergency care, sick leave days)
Costs of unplanned care due to complications and inappropriate use of care	Number and severity of complications and adverse events, costs related to redundant services (unnecessary parallel activities), savings from avoided emergency situations and hospitalisations, average number of hospital days, proportion of patients passed to higher levels, rate of administering drugs with drug-drug interactions, prevention of over and under treatment, savings due to disinvestment from unnecessary and obsolete technologies, transition from secondary to primary care, patient safety (polypharmacy, secure for hygiene standards and care pathways)
Productivity costs	Lost income due to absence of work (patient, family), average number of sick leave days
Out-of-pocket costs	Co-payment for treatments (e.g., drugs), co-payment for preventive activities
Travel/parking costs	Cost of patients or partners related to accessing care (e.g., travel costs)
Generous treatment coverage	Accessibility and affordability of complementary healthcare services (physiotherapy, dietetics, psychological support), availability and level of home care subsidy and social benefit for partners, difference in coverage between diseases
Costs of informal care	Level of informal payments (gratuities, tips), lost income due to absence of work (informal caregiver)
Risk adjustments / shared savings	Institutional financial balance (income vs. costs), shift in costs
Financial access	Budget impact, a substantial number of care recipients (large volume, economy of scale)
Programme costs	Investment cost and operational costs of the system

4.3. Focus groups

The third source of information to inform our choice of outcome measures in SELFIE were the focus groups with persons who had more than one disease or condition. Eight focus group meetings were held between June and September 2016, including in total 58 persons with multi-morbidity. Their characteristics are presented in **Table 7**. The average age of the participants ranged from 62 (Germany) to 73 (Austria). Approximately half of the participants were female. Reported morbidities of the respondents were categorised according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10). Variation in type of multi-morbidity existed, but most participants reported chronic conditions within the categories diseases of the circulatory system, endocrine, nutritional and metabolic diseases, and musculoskeletal disease. Only 3 of the 58 (5%) persons with multi-morbidity reported mental disorders.

The focus group started with a brainstorm session on possible outcomes by discussing what ‘good health’ means to them, and how they define ‘a good care process’. Thereafter we asked the participants to draft their own ‘top-10’ list of relevant outcomes. Their individual answers were classified into the categories shown in **Table 8** (on health/well-being), **Table 9** (experience with care) and **Table 10** (costs) by the researchers. If participants framed the outcomes in more detail, like for example “moving around freely without physical limitations” we as researchers assigned this to the category “physical mobility”. The numbers in these tables refer to the number of times that this outcome is included in the top-10 list of most important outcomes. For example, energy and fatigue was four times in the top-10 lists from the seven participants of the focus group in the Netherlands.

The results from the focus group showed that persons with multi-morbidity in the different European countries placed a lot of emphasis on experience with care outcomes, followed by health and well-being outcomes, and lastly outcomes related to costs. Interestingly, clinical indicators were less frequently included in the top-10. Social well-being outcomes (e.g., maintaining social status, respect from others, and social relationships/participation), self-management outcomes (e.g., resilience, self-sufficiency), and having enjoyment in life were often mentioned by the persons with multi-morbidity (see **Table 8**). When comparing the countries, it is interesting to note that participants in the

UK and Spain did not have clear preferences for particular health and well-being outcomes. This is in contrast with the participants in Germany, where all participants included self-management in their top-10 list.

With regard to experience with care outcomes, a lot of value was placed on the interactions with care providers: a respectful treatment, shared decision-making, and good communication both between provider and participant as between multiple providers (see **Table 9**). Especially relevant in the case of multi-morbidity and often mentioned by participants was that the care providers had insight into and attention for their entire situation. Not only their different health problems but also their preferences and wishes should be taken seriously. Moreover, knowledge and skills of care providers/caregivers was included in the top-10 lists in almost all countries. General satisfaction is not frequently reported by the patients with multi-morbidity, probably because it is an overall measure capturing many of the aspects they had already mentioned before.

In all European countries, one or more cost outcomes were mentioned in the top-10 lists (see **Table 10**). Interesting to note is that participants in all countries except the UK stressed the importance of sufficient coverage of healthcare and social support services (e.g., limited co-payments, low deductible and financial access to services). Participants in Croatia specifically mentioned the importance of not losing income.

Table 7: Characteristics of the participants

	Dutch participants (n= 7)	German participants (n=12)	Norwegian participants (n=7)	English participants (n=6)	Croatian participants (n=7)	Spanish participants (n=6)	Hungarian participants (n=6)	Austrian participants (n=7)
Mean age in years (range)	66 (53-74)	62 (37-78)	66 (42-71)	69 (58-86)	52 (31-69)	70 (60-81)	65 (47-78)	73 (62-84)
Female	2/7	8/12	5/7	2/6	3/7	1/6	5/6	2/7
Health problems								
Neoplasms	14% (n=1)	17% (n=2)	-	-	29% (n=2)	-	-	29% (n=2)
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	-	-	14% (n=1)	-	14% (n=1)	-	-	-
Endocrine, nutritional and metabolic diseases	43% (n=3)	42% (n=5)	43% (n=3)	83% (n=5)	14% (n=1)	50% (n=3)	83% (n=5)	29% (n=2)
Mental and behavioural disorders	-	-	-	50% (n=3)	-	-	-	-
Diseases of the nervous system	-	75% (n=9)	14% (n=1)	17% (n=1)	29% (n=2)	-	-	14% (n=1)
Diseases of the eye and adnexa	57% (n=4)	-	-	-	-	-	17% (n=1)	-
Diseases of the ear and mastoid process	-	17% (n=2)	14% (n=1)	17% (n=1)	-	-	-	-
Diseases of the circulatory system	43% (n=3)	75% (n=9)	43% (n=3)	50% (n=3)	43% (n=3)	67% (n=4)	100% (n=6)	14% (n=1)
Diseases of the respiratory system	43% (n=3)	-	43% (n=3)	-	-	100% (n=6)	-	-
Diseases of the digestive system	14% (n=1)	8% (n=1)	43% (n=3)	17% (n=2)	14% (n=1)	17% (n=1)	17% (n=1)	14% (n=1)
Diseases of the skin and subcutaneous tissue	-	-	-	17% (n=2)	29% (n=2)	-	-	29% (n=2)
Diseases of the musculoskeletal system and connective tissue	29% (n=2)	42% (n=5)	29% (n=2)	67% (n=4)	43% (n=3)	17% (n=1)	17% (n=1)	57% (n=4)
Diseases of the genitourinary system	-	-	-	-	-	17% (n=1)	-	-
Congenital malformations, deformations and chromosomal abnormalities	-	-	-	-	29% (n=2)	-	-	-
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	-	25% (n=3)	-	-	-	-	-	-
Injury, poisoning and certain other consequences of external causes	-	-	14% (n=1)	-	-	-	-	-
External causes of morbidity and mortality	29% (n=2)	-	-	-	-	-	-	-
Factors influencing health status and contact with health services	57% (n=4)	-	-	-	-	-	-	-
Date of focus group	June 8th	June 30th	June 30th	July 5th	July 5th	July 15th	July 21st	September 2nd

Table 8: Top-10 outcomes related to health and well-being

Outcome category	Outcome	NL N=7	GER N=6	NOR N=7	UK N=6	CRO N=7	SPA N=6	HUN N=6	AUS N=7
Mortality	Mortality	1							
Physical well-being	Energy and fatigue	4		2	1			1	4
	Pain and discomfort				1				3
	Physical mobility	1	1	2		1	1	1	
	Work ability	2				3	2	1	1
	Activities of daily functioning (ADL)	1	3	2	1	2		1	
	Disability			1	1	2		1	
	Biomedical outcomes							3	2
Psychological well-being	Cognitive functioning	2	1	1	1		3		4
	Anxiety and depression				1			1	
	Stress			1	3			3	
	Worrying				3				
	Listlessness						1		1
	Self-esteem	3	3	2	1	1			1
	Loneliness								1
	Suicide								
	Conscience / Feeling of guilt								
	General mental health well-being		3			1			
	Feeling disabled								1
Social well-being	Respect from others	2		2	1	4	1		
	Maintaining social status	4	5						2
	Societal relationships/participation	3	3		2	3	3	2	6
	Social support			2		2	1		2
	Social expectations					1			
	Social status		3						

Outcome category	Outcome	NL N=7	GER N=6	NOR N=7	UK N=6	CRO N=7	SPA N=6	HUN N=6	AUS N=7
Emotional well-being	Feeling safe	3					3	3	
	Enjoyment in life	3	4	3	3			1	2
	Maintaining dignity						2	4	1
	Living comfortably	1	2		1				1
	Creativity					2			
	Daily structure / being active		4						
	Self-confidence						1		
Generic health-related quality of life	Generic health-related quality of life			1					
Frailty	Frailty								
Caregiver burden	Caregiver burden		2			3			
Self-management	General self-management abilities	2	6						
	Investment behaviour (in future health and well-being)	1	2			1	1		
	Self-efficacy				2	1	1	1	
	Resilience	1	2	4	2	3	2	2	2
	Coping	1	3	2	1		1		1
	Health literacy	1	5					1	
	Compliance/adherence to treatment		2		1			1	1
	Lifestyle	4	1		1				2
	Self-sufficiency, autonomy	1	5		2	2	3	2	2

Note: The number in the table refers to the number of times that this outcome was included in the top-10 list of most important outcomes.

Table 9: Top-10 outcomes related to experience with care

Outcome category	Outcome	NL N=7	GER N=6	NOR N=7	UK N=6	CRO N=7	SPA N=6	HUN N=6	AUS N=7
Person-centeredness	Shared decision making	1	4		4			1	2
	Holistic assessment	3	5	5	1	1		2	1
	Tailored care / Individualised care planning	2	4	4	1			1	1
	Good communication	1	2	1	6	1	5		
	Respectful interaction between provider-patient		5	4	4	1	2		6
	Good/clear information/explanation	1						1	1
Integration and coordination of care	Named coordinator	1	4	1		1			
	Team work and collaboration between care providers	1	4	3	4	1	3	2	3
	Shared information between professionals (& patients)	6	7	2	1	1	1	4	2
	Clear responsibilities and accountability	1	3	1	1	1			
Continuity of care	Advance care planning								
	Pro-active care, prevention oriented care	4	1	2	3	1	2	5	
	Transfer care / after care	2	4			1			
	Continuity	1	1		1	2	1	6	
Knowledge and skills	Knowledge and skills of care providers /caregivers	5	6	2		5	1	2	6
Access to care	Geographical access				1	1	1		
	Physical access	2	1			1	1		
	Timely access	1	1		4	6	2	2	
	Equal access								
Satisfaction	Patient satisfaction with care process							2	
	Patient satisfaction with the care quality/facilities								
	Informal caregiver satisfaction with care process								
	Professional satisfaction with care process						1		
	Satisfaction with care process		4						1

Note: The number in the table refers to the number of times that this outcome is included in the top-10 list of most important outcomes.

Table 10: *Top-10 outcomes related to costs*

Outcome category	Outcome	NL N=7	GER N=6	NOR N=7	UK N=6	CRO N=7	SPA N=6	HUN N=6	AUS N=7
Costs borne by patients for disease-related out-of-pocket expenses	Service and support coverage (co-payments/deductible and financial access to services)	1	1	1		1	1	1	2
	Travel and parking costs				1		1	1	
Productivity costs	Loss of income - patient					3	1	1	1
	Loss of income – informal caregiver					1			
	Productivity costs				1				

The number in the table refer to the number of times that this outcome is included in the top-10 list of most important outcomes.

4.4. Outcomes measured in promising integrated care programmes

The final source of information to inform our choice of outcome measures were the outcomes already being measured in the 17 promising integrated care programmes. We compared our draft list of outcomes from the previous three sources with the outcomes already measured in the 17 ongoing integrated care programmes and we discussed with our partners which additional outcomes they considered most relevant. This led to a revised list of outcomes that was discussed with the SELFIE partners over email and during teleconferences until consensus was reached. Furthermore, this led to the decision that, besides the core set of outcomes, we would define additional programme-type specific outcomes for the four types of integrated care programmes selected for further empirical evaluation in SELFIE. These four groups are population health management programmes, frail elderly programmes, palliative care / oncology programmes, and programmes targeting persons with problems in multiple life domains. These additional outcomes were also discussed among the SELFIE partners until consensus was reached. In the text blocks below we describe the outcomes and indicators already being measured in the four types of programmes.

Population health management programmes (in Germany, Spain, UK)

The population health management model 'Gesundes Kinzigtal' (GK) organises care across all health service sectors and indications. The GK model addresses the entire Kinzigtal population and offers a broad range of activities for all ages in the region. The overall aim is to foster patient self-management and enhance shared decision-making with individual care plans and shared goal setting agreements between the physicians and the patients. The system-wide access to electronic health records supports information exchange, transparency and an improvement of the quality of care. Funding includes a shared savings contract. Since the beginning 'Gesundes Kinzigtal' is continuously internally and externally evaluated using outcomes like healthcare utilisation (e.g., ambulatory care sensitive hospital admissions, re-admissions), healthcare expenditures, disease prevalence, and mortality. There are cross sectional surveys using the Patient Activation Measurement (PAM), the EQ-5D and a 'patient satisfaction with care' questionnaire including questions about communication, information sharing, shared decision-making and overall satisfaction.

The Community-based Collaborative Management of Complex Chronic Patients at Ais-Be (Area Integral de Salut, Barcelona Esquerra) targets chronic complex patients with a high risk of hospitalisation requiring specialised care. It is a multi-faceted programme. Core components of the programme are a regional population-health risk assessment tool to enhance clinical risk assessment and stratification, adaptive case management, and the convergence of existing/prioritised ICT-supported clinical programmes linking tertiary care with the community. The services provided by the programme have been thoroughly evaluated using a wide range of outcome measures covering clinical and technical safety, efficacy, healthcare utilisation, patient satisfaction, provider satisfaction, and organisational aspects. The main indicators cover the following dimensions: i) Characteristics of the study groups and health status (e.g., users attended in primary care, health-related quality of life of patients and caregivers), ii) Intermediate outcomes (emergency department visits, General Practitioner visits, cumulative days per year admitted in hospital, polypharmacy, potentially avoidable hospitalisations, hospital readmissions, needs for social support), iii) Empowerment (unhealthy lifestyles), iv) Structure (access to ICT-supported integrated care).

The South Somerset Symphony Programme in the UK is a population health management model based on patient segmentation. It includes Complex care hubs for 'complex patients with many conditions' (~4%), Enhanced primary care for 'less complex patients with fewer conditions' (~18%), and Proactive health and well-being support for 'mainly healthy patients' (~78%). The outcomes primarily include hospital episode statistics such as number of bed days, length of hospital stay, 30-day re-admissions, and avoidable emergency admissions. There is also a GP patient survey that measures the confidence to manage one's own health, whether the level of support was sufficient, whether patients have a written care plan, whether that plan is regularly reviewed, whether access to services is good, etc. In the Health and Well-being domain, mental health is measured with the Warwick-Edinburgh Mental Well-being Scale, patient engagement is measured with the Patient Activation Measurement (PAM) and loneliness is measured with the DeJong Loneliness Score. Surveys are used to measure patient and provider experience.

Frail elderly programmes (in Austria, Croatia, Germany, Netherlands, Spain, UK)

The Austrian Health Network Tennengau is a population-based integrated care programme with multiple different sub-programmes. It aims at fostering the cooperation between inpatient and outpatient healthcare as well as social services. Two initiatives of the Health Network Tennengau have been evaluated to date, namely the counselling service for the elderly and the discharge management. In these evaluations a survey was used that addressed the bio-psycho-social factors concerning the activities of daily living (ADL) and the instrumental activities of daily living (IADL), the composition of household and the state of health in general, the frequency of falls, as well as the need for counselling by descriptive statistics, the patient's knowledge about the available care services and satisfaction. The evaluation of the discharge management focused on re-hospitalisations, length of stay and costs.

In GEROS, an ICT-based geriatric support programme in Croatia, they mainly measure the frequency distribution of geriatric persons by diagnosis, clinical characteristic, level of risk factor (e.g., BMI, blood pressure), negative behaviour (e.g., unhealthy lifestyle, refusal of occupational therapy), medication used, level of mobility, degree of independence and level of care needed. Positive changes in these frequency distributions are indicative for the effectiveness of the elderly care. In addition, they record the proportion of patients in which fall risk, decubitus risk, nutritional risk, incontinence and functional status are assessed. The occurrence of events and complications like fractures, bedsores, decubitus, and malnutrition is also recorded. Other indicators include measures of service utilisation (e.g., number of patients in rehabilitation, number of patients in palliative care), number of contacts between professionals, and number of procedures done. It is recorded whether patients' expectations and their satisfaction with overall care are measured. Furthermore they record whether the quality of care is monitored, and whether there is a person responsible for quality of care.

In the German Casaplus case management programme they address persons older than 55 years, with multiple chronic conditions and a high risk for hospital admission within the next 12 month. Casaplus offers a case management service with a mandatory risk assessment, patient education and a 24/7 crisis management service. The programme aligns and coordinates care services mainly provided by nursing professionals. Outcome measurements primarily include hospital and other healthcare services utilisation, morbidity prevalence, fall incidence, and mortality. There is also a patient (satisfaction) survey addressing satisfaction with health, self-management abilities, relationship with the consultant, etc.

The Utrecht Proactive Primary Care Approach for Frail Elderly (U-PROFIT) in the Netherlands is a nurse-led intervention for frail elderly (>60) living at home. The care process in the U-PROFIT approach consists of two steps: 1) a screening that makes use of routinely collected data in Electronic Medical Records (EMRs) (U-PRIM), and 2) an elderly care nurse-led programme (U-CARE). In U-CARE, the elderly care nurse provides integrated and tailored care, by taking the findings from the holistic assessment and the preferences of the frail elderly and his/her informal caregiver to create an individualised care plan. This plan is carried out in collaboration (e.g., multidisciplinary team meetings are held) with the GP and other relevant disciplines (e.g., elderly care physicians, pharmacists and mental health services). The programme was initially implemented in the form of a cluster-randomised controlled trial, where the evaluation included activities of daily living (Katz-15), quality of life (EQ-5D, RAND-36), mortality, nursing home admission, emergency department admission, out-of-hours GP surgery visits, caregiver burden (visual analogue scale), caregiver quality of life, and cost-effectiveness. The currently ongoing wider implementation is monitored using clinical and

implementation data extracted from the electronic medical records, and a patient survey with general quality of life and well-being questions.

The care programme Care Chain Frail Elderly (CCFE) in the Netherlands also targets vulnerable older persons living at home with complex care needs. Unlike the programme above it is not based on screening but on a pro-active approach to case finding. Person-centred integrated care in the CCFE is mainly provided by a GP, a nurse practitioner specialised in elderly care, an elderly care physician and a district nurse. A holistic assessment of the frail elderly is conducted by the nurse practitioner during a home visit, on the basis of which an individual care plan is developed. There are regular multidisciplinary team meetings which are also attended by the frail older person and his or her informal caregiver themselves. The programme is funded by a bundled payment. Currently, the CCFE primarily uses process indicators to measure the progress of implementation. In addition, an ongoing evaluation is being conducted by the insurer who focuses on substitution of secondary to primary care, and the prevention of long-term institutional care. In addition the insurer assesses the quality of life of the frail elderly and his/her surrounding (e.g., informal caregiver), the appropriateness of care, in terms of efficiency, and how the care model is experienced. However, this is not formally measured but an impression of improvements is obtained in focus groups.

The Norwegian Learning Network for whole, coordinated and safe pathways (Learning networks) is a national programme targeting older persons newly enrolled in a home nursing service or short term stay in a nursing home, e.g., after hospital discharge. The aim is to improve pathways in the municipalities for older patients with recognised functional impairment, being new users of the municipal home care service or nursing home. Assessment of patient functioning, focus on ability rather than impairment, follow up of what matters to the patient, a designated coordinator, and early involvement of patients' GPs are core elements of the programme that has been implemented in 35 municipalities so far. Municipalities collect data on whether the service delivery items are provided, data from assessment tools and data on patient experience.

The Spanish Badalona Serveis Assistencials provides healthcare and social support services with a patient-centred approach through the Care Model for Patients with Complex Chronic Conditions programme. The target candidates for inclusion in the programme are frail, elderly citizens often with several chronic disorders. The main aims of the programme are to promote independent living by offering support to prevent institutionalisation and avoidable hospitalisation. Key performance indicators are hospitalisation rates, length of hospital stay, bed occupancy days, emergency visits, process outcomes (including compliance and adherence to the guidelines), clinical data, and operational costs of clinical services.

The Salford Integrated Care Programme in the UK is designed to improve care for the broad population of people with long-term conditions, with an initial focus on older people, targeting the population aged 65+ with long-term conditions. It consists of three broad interventions: i.e., 1) multidisciplinary groups that offer case management of the highest-risk patients by neighbourhood groups, 2) investments in community assets to promote social interaction and active lifestyle, and 3) a centralised telephone hub to help with navigating services and self-management. Like in South Somerset the key outcomes that are used to measure the success of the programme are taken from the Hospital Episode Statistics and the GP patient survey. The Salford programme has been evaluated in the CLASSIC study that included a wide range of patient reported outcome and experience measures including health literacy, the Patient Assessment of Chronic Illness scale (PACIC), the Patient Activation Measurement (PAM), the experience with Long-Term Care questionnaire (LTC-6), the Mental Health Inventory (MHI-5), the WHO Quality of Life Questionnaire, the ICE-CAP-O for well-being, the EQ-5D, the SDSCA for self-care activities, the ENRICHED Social Support Inventory, and the Multi-morbidity Illness Perception Scale.

Palliative care/oncology programmes (in Croatia and Hungary)

In the palliative care programme in Croatia they primarily record whether a certain component of the palliative care programme is implemented. These components include for example the presence of a (mobile) palliative care team, the involvement of volunteers, the presence of educational plans for the nurses, a plan to further develop the palliative care service, a system for the identification of patients requiring palliative care, the type of palliative home services offered, existence of an adequate space for private communication, and the existence of a standardised procedure to

inform the family when the patient has died. They further monitor the number of service users, the number of services provided, the number of contacts between providers, the distance that the mobile palliative care team has to travel and the costs. Mortality and morbidity are recorded as well as functional status and overall satisfaction.

The Palliative Care Consult Service programme is the first initiative in Hungary to provide palliative care within an acute care hospital. The multidisciplinary team of the programme serves as a bridge between the clinical departments, home-based hospice-palliative care, institutional hospice care and home-based social care to achieve a higher level of coordination in the process of palliative care for seriously-ill patients. Holistic assessment of the patient's need is a core element of the programme, which covers not only clinical information but also physical and mental status, pain, other symptoms as well as performance status, social, spiritual and cultural aspects. The assessment aims to offer a treatment plan in line with the preferences of the patient and the family members. The following indicators are regularly monitored: number of consultations requested by clinical departments, reasons for referral (symptom management, organisation of palliative home care or inpatient care, psychosocial support), time-data on entering and leaving the palliative care process (average time between admission and consultation referral, average time between consultation and transfer to home-care, average time between consultation and transfer on inpatient hospice-care, average time of patient's death within the Medical Centre after consultation), and leading symptoms at enrolment: pain, cachexia, dyspnoea, confusion, exsiccation, bleeding, constipation/diarrhoea, nausea/vomiting.

The Onkonetwork in Hungary targets newly diagnosed patients with solid tumours. The enrolled population has a high rate of hypertension, cardiovascular diseases, or diabetes in general, while an increased rate of additional chronic comorbidities is observed in specific cancer types (e.g., musculoskeletal diseases including osteoporosis in breast cancer patients, or chronic liver disease and chronic alcoholism in rectal cancer patients). Some of these chronic comorbid conditions influence the diagnostic protocol and therapy selection in cancer patients. Outcome measurement focuses on biomedical and clinical outcomes extracted from medical patient records (progression of cancer, occurrence of complications), use of specific treatments and services, and mortality. More specifically, the data collection in the ICT system OncoLogistic covers healthcare events throughout all departments of the Centre with their timelines, medical decisions with their rationale, and the full related medical documentation including the results of diagnostics, and inpatient and outpatient service delivery reports. At hospital discharge a general patient satisfaction questionnaire that is not specific for Onkonetwork is administered that contains questions about the provision of information, communication, waiting times, access to services, and general satisfaction.

Programmes targeting persons with problems in multiple life domains (in Austria, Norway and the Netherlands)

The Sociomedical Centre Liebenau in Graz, provides a wide variety of integrated services in the fields of mental, social and physical health care for the entire population in this relatively deprived district of Austria. Services include diagnosis and treatment of chronic conditions (e.g., medication, psychotherapy etc.), various counselling services, support with administrative and legal issues, mobile psychosocial assistance, cooperation with mobile long-term care services to support home care and physiotherapy. There is no systematic registration of outcomes data.

The 'Better Together in Amsterdam North' programme in the Netherlands targets persons with complex needs in multiple life domains. The programme includes a triage with the Self-Sufficiency Matrix which identifies problems in the following life domains: finances, daily activities, housing, relationships at home, mental health, physical health, addiction, activities of daily living, social network, social participation and justice. When case management is required, care is integrated and coordinated, an individualised care plan is drawn up together with the person, and progress is routinely monitored by the case manager. The person of interest is actively involved, and a focus is placed on his/her own abilities in solving problems. The programme is evaluated using a wide range of indicators, including the level of participation in the programme, the level of societal participation, the Self-Sufficiency Matrix, perceived general health, the presence of 15 types of chronic illnesses, the amount of disability and discomfort from these illnesses and treatment and medication used, mental health, vitality, lifestyle, self-efficacy, a question about the satisfaction with care providers, costs and absence from work.

Medically Assisted Rehabilitation (MAR Bergen) is an interdisciplinary specialised treatment programme for opioid addiction at Haukeland University Hospital, Health Enterprise Bergen. Substitution treatment (i.e., requisition of

addictive medicine in a fixed dose) is a core component of the programme, and considered as an 'entrance ticket' to an overall rehabilitation pathway. The patients are in a phase where survival is the key objective, and the programme aims to support patients in changing their opioid intakes. The patients have typically several diagnoses, mental and physical, in addition to addiction, and they have often problematic living conditions. There has been no systematic evaluation, but some medical consequences have been investigated. However, from 2017 onwards individual data will be collected systematically, and a survey will be carried out. The Bergen Addiction Research group also aims to establish a Biobank.

Reflecting on these outcomes and indicators, we observed that many indicators were highly specific to the target population, the type of programme and the context or system in which they were embedded. Countries differ in the 'stage' of their transition to more integrated care systems. This probably explains why CEE countries, which are in an earlier stage of this transition, focus on improving mortality and medical outcomes. They do so in disease areas where better integration within the healthcare sector may generate the highest gains within a relatively short time horizon (i.e., oncology and palliative care). In contrast, countries in a more advanced stage of this transition may focus on integrating and aligning services for an entire population in a certain geographic area or for a very difficult subgroup, like patients with problems in multiple life domains who benefit from the integration of health and social care.

We observed that across the types of programmes and countries, the majority of indicators are extracted from routine organisational and system-level databases. Examples include population-level health indicators such as mortality and incidence of disease, and service proxies of health outcomes such as hospital admissions for conditions considered avoidable by good ambulatory care. The use of healthcare utilisation indicators as proxies of health outcomes was observed in many programmes. Only several programmes review the frequency distribution of risk factors, diseases and clinical characteristics in their population to monitor effects of the programmes.

We also observed a relatively large number of structural indicators to assess whether some basic conditions, and important components of integrated care are present or not. Examples include the presence of a shared information system or a professional with particular skills (e.g., elderly care nurse). There were no indicators that went beyond a simple binary assessment of how well certain components do indeed support the integration of service delivery.

We further observed the use of measures that are indicative of the level of implementation of integrated care, such as the proportion of programme participants that has an individual care plan, or the proportion discussed in a multi-disciplinary team meeting.

Although all of these indicators provide useful insights in certain aspects of integrated service delivery, looking back at **Figure 2**, these pertain to the system level and the objective categorisations. The SELFIE partners agreed on the need for additional outcome indicators, capturing patient-reported health and well-being outcomes and patient-reported experience measures. In some cases these are present among the currently measured outcomes, but these often attempt to capture 'quality of life overall' or 'satisfaction overall' in a global sense. Satisfaction data are sometimes extracted from routine patient satisfaction surveys. In some cases these include questions relevant to integration of care, such as the patient GP survey in the UK, but general hospital care satisfaction surveys that are not specifically addressing the aims of a programme provide less useful insight into the effectiveness of a programme. Only in situations where a separate scientific evaluation of a programme was conducted, do we observe a broader use of patient-reported health, well-being and experience measures. However, even then there is not always a specific focus on the issues most relevant for people with multi-morbidity.

4.5. Long-list of candidate outcomes

From the four sources, i.e., scientific and grey literature, national stakeholder meetings, focus groups with persons with multi-morbidity, and outcomes currently measured in the 17 integrated care programmes, we created the following long-list of 82 candidate outcomes. We clustered these outcomes into higher-level concepts and categorised them according to the Triple Aim. This is shown below.

Health and well-being

- **Mortality;** mortality and life expectancy
- **Physical well-being;** energy and fatigue, pain and discomfort, physical mobility, work ability, activities of daily functioning (ADL), disability, biomedical outcomes
- **Psychological well-being;** cognitive functioning, anxiety and depression, stress, worrying, listlessness, self-esteem, loneliness, suicide, conscience, feeling of guilt, general mental health well-being, feeling disabled
- **Social well-being;** respect from others (discrimination, stigmatization, empathy), maintaining social status, social relationships, social participation, social support (associations of patients, family support), social expectations, social status
- **Emotional well-being;** feeling safe, enjoyment of life, maintaining dignity, living comfortably, creativity, daily structure, being active, self-confidence
- **Generic health-related quality of life**
- **Frailty**
- **Caregiver burden**
- **Self-management:** general self-management abilities, investment behaviour (in future health and well-being), self-efficacy, resilience, coping, health literacy, compliance/adherence to treatment, lifestyle (health risk appraisal, physical activity, smoking, diet, drugs/alcohol use), self-sufficiency, autonomy (maintaining independence, independence on medical aids)

Experience with care

- **Person centeredness**; shared decision making, holistic assessment, tailored care, individualised care planning (goal attainment) , good communication, respectful interaction between provider-patient, good/clear information/explanation, empathy
- **Integration and coordination of care**; named coordinator, team work and collaboration between care providers, shared information between professionals (and patients), clear responsibility and accountability
- **Continuity of care**; advance care planning, pro-active, prevention oriented care, transfer care, after care, continuity
- **Knowledge and skills of care provider / caregivers**
- **Access to care**; geographical access, physical access, timely access, equal access
- **Satisfaction**; patient satisfaction with care process, patient satisfaction with the care quality/facilities, informal caregiver satisfaction with care process, professional satisfaction with care process

Costs

- **Costs of informal care**;
- **Costs of health and social care utilisation**; health care costs, social care costs
- **Costs of unplanned and emergency care**
- **Costs borne by patients for disease-related out-of-pocket expenses**; travel and parking costs, service and support coverage
- **Productivity costs**; absenteeism and presentism
- **Programme costs**; development costs and operating costs

5. Resulting lists of outcome measures

As described in the methods chapter, the long-list of potential outcomes had to be reduced to a core set of outcomes for which we will elicit weights for the MCDA. The outcomes in the core set had to meet our pre-defined conditions (see **Chapter 3.1.2.**). A draft of the core set of outcomes was created by the SELFIE-EUR team. The researchers from the SELFIE University in Bergen team provided feedback on the draft core set of outcomes. This led to an adapted draft core set that was presented to and discussed with each of the SELFIE partners at the SELFIE Steering Committee Meeting in October 2016. This led to a second revision of the core set that was discussed with the SELFIE partners over email and during teleconferences until consensus was reached.

The number of outcomes that can be included in the core set is limited because the chosen weight-elicitation method, i.e., a Discrete Choice Experiment (DCE), should avoid cognitive overload in the choice scenarios (see **WP4 Deliverable Report 2**). Therefore, it was decided during the SELFIE Steering Committee Meeting in October 2016 that we would define programme-type specific outcomes in addition to the core set. To keep the weight-elicitation method feasible, we grouped the 17 integrated care programmes selected for further empirical evaluation in SELFIE into 4 groups, i.e., population health management programmes, programmes targeting frail elderly, palliative care / oncology programmes, and programmes targeting persons with problems in multiple life domains. For each type of programme we defined a small number of additional outcome measures, for which we will also elicit weights, using a simpler weight-elicitation method, i.e., Swing Weighting. The choice for these programme-type specific additional outcomes was driven by the target group, focus, and scale of the programme. Furthermore, these outcomes should more closely line up with the specific aims of such programmes. Defining these programme outcomes was driven by discussions between the SELFIE partners and programme organisers about those outcomes most relevant to measure the impact of their programmes.

Both the core set of outcomes and the programme-type specific outcomes will be presented in this chapter. All of these outcomes were defined at a conceptual level in order to allow the use of different instruments or indicators to measure a particular outcome.

5.1. Core set of outcomes

The core set of outcomes includes physical functioning, psychological well-being, social relationships and participation, enjoyment of life and resilience (covering health/well-being aim), person-centeredness and continuity of care (covering experience with care) and total health and social care costs.

5.1.1. Health and well-being

To measure the improvement in health and well-being, we included five outcomes that are further defined below. The outcomes physical functioning and psychological well-being are included because these are generally accepted as important outcomes to measure health and well-being. These are the more traditional health and well-being outcomes that are applicable in persons with all different types of multi-morbidities. The other three outcomes, i.e., enjoyment of life, social relationships and participation, and resilience, were included in the core set because especially the focus groups demonstrated that persons with multi-morbidity place a lot of value on these outcomes. These aspects go beyond the traditional 'health' outcomes and touch upon the wider aspects of well-being. Especially in vulnerable groups it is likely that these aspects are more likely to change as a result of an integrated care programme, whereas it might be an 'outcome' that health (in the traditional clinical sense) remains stable.

Physical functioning

In SELFIE we define physical functioning as being in acceptable physical health and being able to do daily activities without needing assistance. These can influence the degree of independent living and subsequently the level of assistance a person might need.⁸⁶

In SELFIE we focus on both general physical health and on activities of daily living (ADL) in broad terms. The reason that these two facets of physical functioning are included is because of the variety of programmes that will be evaluated in SELFIE. In healthier populations (e.g., in population health management programmes) general physical health is the outcome of interest. In more vulnerable groups (e.g., frail elderly) general physical health may not be responsive to change, and thus we focus more specifically on ADL.

Activities of Daily Living, in SELFIE, pertains to both basic ADL (bADL) and instrumental activities of daily living (iADL). While bADL includes the basic activities that are necessary to live independently (e.g., eating, bathing, dressing, toileting, walking, and continence), iADL includes the more complex activities of daily living pertaining to domestic care and community participation that support an independent life style (e.g., shopping, cooking, housekeeping, laundry, use of transportation, managing money, managing medication, and use of the telephone).⁸⁷

Psychological well-being

Psychological well-being can be defined as positive affective states (e.g., happiness, optimism, hopefulness) and being free from fear, anxiety, stress, depression, and other negative states.^{66,88} In SELFIE we define psychological well-being as the absence of stress, worrying, listlessness, anxiety, and feeling down. It is important to realise that the presence of these symptoms can occur with and without clinical diagnosis of psychological disorders like anxiety or depression.

For both physical functioning and psychological well-being we have consciously chosen to label these in the positive sense: functioning and well-being, as opposed to dis-functioning, problems, or disorders. This was done to align our SELFIE concepts to the ‘positive health’ movement.

Social participation and relationships

Social relationships and participation can be defined as positive experiences via social contacts, contributing to society (e.g., volunteer work, employment), or receiving from society (e.g., having company). Other examples include going to church or clubs (e.g., sports, games).⁸⁹ In SELFIE we define social participation/relationships as having meaningful connections with others, (e.g., family, friends, neighbours) as desired. We specifically did not focus on the quantity of social relationships or participation or that static level thereof, but focus on the personal experience of these connections.

Enjoyment of life

Enjoyment of life can be defined as a cognitive-judgemental aspect of emotional well-being.⁹⁰ This may pertain to a reflection (i.e., judgement) of one’s own situation/life, and not an expression of emotion or symptoms; to what extent is an individual satisfied with his life, to what extent does the

quality of life meet his or her needs? It may also pertain to the ability and opportunity to enjoy life and be happy. In SELFIE we define enjoyment of life as having pleasure and happiness in life. Especially this concept of enjoyment of life came forth during the focus groups. Persons with multi-morbidity mentioned when defining good health what it really comes down to for them is the ability to enjoy their lives.

Resilience

Resilience refers to the capability to successfully adjust, maintain, and restore one's integrity, equilibrium, and sense of well-being in the face of adversity.⁹¹ In SELFIE we define resilience as the ability to recover from or adjust to difficulties and to restore one's equilibrium. This concept was initially placed under the higher-level concept self-management because of its association with coping. However, self-management was considered too broad and several programmes in SELFIE did not specifically aim for an improvement in this concept. During the focus groups and in discussions with SELFIE partners it was also brought up that self-management might have a paternalistic connotation: it is not possible for everyone to self-manage. Instead, there should be attention for personal capabilities. For this reason we focused on what was considered to be an important capability and starting point to dealing with multiple health- and social problems: resilience.

5.1.2. Experience with care

To measure the improvement in experience with care, we included two outcomes in our core set, namely (1) person-centeredness and (2) continuity of care. It was difficult to reduce outcomes from the long-list of experience with care to only these two outcomes for several reasons. First, from the literature we extracted a broad range of experience with care outcomes, but virtually no indicators that were specifically developed to measure the impact of integrated care in persons with multi-morbidity. Secondly, the experience outcomes already measured in the 17 promising integrated care programmes were mainly objective and not subjective measures (see **Figure 2**). These were mostly process indicators, such as the percentage of persons with an individualised care plan. Thirdly, the stakeholders in the workshops and focus groups did not give a clear preference for specific experience outcomes. For this reason, we clustered narrower concepts into person-centeredness and continuity of care. We chose to include these outcomes in our core set because these are deemed especially relevant for persons with multi-morbidity.^{13,14} Moreover, these are umbrella

terms that cover a lot of relevant experience outcomes that were mentioned by the stakeholders and in the focus groups. It is important to note that some experience outcomes that were reported to be relevant from our focus groups were not included in our core set because these did not meet our conditions (see **Chapter 3.1.2.**). For example, we did not include access to care in our core set because that outcome did not meet the requirement of sensitivity to change within one year and we did not include knowledge and skills of care providers as this is more a structural indicator of a programme than a patient-reported experience measure. Below we give the definition of the two experience outcomes who were included in our core set.

Person-centeredness

In SELFIE, we define person-centeredness as care that matches an individual's needs, capabilities and preferences and whereby informed decisions are made jointly. Person-centeredness pertains to tailored care whereby care providers have a holistic understanding of the person's problems, preference, and needs. This care is respectful and supportive. There is good communication between patient- and provider, which forms the basis of shared decision-making.

Continuity of care

In SELFIE we define continuity of care as good collaboration, smooth transitions between caregivers, and no waste of time. This includes team continuity and cross-boundary continuity between organisations.⁹² Factors that might facilitate team continuity include clear responsibilities and accountability, a named coordinator, and shared information between providers. Continuity in the SELFIE definition pertains to both continuity between persons (i.e., care providers) and between organisations, teams, and centres.

The following sub-concepts of continuity of care are also included in the definition:

- *Transfer care*, which refers to the transition of individuals from one care setting to another (e.g., from hospital to primary care). Transfer care also includes the transition of care from a care organisation to home, which is also defined as “after-care”.⁹³
- *Advanced care planning*, which can be defined as planning in advance for decisions that may have to be made prior to incapability or at the end of life. People may choose to do this planning formally, by means of advance directives, or informally, through discussions with

family members, friends and health care and social service providers, or a combination of both.⁹³

- *Pro-active care*, which refers to a planned approach that aims to prevent a disease, reduce progression or minimise further suffering and deterioration.

5.1.3. Costs

In SELFIE we define costs as the total health and social care costs per participant in the programme, per year. These total costs include the programme costs and the costs of health and social care services utilisation, irrespective of who bears them. We do not include productivity costs or costs of informal care because estimates of these costs are unavailable in many of the SELFIE programmes. The latter may, however, be included in additional evaluation analyses. Costs will be addressed more extensively in **Chapter 6.3**.

5.2. Programme-type specific outcomes

In addition to the core set of eight outcomes described above, we have defined programme-type specific outcomes. These are defined across the four types of programmes:

1. Population health management programmes: activation and engagement, ambulatory care sensitive hospital admissions, and hospital re-admissions.
2. Programmes targeting frail elderly: autonomy, burden of medication, burden of informal care giving, living at home, and falls leading to an emergency room visit or hospital admission.
3. Palliative care / oncology programmes: mortality, pain and other symptoms, compassionate care, timely access to care, preferred place of death, and burden of informal caregiving.
4. Programmes targeting persons with problems in multiple life domains: self-sufficiency and justice costs.

An overview of these outcomes including their definition is provided in **Table 12**.

Table 12: *Programme-type specific outcomes*

Type of programme	Outcome
Population health management programmes	<p>Health and well-being</p> <ul style="list-style-type: none"> • <u>Activation & engagement</u> Defined as taking on the role of managing one's own health and care <p>Costs</p> <ul style="list-style-type: none"> • <u>Ambulatory care sensitive hospital admissions</u> Defined as the amount of hospital admissions that could have been avoided with better care • <u>Hospital re-admissions</u> Defined as the amount of persons who are re-admitted to a hospital within 30 days of their prior hospital discharge.
Programmes targeting frail elderly	<p>Health and well-being</p> <ul style="list-style-type: none"> • <u>Autonomy</u> Defined as remaining in charge and making own decisions on how one lives his/her own life <p>Experience with care</p> <ul style="list-style-type: none"> • <u>Burden of medication</u> Defined as the amount of burden medicines are (considering for example administering/taking the medicines, side effects, understanding their purpose and why they're being taken, worries about interaction between medicines, and expenses) • <u>Burden of informal caregiving</u> Defined as the stress of informal caregiving due to the energy it costs, the little time it leaves for own interests and recovery and the sadness over the fate of the supported person <p>Costs</p> <ul style="list-style-type: none"> • <u>Living at home</u> Defined as the amount of participants admitted to long-term institution care (for example a nursing home), during the programme • <u>Falls leading to hospital admissions</u> Defined as the proportion of frail elderly that is admitted to an emergency room or hospital because of a fall

Type of programme	Outcome
Palliative care/ Oncology programmes	<p>Health and well-being</p> <ul style="list-style-type: none"> • <u>Mortality</u> • <u>Pain and other symptoms</u> Defined as physical symptoms like pain, fatigue, nausea/vomiting, short of breath, appetite loss, constipation/diarrhoea, insomnia <p>Experience with care</p> <ul style="list-style-type: none"> • <u>Compassionate care</u> Defined as care that is provided in a warm, sensitive and dignified way with sympathy and respect • <u>Timely access to care</u> Defined as the time between referral and start of treatment or care of interest • <u>Preferred place of death</u> Defined as the amount of participants that pass away in the location of their preference (e.g., at home). • <u>Burden of informal caregiving</u> Defined as the stress of informal caregiving due to the energy it costs, the little time it leaves for own interests and recovery and the sadness over the fate of the supported person
Programmes targeting persons with problems in multiple life domains	<p>Health and well-being</p> <ul style="list-style-type: none"> • <u>Self-sufficiency</u> Defined as being financially in control to meet basic needs with little or no debts. <p>Costs</p> <ul style="list-style-type: none"> • <u>Justice costs</u> Defined as contact with justice system, such as with criminal justice services, nights in police cell, and court attendance

6. Main instruments to measure the Triple Aim

For the core set of outcomes and for the programme-type specific outcomes, we made recommendations for instruments that best operationalise the outcomes as defined in SELFIE. To this end, the literature was searched and a conceptual, feasibility, and methodological check was conducted to determine which instrument(s) could be recommended to assess each outcome. In this chapter we describe the selection process of the instruments and present detailed information on the recommended instruments for the core set of outcomes.

Based on the instruments and indicators deemed most appropriate, we developed the SELFIE questionnaire for the four types of integrated care programmes (see **Appendix 4**). Although each instrument provides a recommended recall period, for the purpose of SELFIE this has been harmonised to be three-months. Again, this is a recommendation and depending on the nature of the programme being evaluated this may be adapted. For example, a palliative care programme might focus on a shorter recall period because the follow-up period is shorter.

Because some programmes have already been measuring certain outcomes for years, and because this retrospective data is of great value, in SELFIE we permit the use of different instruments and indicators to measure the same outcome.

6.1. Health and well-being

In the dimension health and well-being, the following five outcomes are in our core set, namely (1) physical functioning; (2) psychological well-being; (3) enjoyment of life, (4) social relationships and participation, and (5) resilience. Instruments to operationalise these are described below.

6.1.1. Physical functioning

There is a tremendous amount of instruments available to measure physical functioning. Thus for SELFIE, we started to search for instruments that are specifically relevant for multi-morbidity. In PubMed we found a review on the association between multi-morbidity and functional decline.⁹⁴ Different validated outcome measures were used to measure functional decline in the 37 studies in this review. Approximately half (46%) used the Short-Form Health Survey 36 (SF-36/SF-12), followed by 19% that used the EuroQol-5 Dimensions (EQ-5D). Next to these generic instruments various, ADL scales were used as measure of physical functioning. Searching for specific instruments to measure ADL in PubMed resulted in several reviews which led us to four potential ADL instruments: the Katz-15, the Barthel Index, Bayer ADL scale, and the ADL-Q. Below we summarise several key features of these instruments to help inform our instrument recommendation.

Potential instruments

- **EQ-5D³⁶:**
 - 5 items with a 3 or 5 point Likert scale
 - Five domains: mobility, self-care, usual activities, pain/discomfort, anxiety/depression
- **SF-36³⁸:**
 - 36 items, various response options
 - Eight domains: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health
- **ADL & iADL: Katz-15⁹⁵:**
 - 15 items, response options: (1) dependent/ (0) independent
 - ADL items from Katz-6 (bathing, dressing, toileting, transference, continence, feeding), 7 items from the Lawton iADL instrument plus two extra items.

- **ADL & iADL: Barthel Index⁹⁶:**
 - 15 items, 2 response options: (a) dependent/independent or (b) 3-point scale: independent/mildly-dependent/fully dependent
 - Items: Bathing, dressing, toileting, transference, continence, feeding
- **iADL: Bayer ADL scale⁹⁷:**
 - 25 items, 10-point Likert scale, never – always
 - E.g., Does the person have difficulty with... “Managing everyday activities”, “Personal finances”, “Continuing after interruption”, “Doing things safely”
- **ADL & iADL: Activities of Daily Living Questionnaire (ADLQ)⁹⁸:**
 - 28 items, 6 domains: self-care, household care, shopping/money, employment/recreation, travel, communication, 4-point response scale, no problem/as usual – no longer/never
 - E.g., Bathing, Housekeeping, Managing finances, Mobility around the neighbourhood, Understanding

Preferable instrument(s)

Of the potential instruments, we included the physical functioning domain of the SF-36 in the SELFIE questionnaire because it covers our definition of physical functioning, it is a frequently used instrument to measure physical functioning among persons with multi-morbidity, it is a validated instrument translated into several languages, and it is a well-known instrument among the SELFIE partners. As an alternative, especially relevant for the frail elderly programmes and palliative/oncology programmes, we chose to include the Katz-15 because this covers both ADL and iADL and is a simple instrument to fill in. Detailed information about these instruments can be found in **Table 13** and **Table 14** below.

Table 13: Short Form 36 (SF-36)

General information	
Instruments' name	Short Form 36 (SF-36)
# of articles on instrument	Number of citations in PubMed: 3135
Author(s), year	Brazier et al. 1992
Population targeted	General population
Objectives	To develop a general health survey that is comprehensive and psychometrically sound, yet short enough to be practical for use in large scale studies of patients in practice settings
Main topic	General health
Domains	Vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health (mental health inventory)
Items	36 items with various response options
Time recall	No specific recall period (but in some domains there is a recall-period of 4-weeks)
Methodological quality	
	The validity and reliability of the instrument has been demonstrated in several publications throughout the years.
Feasibility & availability	
Scoring	Each scale is directly transformed into a 0-100 scale on the assumption that each question carries equal weight. The lower the score the more disability. The higher the score the less disability i.e., a score of zero is equivalent to maximum disability and a score of 100 is equivalent to no disability.
Language	The SF-36 has been translated and adapted to several languages, including: English, Spanish, German, Dutch, Hungarian, Norwegian, and Croatian.
Duration (time to complete)	It takes approximately 5-10 minutes to complete the 36 items
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	The SF-36 is free to use under conditions (see below).
Conditions of use (license fee)	<p>RAND grants permission to use RAND 36-Item Short Form Health Survey in accordance with the following conditions:</p> <ul style="list-style-type: none"> • Changes to the Health Survey may be made without the written permission of RAND. However, all such changes shall be clearly identified as having been made by the recipient. • The user of this Health Survey accepts full responsibility, and agrees to indemnify and hold RAND harmless, for the accuracy of any translations of the Health Survey into another language and for any errors, omissions, misinterpretations, or consequences thereof. • The user of this Health Survey accepts full responsibility, and agrees to indemnify and hold RAND harmless, for any consequences resulting from the use of the Health Survey. • The user of the 36-Item Health Survey will provide a credit line when printing and distributing this document acknowledging that it was developed at RAND as part of the Medical Outcomes Study. • No further written permission is needed for use of this Health Survey

Table 14: Katz-15

General information	
Instruments' name	Katz-15
# of articles on instrument	Number of citations in PubMed:20
Author(s), year	Laan et al. 2004
Population targeted	Community-dwelling older people
Objectives	Determining both basic and instrumental activities of daily living.
Main topic	ADL and iADL
Domains	15 domains: 6 domains from the Katz-6 ADL instrument (bathing, dressing, toileting, transference, continence, feeding), 7 domains from the Lawton iADL (using the telephone, shopping, preparing a meal, taking care of your house, travelling, taking medications, handling finances) instrument plus two extra domains (brushing your hair or shaving and walking)
Items	15 items with two response options yes(score=1) or no (score=0)
Time recall	No specific recall period
Methodological quality	
	Laan and colleagues found that the Katz-15 is internal consistent and strongly associated with quality of life measures (e.g., SF-36, EQ-5D, Frailty index) and moderately to strongly correlated with unfavourable health outcomes (e.g., hospitalisations, nursing home admissions, dead). ⁹⁵
Feasibility & availability	
Scoring	All response options of the items are linked to a score (yes=1, no=0) with higher scores representing greater dependency of the individual to perform daily activities.
Language	The Katz-15 has been translated in Dutch.
Duration (time to complete)	Unknown, although the authors reported that a strength of the Katz-15 is that it does not require a lot of time to answer ⁹⁵
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	The Katz-15 is free to use.
Conditions of use (license Fee)	Users need to refer to the article of Laan and colleagues ⁹⁵

6.1.2. Psychological well-being

A Google search for 'self-report mental health instruments' led us to find a recent review of self-report measures for assessing well-being in the BMJ Open.¹⁷ This review distinguished different dimensions of well-being and identified these according to: mental, social, physical, spiritual, activities and functioning, and personal circumstances. For this SELFIE core set concept, we looked at the mental well-being dimension. The review identified more specific facets of mental well-being and matched instruments to these. Considering our definition, we focused on 'overall psychological well-being' but also looked at instruments identified for anxiety, depression, and negative affect. For overall psychological well-being the review identified 13 instruments. Preference was given to instruments that were relatively short and conceptually matched our definition of psychological well-

being. This led, for example, to the exclusion of instruments focusing on personality, as it is not likely in SELFIE that this will be the focus of an intervention nor do we expect that this will change during the follow-up. Next, we selected instruments that had recently been updated (thus excluding instruments from <1990). We also did not include generic quality of life instruments with one psychological well-being indicator. Five instruments were selected from this review:

- Positive Functioning Inventory;⁹⁹
- Psychological General Well-Being Index;¹⁰⁰
- Short form 12 Health Survey, mental health component;¹⁰¹
- The five item Mental Health Inventory (MHI-5) of the Short form 36 Health Survey;¹⁰²
- Warwick-Edinburgh Mental Well-Being Scale-Short;¹⁰³

In a PubMed search for review papers on 'self-reported mental health instruments', a review on anxiety instruments was found.¹⁰⁴ In this review both generic anxiety questionnaires as well as more specific anxiety type questionnaires (e.g., test, social) were described. The questionnaires identified in this review pertain to symptoms, experiences, and screening and diagnosis. For SELFIE, we looked at the instruments identified in this review that were meant for more general anxiety symptoms. Two instruments from this review were selected: 1) the Hospital Anxiety and Depression Scale (HADS)⁵⁶ and 2) the Patient Health Questionnaire-4 (PHQ-4)¹⁰⁵. These two were selected because they cover both anxiety and depression concepts, are not meant to be used as clinical diagnosis tools, are short and easy to fill in, have moderate to good psychometric properties, and have norm data available. Below we summarise several key features of five psychological well-being and two anxiety instruments to help inform our instrument recommendation.

Potential instruments

- **Positive Functioning Inventory**⁹⁹
 - 12 items, 4 point Likert-scale: Never – Often
 - Domains: 6 items stem from a depression scale, 6 from an anxiety scale. Both these original scales had a mix of positive and negative items. The idea is that results can show both the negative side of the continuum as the positive side.

- **Psychological General Well-Being Index-Short**¹⁰⁰
 - 6 items, 6 point Likert-scale: not at all – extremely / all the time
 - Domains: 2 items from vitality, 1 from anxiety, depressed mood, self-control, and positive well-being
- **Short-Form 12 Health Survey – Mental Component Score**¹⁰¹
 - 12 items, various response options
 - Domains: general health, vitality (energy/fatigue), social functioning (as a result of limitations due to physical health or emotional problems), role limitations due to emotional problems, mental health (psychological distress, psychological well-being).
- **Warwick-Edinburgh Mental Well-Being Scale-Short**¹⁰³
 - 7 items, 5 point Likert-scale: none of the time – all of the time
 - Domains: the full 14-item scale covers both hedonic (increased pleasure, decreased pain, happiness) and eudemonic (self-actualisation, fully functioning, self-determination) perspectives of mental well-being. Does not cover spirituality or purpose in life. Mental well-being itself is assessed, and not its determinants. The 7-item short version focuses on eudemonic well-being, and thus more mental well-being as functioning as compared to feelings.
- **Hospital Anxiety and Depression Scale (HADS)**⁵⁶
 - 14 items, 4 point Likert-scale: varying (e.g., not at all – most of the time; not at all – nearly all of the time)
 - Domains: Anxiety (7 items) and depression (7 items)
- **Patient Health Questionnaire-4 (PHQ-4)**¹⁰⁵
 - 4 items, 4 point Likert scale: not at all – nearly every day
 - Domains: Anxiety (2 items), depression (2 items). Anxiety items stem from the Generalized Anxiety Disorder Scale (GAD-7), and the depression items from the Patient Health Questionnaire-2 (PHQ-2)
- **Mental Health Inventory (MHI-5) of the Short Form 36 (SF-36)**¹⁰²
 - 5 items, 6 point Likert scale: all of the time – none of the time
 - Both positive items (e.g., feeling happy) as negative items (e.g., feeling down).

Preferable instrument

Of the potential instruments, we include the MHI-5 domain of the SF-36 in the SELFIE questionnaire because it measures both positive and negative states of psychological well-being, it is a short instrument (only 5 items), it is a validated instrument translated into several languages, and it is frequently used. **Table 12** provides more information about the SF-36.

6.1.3. Social participation/relationships

In a PubMed search for review papers on ‘social participation and social support’, one review on social participation by Dalemans and colleagues¹⁰⁶ was found. In this review 12 instruments measuring aspects of participation were described in terms of feasibility, internal consistency, validity, and reliability. Three instruments from this review were selected as potential instruments in SELFIE: 1) Impact on Participation and Autonomy (IPA), 2) Participation Scale, and 3) Participation Objective, Participation Subjective (POPS). These instruments were selected because they did not only measure the quantity of social relationships and level of participation, but also the quality thereof.

Potential instruments

- **Impact on Participation and Autonomy (IPA)**¹⁰⁷
 - 40 items; individual’s perceived limitations in 32 items and problems with participation in 8 items.
 - 9 domains, including leisure and social life and relationships
- **Participation scale**¹⁰⁸
 - 18 items; First participants are asked whether they perceives their level of participation to be the same as peers. If a potential problem is indicated, they are asked how big this problem is.
 - 7 domains, including communication and interpersonal interactions
- **Participation Objective, Participation Subjective (POPS)**¹⁰⁹
 - 26 items
 - Participation objective: (all, most, some, none) “in a typical week, do you do/how many hours do you...?”

- Participation subjective: desired level (more, less, same) and importance (most, very, moderate, little, not)
- 5 domains, including interpersonal interactions and relationships, community, recreation and civic life.

Preferable instrument

Of the three potential instruments, we include the social life & relationships domain from the Impact on Participation and Autonomy (IPA) in the SELFIE questionnaire because the items of this domain have the best fit with the SELFIE definition of social participation.

Table 15: Impact on Participation and Autonomy (IPA)

General information	
Instruments' name	Impact on Participation and Autonomy (IPA)
# of articles on instrument	Number of citations in PubMed: 243
Author(s), year	Cardol et al. 1999
Population targeted	Adults with chronic diseases
Objectives	To evaluate the effect of rehabilitations and as part of rehabilitation research.
Main topic	Participation and autonomy
Domains	<p>A. Limitations in participation and autonomy in 5 domains:</p> <ul style="list-style-type: none"> • Autonomy indoors; • Family role; • Autonomy outdoors; • Social relations; • Work and educational opportunities <p>B. Problem experience in 9 domains:</p> <ul style="list-style-type: none"> • Mobility: getting around where and when you want; • Self-care; • Activities in and around the house; • Looking after your money; • Leisure; • Social life and relationships; <i>*This is the domain included in SELFIE</i> • Helping and supporting other people; • Paid or voluntary work; • Education and training.
Items	Individual's perceived limitations is covered in 32 items (on a 5-point scale [very good, good, fair, poor, very poor]) and problems with participation are covered in an additional 8 items (on a three-point scale [no problems, minor problems, major problems])
Time recall	No specific recall period
Methodological quality	
	There is evidence that the IPA is valid, reliable and responsive to change. Validation studies have been carried out in the Netherlands, the UK and Sweden using factor analysis, confirmatory factor analysis and Rasch analysis. ¹¹⁰⁻¹¹³
Feasibility & availability	
Scoring	<p>All response options of the items are linked to scores from zero to four with higher scores representing greater problem experience.</p> <p>Note: at least 75% of a subscale needs to be completed to calculate a score.</p>
Language	Original Dutch, translated into multiple languages, e.g., English, Norwegian, and German
Duration (time to complete)	20 minutes for the whole questionnaire
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	The IPA is free to all users
Conditions of use (license fee)	Users need to refer to the article of Cardol and colleagues ¹⁰⁷

6.1.4. Resilience

Different reviews on resilience were found in the literature, however, many were developed for adolescents. A slightly older review from 2011 by Windle and colleagues looked at the psychometric properties of 15 resilience scales for general and clinical populations.¹¹⁴ The strongest evidence was found for the Connor-Davidson Resilience Scale (CD-RISC), the Resilience Scale for Adults (RSA), and the Brief Resilience Scale (BRS). Due to the length of the RSA (33 items) this instrument is not further described. The BRS and CD-RISC (and its short version) are described below, for potential inclusion in the SELFIE questionnaire. An additional review by Cosco and colleagues from 2016 addressed resilience measures specifically for older (≥ 60 years) populations.¹¹⁵ This review compared the psychometric properties of the CD-RISC, the 10-item version thereof (CD-RISC10), the Resilience Scale (RS), and the shortened versions thereof (RS-5, RS-11), and the Brief Resilient Coping Scale (BRCS). The study found most support for the RS. It is important to note that this is the case for older populations. Due to the length of the original RS (25 items), only the CD-RISC10, BRS, and RS-5 are described further below.

Potential instruments

- **Connor-Davidson Resilience Scale – 10 item version (CD-RISC10)¹¹⁶**
 - 10-items, 5 point Likert scale (not true at all – true nearly all the time).
 - 2 domains – hardiness and persistence. Specific facets: able to adapt to change, can deal with whatever comes, tries to see humorous side of problems, coping with stress can strengthen me, tend to bounce back after illness or hardship, can achieve goals despite obstacles, can stay focused under pressure, not easily discouraged by failure, thinks of self as a strong person, can handle unpleasant feelings.
- **Brief Resilience Scale (BRS)¹¹⁷**
 - Looks at an individual's ability to 'bounce back' from stressful situations and adversity.
 - 6 items; 3 positive, 3 negative.
 - 5 point Likert scale (strongly disagree – strongly agree).
- **Resilience Scale – 5 item version (RS-5)¹¹⁸**
 - Original scale has 25 items, assesses resilience via the capacity to withstand stress and create meaning from challenges. Two domains: Personal Competence, Acceptance of Self and Life.

- Disagree – Agree scales, variations exist: 7, 5, and 4 point scales exist.
- 11- item and 5-item short scales exist.

Preferable instrument

Of the three potential instruments, we include the Brief Resilience Scale (BRS) in the SELFIE questionnaire because it is a short validated questionnaire that measures resilience with both positive and negative items. The items in this scale conceptually overlap with the SELFIE resilience definition.

Table 16: *Brief Resilience Scale (BRS)*

General information	
Instruments' name	Brief Resilience Scale (BRS)
# of articles on instrument	Number of citations in PubMed: 474
Author(s), year	Smith and colleagues 2008
Population targeted	Not specifically mentioned
Objectives	To assess the ability to bounce back or recover from stress
Main topic	Resilience
Domains	Positive and negative items
Items	6 items with a five-point scale (strongly disagree – strongly agree)
Time recall	No specific recall period
Methodological quality	
	The study of Smith and colleagues showed that the BRS is reliable and measures a unitary construct. Furthermore, they showed that the BRS is predictably related to personal characteristics, social relations, coping, and health in all samples. It was negatively related to anxiety, depression, negative affect, and physical symptoms when other resilience measures and optimism, social support, and Type D personality (high negative affect and high social inhibition) were controlled for.
Feasibility & availability	
Scoring	Add the responses varying from 1-5 for all six items giving a range from 6-30. Divide the sum by the total number of questions answered to yield a total score. A higher score indicates a higher level of resilience.
Language	English, Dutch and Spanish
Duration (time to complete)	Unknown
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	The BRS is free to all users
Conditions of use (license fee)	Users need to refer to the article of Smith and colleagues

6.1.5. Enjoyment of life

The review by Linton and colleagues on self-report measures for assessing well-being in the BMJ Open that was also used in the search for instruments for psychological well-being, was used to identify potential instruments to assess enjoyment of life.¹⁷ Instruments were looked at that pertained to the following sub-concepts defined in the review: 'Enjoyment', 'Life purpose and satisfaction', 'Life satisfaction', and 'Life satisfaction/self-actualisation'. Instruments that were very lengthy or old were not looked into. Two quality of life instruments were identified, the ICECAP-A on capability well-being for adults, and the ICECAP-O for older persons.¹¹⁹ These scales have one item/domain that is related specifically to enjoyment of life that may be relevant in SELFIE. Next, the 'Life Satisfaction Questionnaire-9'¹²⁰ was identified, which asks about the satisfaction of respondents with different facets of their life, the first being 'Life as a whole'. The respondent is asked 'How satisfactory are these different aspects of your life? Indicate the number that best describes your situation.' Answers are on a 6 point Likert scale 'Life as whole is...' 1- Very dissatisfying – 6-Very satisfying. Several other questionnaires were found that also assess life satisfaction, often alongside quality of life, as related to health, e.g., Questions on Life Satisfaction and the Self-Evaluated Quality Of Life Questionnaire. Another example is the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q, short version).¹²¹ This questionnaire in essence covers both life enjoyment and satisfaction, it asks about respondent's satisfaction with many specific life-domains, but also asks "How would you rate your overall life satisfaction and contentment during the past week?" Answers range from 1 (Very Poor) to 5 (Very Good). The Satisfaction with Life Scale (SWLS) was identified (which is part of the Public Health Surveillance Well-Being Scale) which has 5 items, one of which is simply 'I am satisfied with my life', that are scored on a 7 point Likert scale (1- strongly disagree, 7 – strongly agree).⁹⁰ Several potential instruments to measure enjoyment of life are shortly described below.

Potential instruments

- **ICECAP-O: Enjoyment & pleasure domain¹¹⁹**
 - "Please indicate which statements best describe your overall quality of life at the moment by placing a tick in ONE box for each of the five groups below."
 - I can have all of the enjoyment and pleasure that I want
 - I can have a lot of the enjoyment and pleasure that I want

- I can have a little of the enjoyment and pleasure that I want
 - I cannot have any of the enjoyment and pleasure that I want
- **Life Satisfaction Questionnaire-9 (LSQ-9) / Quality of Life Enjoyment and Satisfaction Questionnaire**
 - Two instruments that each have similar single items that could be used:
 - LSQ-9: ‘Life as whole is...’ 1- Very dissatisfying – 6-Very satisfying
 - Q-LES-Q-SF: ‘How would you rate your overall life satisfaction and contentment during the past week?’ 1 (Very Poor) - 5 (Very Good).
- **Satisfaction With Life Questionnaire (SWLQ)⁹⁰**
 - 5 items: In most ways my life is close to my ideal / The conditions of my life are excellent / *I am satisfied with my life* / So far I have gotten the important things I want in life / If I could live my life over, I would change almost nothing.
 - 7 point Likert scale (1 – strongly disagree, 7 – strongly agree)

Preferable instrument

Of these potential instruments, we include enjoyment and pleasure domain from the ICECAP-O in the SELFIE questionnaire because it covers our SELFIE definition of enjoyment of life with one short item, and the ICECAP-O is translated into several languages (including Spanish, German, and Dutch). After a discussion with our partners, we realised that although “enjoyment of life” is an important outcome for persons with multi-morbidity in general, this outcome may be inappropriate for palliative patients. Therefore, as an alternative, for the oncology and palliative programmes, we chose to include one item from the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q, short version). Detailed information about the ICECAP-O instrument can be found in **Table 17** below.

Table 17: ICECAP-O

General information	
Instruments' name	Investigating Choice Experiments for the Preferences of Older People (ICECAP-O)
# of articles on instrument	Number of citations in PubMed: 246
Author(s), year	Coast et al. 2008
Population targeted	Older population
Objectives	To provide information for decisions about the allocation of resources across health and social care, rather than just across health
Main topic	Capability (what individuals can do instead of focussing on functioning, i.e., what individuals actually do)
Domains	Five domains: attachment, Security, Role, Enjoyment, Control
Items	5 items with a four point Likert scale (none, a little, a lot, all)
Time recall	No specific recall period
Methodological quality	
	A study performed by Makai and colleagues demonstrated that the ICECAP-O has good convergent validity with well-being measures (e.g., Cantril's ladder) as well as health measures (e.g., iADL, EQ-5D) and they showed that the ICECAP-O was able to discriminate between various groups of post-hospitalised older people (e.g., young vs. old, multi-morbid vs. single-morbid). ³⁵
Feasibility & availability	
Scoring	Each domain can be scored on four levels, resulting in 1024 possible "capability states". The values for each attribute is obtained by using best-worst scaling. Values were then rescaled such that the final tariffs have values between 0 (no capability; score 11111) and 1 (full capability; score 44444). The STATA code to score the ICECAP-O instrument can be found here
Language	The ICECAP-O has been translated into several languages including Spanish, German, Dutch, and Norwegian.
Duration (time to complete)	It takes approximately 5 minutes to complete the 36 items
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	The ICECAP-O is free to use under conditions (see below).
Conditions of use (license fee)	The ICECAP-O is free to use, but users need to fill in the registration form .

6.2. Experience with care

In the dimension experience with care, two outcomes are included in the SELFIE core set, namely (1) person-centeredness and (2) continuity of care. Below we describe the selection process and our recommended instruments to measure these outcomes.

6.2.1. Person-centeredness

To find instruments to measure person-centeredness, we searched in PubMed by using the following search terms: tailored care, shared-decision making, and patient-centeredness. Based on these searches, one potential relevant instrument was identified: the Patient Assessment of Integrated Elderly Care (PAIEC). Furthermore, we asked experts for relevant (new) instruments to measure person-centeredness. These experts recommended the Person Centred Coordinated Care Experiences Questionnaire (P3CEQ). These two potential instruments to measure person-centeredness are shortly described below.

Potential instruments

- **Patient Assessment of Integrated Elderly Care (PAIEC)**¹²²
 - 20 items 5-point scale (none of the time – always)
 - 4 domains, biological, psychological, social and health-care domains
- **Person Centered Coordinated Care Experiences Questionnaire (P3CEQ)**¹⁶
 - 11 items 4-point scale and 5 point-scale
 - 8 domains: Goal setting, empowerment/activation, self-management, carer involvement, care planning, decision making, information and communication, knowledge of patient

Preferable instrument

The P3CEQ was chosen because this instrument covers the SELFIE definition of person-centeredness and because the instrument was developed through extensive stakeholder engagement with patients, commissioners, and practitioners. Detailed information about the P3CEQ can be found in **Table 18** below.

Table 18: P3CEQ

General information	
Instruments' name	P3CEQ
# of articles on instrument	The article about the P3CEQ is currently under review
Author(s), year	2015
Population targeted	Long term condition / adults
Objectives	To measure aspects of Person Centred Coordinated Care
Main topic	Patient experiences of care delivery
Domains	Three domains: Experience of Person Centred Care (PC), Experiences of Care Coordination and Continuity (CC), and confidence to self-manage (CSM)
Items	11
Time recall	Open
Methodological quality	
	Face & Content validity established Co-developed with patients
Feasibility & availability	
Scoring	Scores for each question are summed to provide a subscale score as follows: P3CEQ-PC: items 1) 2) 3) 4) 9) and 10). Scores range from 6 – 24 with a higher score indicating a good experience. P3C – CC: items 5) 6) 7) 8a) 8b) 8c) 8d). Scores range from 4 – 22 with a higher score indicating a good experience. P3C – CSM: item 11. Scores range from 1 – 4. Scores range from 1 = no confidence, 2 = not too much confidence, 3 = some confidence and 4 = very confident. A composite score can be achieved by summing the 3 subscales: PC + CC + CSM with a range from 11 – 50.
Language	English, Currently being translated into Estonian, German, Spanish, Norwegian & Dutch.
Duration (time to complete)	Unknown
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	No copyright, notification to authors about use necessary.
Conditions of use (license fee)	Users need to feel in the user agreement.

6.2.2. Continuity of care

In a PubMed search for review papers on “continuity of care”, one review by Uijen and colleagues⁹² was found. In this review 21 instruments measuring continuity of care were identified and assessed in terms of quality. Unfortunately, none of the instruments were self-report measures. Looking further in Google, PubMed, and the review from WP1 resulted in three potentially relevant instruments to measure the experience of care: the Nijmegen Continuity Questionnaire (NCQ), the Client Perceptions of Coordination Questionnaire (CPCQ), and the Patient Continuity of Care Questionnaire (PCCQ).

Potential instruments

- **Nijmegen Continuity Questionnaire (NCQ)¹²³**
 - 28 items, 5-point scale (strongly agree -strongly disagree).
 - Three domains, measures continuity of care between and within one care organisation.
 - Continuity of care between primary and secondary care
- **Client Perceptions of Coordination Questionnaire (CPCQ)¹²⁴**
 - 31 items, various scales
 - 6 domains, including access to care
- **Patient Continuity of Care Questionnaire (PCCQ)¹²⁵**
 - 27 items, 5-point scale (strongly disagree –strongly agree)
 - 6 domains, including follow-up, information transfer.

Preferable instrument

Items from the Nijmegen Continuity Questionnaire were chosen because the NCQ covers the SELFIE definition of continuity of care and because it is based on a systematic literature review and analysis of 30 patient interviews. We chose 4 relevant items from the NCQ. We supplemented this with one item from the CPCQ to fully cover the SELFIE definition of continuity of care. The latter was added to also capture timely access. Detailed information about the NCQ can be found in **Table 19** below.

Table 19: Nijmegen Continuity Questionnaire (NCQ)

General information	
Instruments' name	Nijmegen Continuity Questionnaire
# of articles on instrument	38
Author(s), year	Uijen and colleagues 2011
Population targeted	Patients with a chronic disease
Objectives	A generic questionnaire to measure continuity of care from the patient's perspective across primary and secondary care settings.
Main topic	Continuity of care
Domains	Personal continuity: care provider knows me, Personal continuity: care provider shows commitment and Team/cross-boundary continuity
Items	28 items (In the SELFIE questionnaire we included 4 items)
Time recall	12 months
Methodological quality	
	Construct validity was further supported by the high internal consistency of the subscales. The moderate correlations between "personal continuity" and "team/cross-boundary continuity" provide evidence of good discriminant validity. The high correlation (0.61) between "personal continuity: care provider knows me" and "personal continuity: care provider shows commitment" was expected because they both measure aspects of personal continuity
Feasibility & availability	
Scoring	
Language	Dutch, English
Duration (time to complete)	5-10 minutes
Requirements (administration mode)	Individuals can fill out the questionnaire without assistance
Copyright	
Conditions of use (license fee)	

6.3. Costs

To operationalise the third aim of the Triple Aim we included ‘total annual health care and social care costs per participant’ as an outcome in the SELFIE core set. In this chapter we describe the steps and considerations to measure this outcome.

6.3.1. Perspective of the economic evaluation

First, it is essential to specify the perspective or viewpoint of the cost analysis.^{1,126} Various perspectives are possible, including a societal, healthcare, payer, provider, and patient perspective. What is considered an important cost to include in the analysis from one point of view, may not be relevant from another point of view. For example, the travel and parking costs are relevant from the patient’s point of view but not from the health care insurer’s point of view. The societal perspective includes the direct health and social care costs, co-payments and other out-of-pocket costs by the patients, the costs of informal caregiving, the indirect costs of productivity loss, and the additional health and social care costs during life years that are gained when the integrated care programme improves survival. Theoretically it is best to start with the broadest, i.e., societal, perspective which can then be followed by analyses from other perspectives. The societal perspective includes all costs irrespective of who actually bears them. The other perspectives, especially that of the payer and the organisation(s) providing the integrated care programme, can provide relevant insights into economic arguments to support the decision-making process on reimbursement, continuation, extension, and/or wider implementation of integrated care programmes. In SELFIE we advocate the use of multiple viewpoints. However, we expect that it will be difficult to apply a societal viewpoint because we may not be able to gain insight into cost categories needed for this, such as the cost of productivity loss due to absence from work or the costs of informal caregiving. Especially the programmes for which the evaluation is based on data extracted from available registry data sources and where no primary data collection is done will not be able to estimate these two cost categories.

6.3.2. Types of costs

After the perspective has been chosen, it is important to identify all relevant costs. In SELFIE total health- and social care costs per participant in a programme per year are included as a core set outcome. This includes all costs covered by the healthcare budget or the social care budget. This encompasses the cost of the integrated care programme and all health and social care costs influenced by the programme. The latter refers to medication costs, costs of contacts with care providers (e.g., GP, medical specialist, nurse, case manager, physiotherapist, dietician, podiatrist, occupational therapist, and counsellors), home care, hospital admissions, emergency department visits, ambulance rides, long-term institutional care, social and welfare. The SELFIE consortium is instructed to describe the integrated care process in detail in order to identify the relevant costs that should be included in the evaluations.¹²⁶

One cost driver that is often neglected but is essential to determine if a programme generates net cost savings are the programme costs.¹²⁷ Programme costs consist of development and implementation costs, where the development costs include for example the costs of designing the programme, training of the care providers and the ICT costs, and the implementation costs include the costs of operating the programme, i.e., the costs of triage, multidisciplinary team meetings, and coordination and management costs. It may not always be possible to make a strict distinction between the development and implementation costs because the integrated care programmes are continuously being improved upon and adapted. In SELFIE, it may not be feasible to estimate the development costs of programmes that were developed many years ago. Development and implementation costs are often fixed costs that do not vary with the number of patients included. To include them in the total annual health and social care costs per patient, they need to be amortized over their lifespan and divided by the number of participants included in the programme.

6.3.3. Time horizon

Thirdly, the time horizon of the cost calculation should be chosen such that it includes all costs that are relevant to the integrated care programme.¹²⁶ In SELFIE, this will vary between the programmes because some, like the palliative care programmes, require a shorter time horizon than others, like the population health management programmes. The weights, however, will be elicited for the one year costs per participant.

6.3.4. Operationalising health and social care utilisation

Health and social care costs can be estimated by multiplying health and social care service utilisation in terms of frequency/amounts with the unit costs of these types of care. In the evaluations where primary data collection is possible a questionnaire can be used to measure health and social care utilisation. There are various (validated) questionnaires in the literature to measure [parts of] health and social care utilisation. For example, the Client Service Receipt Inventory (CSRI) measures health and social care utilisation and the iMTA Medical Consumption Questionnaire measures health care utilisation.^{128,129} However, unlike patient-reported outcomes and experience questionnaires, care utilisation questionnaires need to be adapted to the context in which the integrated care programmes are implemented. The questions need to be adapted to the specific services that are offered in the respondent's context: within the programme itself and in the national health- and social care system. For example, some new professional roles may not [yet] exist in certain systems. For those evaluations in SELFIE where primary data collection is possible, we have developed a questionnaire to measure self-reported health and social care utilisation (**see Appendix 4, Part III costs**). This is intended as a starting point from which the partners in the SELFIE consortium can start to adapt the questionnaire to the programme and the context in which it is being evaluated. We have also recommended partners to investigate what patient-level service utilisation can be obtained from registration data (see below). When this is possible, the number of questions on health and social care utilisation in the SELFIE questionnaire can be reduced. This pertains in particular to the costs of medication use. Namely, to estimate the medication costs it is necessary to ask detailed questions, such as on the type of medication, daily dosage, and duration of use. It is thus worth investigating if this can be avoided by extracting individual-level data from pharmacy information systems.

Alongside self-reported costs, registration data can be used to estimate health and social care utilisation and/or costs at a patient-level. Examples include claims data from health insurers and other payers, (financial-) administrative databases from health and social care organisations and electronic medical records from hospitals and general practices. The availability and completeness of registration data varies per country and per programme. It is also important to note that the resource utilisation data that can be extracted from these sources are often not detailed enough for a complete cost calculation. For example, electronic medication records in primary care may indicate

that a patient is referred for outpatient hospital care, but the number of contacts with specialists in outpatient hospital care is not recorded in the medical records.

In some countries, national databases exist from which patient-level resource utilisation or cost data can be obtained. Examples include the National Prescription Database in Norway, that is a pseudonymous central health database at the National Institute of Public Health that includes information on all deliveries of prescription drugs to individuals from all Norwegian pharmacies from 2004 onwards and the Dutch VEKTIS database that contains health care expenditures covered by health care insurers for almost all citizens. However, for claims databases there is often a considerable time lag between care utilisation and registration. Furthermore, getting permission to extract individual-level data of the participants of integrated care programmes from these databases may be a challenge because of privacy and data protection regulations. In SELFIE this is further explored as part of WP5 in which the evaluations of the programmes are actually being performed.

If we compare cost estimates based on self-reported utilisation with cost estimates based on provider registration of health care utilisation one may think that the latter is more adequate because individuals might not recall all of their health care utilisation, especially if the recall period extends beyond a few weeks. However, Hoogendoorn and colleagues compared these two methods and found that the use of self-reported data or data from registrations affected within-group costs, but not between-group costs or the cost utility.¹³⁰ This suggests that in SELFIE we should primarily focus on ensuring that the cost estimates in the integrated care programme and the control group are obtained from the same sources.

6.3.5. Unit costs

The resource utilisation estimates need to be multiplied with the unit costs of the services used. In some countries standardised unit costs for use in economic evaluations are available to improve the comparability of cost estimates across different studies. These standardised unit costs are mean costs that do not differ between different types of patients. When adopting a societal perspective, the unit costs should be a good representation of the market prices (that approximate opportunity costs). If such standardised unit costs are not available or they differ too much from the market prices, unit cost calculations need to be done, using micro-costing methods like Activity Based Costing. This should at least be done for the main cost drivers. For example, in many countries the costs of a DRG is not a good approximation of the true market prices because hospitals cross-

subsidise one activity from another. Hence, if they are used, the cost calculation is done from a payer or budget holder's perspective, unless a correction factor is applied to adjust the DRG costs to better represent the true opportunity costs. When the cost analysis is done from a payer or budget holder's perspective, they are most interested in the costs that incur on their budget, irrespective of whether these reflect true opportunity costs.

As many of the issues surrounding costing are context-specific each SELFIE partner will explore the availability of data, the applicability of existing unit costs, and the opportunities for doing more detailed micro-costing studies as part of the evaluations done in WP5.

6.4. Programme-type specific outcomes: instruments and indicators

As described throughout this report, alongside the core set, there are programme-type specific outcomes. **Table 20** provides an overview of the instruments and indicators recommended to measure the programme-type specific outcomes.

Table 20: Selected instruments/indicators to measure programme-type specific outcomes

Type of programme	Aim	Outcome and definition	Author	Instrument	Reasons for selection	Other information
Population health management	Health and well-being	Activation & engagement <i>"taking on the role of managing one's own health and care"</i>	Hibbard et al. 2005 ¹³¹	Short form Patient Activation Measure (PAM-13)	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of Activation & engagement; ➤ The PAM-13 has been translated and validated in several languages including Dutch, Spanish, and German. ➤ It is a frequently used instrument; ➤ It is a short instrument. 	The complete PAM consists of 22 items
	Costs	Ambulatory care sensitive hospital admissions <i>"the amount of hospital admissions that could have been avoided with better care"</i>	Extracted from registration data ¹³²			
		Hospital re-admissions <i>"the amount of persons who are re-admitted to a hospital within 30 days of their prior hospital discharge"</i>	Extracted from registration data			
Programmes targeting frail elderly	Health and well-being	Autonomy <i>"remaining in charge and making own decisions on how one lives his/her own life"</i>	Pearlin and Schooler 1978 ¹³³	Pearlin Mastery Scale	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of autonomy; ➤ It is a frequently used instrument; ➤ It is a short instrument. 	-

Type of programme	Aim	Outcome and definition	Author	Instrument	Reasons for selection	Other information
	Experience with care	Burden of medication <i>“the amount of burden your medicines are to you (considering e.g., administering/taking the medicines, side effects, understanding their purpose/why you’re taking them usefulness, worry about interaction between medicines, expenses)”</i>	Krska et al. 2014 ¹³⁴	Living with Medicines Questionnaire (LMQ)	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of burden of medicine. ➤ It includes only one-item 	The LMQ consists of 42 items. We have included only the overall item for SELFIE but have extended the question to include examples that are referred to earlier on in the LMQ questionnaire.
		Burden of informal caregiving <i>“the stress of informal caregiving due to the energy it costs, the little time it leaves for own interests and recovery and the sadness over the fate of the supported person”</i>	Hoefman et al. 2011 ¹³⁵	Informal Care Questionnaire	<ul style="list-style-type: none"> ➤ This questionnaire is developed based on several studies on burden of informal caregiving ➤ It covers our SELFIE definition of burden of informal caregiving 	
	Costs	Living at home <i>“the amount of participants admitted to long-term institution care (for example a nursing home), during the programme”</i>	Extracted from registration data			
		Falls leading to hospital admissions <i>“the proportion of frail elderly that is admitted to an emergency room or hospital because of a fall”</i>	Extracted from registration data			

Type of programme	Aim	Outcome and definition	Author	Instrument	Reasons for selection	Other information
Palliative care/ oncology programmes	Health and well-being	Mortality	Extracted from registration data			
		Pain and other symptoms <i>“physical symptoms like pain, fatigue, nausea/vomiting, dyspnoea, appetite loss, constipation/diarrhoea, insomnia”</i>	Groenvold et al 2006 ¹³⁶	Quality of Life Questionnaire-Core 15- Palliative Care (QLQ-C15-PAL)	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of pain and symptoms; ➤ QLQ-C15-PAL is specifically developed to assess the quality of life of palliative cancer care patients. 	The QLQ-C15 is a shortened version of the QLQ-C30, one of the most widely used health-related quality of life questionnaires in oncology.
	Experience with care	Compassionate care <i>“care provided in a warm, sensitive and dignified way with sympathy and respect”</i>	Lown et al. 2015 ¹³⁷	The Schwartz Center Compassionate Care Scale	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of compassionate care; ➤ The instrument is based on focus groups with patients. 	
		Timely access to care <i>“the time between referral and start of treatment or care of interest”</i>	Registration data			
		Preferred place of death <i>“the amount of participants that pass away in the location of their preference (e.g., at home)”</i>	Registration data			
		Burden of informal caregiving <i>“the stress of informal caregiving due to the energy it costs, the little time it leaves for own interests and recovery and the sadness over the fate of the supported person”</i>	Hoefman et al. 2011 ¹³⁵	Informal Care Questionnaire	<ul style="list-style-type: none"> ➤ This questionnaire is developed based on several studies on burden of informal caregiving ➤ It covers our SELFIE definition of burden of informal caregiving 	

Type of programme	Aim	Outcome and definition	Author	Instrument	Reasons for selection	Other information
Programmes targeting persons with problems in multiple life domains	Health and well-being	Self-Sufficiency <i>"financially in control to meet basic needs without debts"</i>	Pearce 1996 ¹³⁸	Self-Sufficiency Matrix (SSM), income domain	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of income; ➤ The instrument was validated and developed for homeless people¹³⁹. 	SSM measures the level of self-sufficiency at various life domains e.g., daily activities, housing; social network)
	Costs	Justice costs <i>"total costs to the justice system per participant"</i>	Chrisholm et al. 2000 ¹²⁹	The Client Service Receipt Inventory (CSRI), justice domain	<ul style="list-style-type: none"> ➤ It covers our SELFIE definition of justice; ➤ The CSRI is translated into several languages, including Dutch, German and Spanish 	The last item of the CSRI was left out, as this seemed to overlap too much with the first items.

7. Conclusion

In this report we described the procedure of how we came to a core set and to a programme-type specific set of outcomes that will be included in the MCDA in SELFIE. These outcomes cover the Triple Aim and move beyond the traditional clinical health outcomes. We aimed to include outcomes that are generically of interest in integrated care for multi-morbidity (core set) and to include outcomes of interest to specific integrated care programmes. A complete overview is given below in **Table 21**.

Table 21: Overview of the recommended outcomes in the core set and programme-type specific set

Outcomes for integrated care for persons with multi-morbidity					
	Core set outcomes	Programme-type specific outcomes			
		Population health management	Frail elderly	Palliative and oncology	Problems in multiple life domains
Health & well-being	Physical functioning	Activation & engagement	Autonomy	Mortality	Self-sufficiency
	Psychological well-being			Pain and other symptoms	
	Social participation/relationships				
	Resilience				
	Enjoyment of life				
Experience	Person-centeredness		Burden of medication	Compassionate care	
	Continuity of care		Burden of informal caregiving	Timely access to care	
				Preferred place of death	
			Burden of informal caregiving		
Costs	Total health- and social care costs	Ambulatory care sensitive hospital admissions	Living at home		Justice costs
		Hospital re-admissions	Falls leading to hospital admissions		

All outcomes were defined at a conceptual level in order to allow the use of different instruments or indicators to measure a particular outcome-concept. The reason that we permit the use of different instruments and indicators to measure a particular concept is that some programmes have already been measuring certain outcomes for years, and this retrospective data is of great value. In the cases when data collection still needs to be set up, we have made recommendations for (domains of) instruments or indicators that best operationalise the outcomes in SELFIE. This led to the SELFIE questionnaire (**Appendix 4**). Depending on how well the outcomes that a programme already measures map to the outcome-concepts in SELFIE, a programme can decide to use the entire SELFIE questionnaire or those parts that are not covered by existing outcomes.

All of the outcomes in the core set and the programme-type specific set will be included in the MCDA, so for all of these outcomes weights will be elicited. The entire MCDA framework and the methods to obtain the weights are described in the **second deliverable report** of WP4. This report also describes the study design that will be applied to measure the performance of the 17 integrated care programmes on the outcome-concepts.

8. Appendix

8.1. Appendix 1. Notes from stakeholder workshops

Hungary, February 11th & 25th 2016

The Syreon Research Institute organised the first Hungarian SELFIE workshop in two separate sessions:

1. A workshop in Pécs on 11th February 2016
2. A workshop in Budapest on 25th February 2016.

A total of 25 stakeholders participated the brainstorm about outcomes (11 in Pécs and 14 in Budapest), which can be divided into the 5Ps:

- Two stakeholders representing the **p**atients (1 in Pécs and 1 in Budapest).
- Three stakeholders representing the **p**artners (2 in Pécs and 1 in Budapest).
- Eight stakeholders representing the **p**rofessionals (5 in Pécs and 3 in Budapest).
- Five stakeholders representing the **p**ayers (1 in Pécs and 4 in Budapest).
- Seven stakeholders representing the **p**olicy makers (2 in Pécs and 5 in Budapest).

Potential indicators of health

Patients

- Health Related Quality of Life (HRQoL)
- Life years gained
- Availability of personalized patient information system

Partners

- HRQoL
- Availability of protocol for cooperation among professionals within the institution

Professionals

- Survival rate
- Incidence rate, prevalence
- Resource utilisation (e.g., patient visits, hospital stays, average length of stay, emergency care, sick leave days)
- Number and severity of complications and adverse events
- Patient rehabilitation measured by time to return to work
- General health perception assessed by general PRO/QoL instruments
- Utility measurement with time-trade-off scales
- Regular monitoring of key clinical parameters (e.g., HbA1c)
- Impact on public health related outcomes (e.g., smoking rate)

Payers

- Health gain at individual level and population/societal level
- Functional abilities e.g., along the International Classification of Functioning, Disability and Health (ICF) codes
- Potential life years lost
- Standardised quality of life measurement (QALY)
- Partners', family members' quality of life

Policy makers

- Clinically meaningful population health gain (i.e., country specific health indicators in major diseases, life expectancy)
- Patients', family members' quality of life
- Rate of administering drugs with drug-drug interactions

Proposed indicators of experience**Patients**

- Patient satisfaction
- Waiting time for treatment, diagnostics and rehabilitation
- Regular and predictable control visits

Partners

- Number of procedures or interventions per patient day
- Existence and use of protocols
- Time spent on listening to the patient's opinion
- The number and duration of patient information events (e.g., explaining the diagnosis)

Professionals

- WHO well-being score
- Satisfaction of healthcare workers by survey
- Patient satisfaction with staff kindness, being informed, cleanliness of the facilities, organisation, waiting time, waiting list transparency and duration
- Functional PRO scales

Payers

- Patient reported outcomes
- Patient's awareness and health literacy
- Involvement of partners in decision making

Policymakers

- Application of mobile/e-health solutions in managed care
- Patient satisfaction by survey
- Availability of personalized and quality assured patient information system

Potential indicators of costs

Patients

- Co-payment for treatments
- Co-payment for preventive activities

Partners

- Cost of patients or partners related to accessing care (e.g., travel costs)
- Accessibility and affordability of complementary healthcare services (physiotherapy, dietetics, psychological support)
- Lost income due to absence of work (patient, family)
- Cost of medicines for patients
- Level of informal payments (gratuities, tips)
- Availability and level of home care subsidy and social benefit for partners

Professionals

- Savings due to disinvestment from unnecessary and obsolete technologies
- Costs related to work absenteeism (patients, family members)
- Trends of informal payment / tips (measurement is challenging)
- Institutional financial balance (income vs. costs): patient-level or department-level aggregation
- Costs related to redundant services (unnecessary parallel activities)
- Proportion of patients passed to higher levels (keep patients at lower level unless it is necessary)
- Savings from avoided emergency situations and hospitalisations
- Monthly co-payment for drugs

Payers

- Costs from different perspectives
 - patient's direct costs (by individual surveys)
 - patient-level costs by provider institutions
 - payer's cost = societal costs, by payment categories (sick leave payment, health contribution, nursing fee, vaccination, etc)
- Budget impact
- Resource use: time of the doctor, waiting time

- Investment cost and operational costs of the system

Policy makers

- Average number of hospital days
- Average number of sick leave days
- Budget impact
- Cost-effectiveness
- Savings due to avoided unnecessary treatments

Other relevant indicators to be considered

Patients: none

Partners:

- Existence of prevention and health promotion activities in the integrated care programme
- Availability of patient (and partner) education and counselling in the programme
- Availability of solutions supporting communication among professionals

Payers: none

Policymakers:

- Burden of disease (number of patients, severity of diseases)
- System capacities (number of care providers, health professionals, available technologies)
- Availability of required levels of competence
- Availability of healthy lifestyle changing programmes/activities at community level

Professionals:

- Availability of clinical guidelines
- Public health care priority of the programme
- Availability of sufficient number of case managers and other health professionals
- Drug purchasing adherence – based on health care payer claims database

Netherlands, March 15th 2016

The first Dutch stakeholder workshop was held at the Erasmus University Rotterdam on 15th March 2016. A total of 15 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- Two stakeholders representing the **p**atients.
- Two stakeholders representing the **p**artners (informal caregivers);

- Five stakeholders representing the **professionals** (two health care providers and three researchers);
- Three stakeholders representing the **payers**;
- Three stakeholders representing the **policy makers**;

Patients / Informal caregivers

- Improvements in quality of life
- Good communication about benefits
- Access and accessibility (both physical and financial)
- Difference in coverage between diseases.
- Continuity of care.
- Active care provision.
- Prevention.
- Tailored programme to lifestyle and world of the patient.
- Pharmacy issues is a 'dissatisfier'; logistical issues leading to medication mistakes

Professionals (researchers)

- Less traditional outcomes.
- Adaptability – coping – resilience (resilience questionnaire TNO)
- Autonomy – self-direction / empowerment
- Shift in costs, is this beneficial? If costs remain equal but have shifted from hospital to home care, this is still a 'win' situation.
- Effects for informal caregivers.
- Care providers: leadership and team climate.
- Positive health.
- PROMS outcomes.

Professionals (providers)

- Meaning of program, does it solve a problem?
- Interactions with care providers (how often, with whom?)
- Personal development of the patient
- Intentions between patient-provider and how to achieve these (time)
- Relationship development between the patient and the provider.

Payers

- Less interest for changes in the patient and 'effectiveness'. This is really a paradigm shift at the health insurer VGZ. They no longer want to see if '(clinical) outcome indicators' improve or differ between programmes because that is so much depending on subtle differences in target populations. E.g., one GP practice includes pre-diabetics whereas the other does not, so the HbA1C values of the first are much better. Hence, they only want to be convinced of the plausibility that a programme may work. If they are convinced they are included to pay for it and measure its success only by looking at the impact on healthcare costs and patient satisfaction.
- Aren't interested in long questionnaires.
- Need to consider three things:
 - Inclusion (are we talking about the small proportion of frequent care-users? Prevent over treatment, but also under treatment)
 - Healthcare costs

- Patient experience of the care process.
- Need to be very careful with financing for outcomes (idea of a selection bias if we speak of pay for performance, for example in some IVF clinics only younger women for whom success is expected are included as this improves their success-rates that can be reported to the insurer).

Policy makers

- Role of loneliness; key to well-being.
- Sustainable changes (long-term follow-up needed).
- Involving the person with MM's network.
- Pressure on informal caregiver needs to be reduced.
- Less bureaucracy.
- Transition from secondary to primary care (costs).
- Satisfaction with care.
- Unstable care demands, how to deal with this (so not a linear care pathway).
- Importance of participation for persons.
- Empowerment and self-direction.

Croatia, April 8th 2016

The first Croatian stakeholder workshop organised by Agency for Quality and Accreditation in Health Care and Social Welfare was held at the Palace Hotel Zagreb on 8th April 2016. A total of 29 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- Two stakeholders representing the **patients**.
- Two stakeholders representing the **partners** (informal caregivers);
- Sixteen stakeholders representing the **professionals**;
- Three stakeholders representing the **payers**;
- Six stakeholders representing the **policy makers**;

WHEN ARE ICC MODELS SUCCESSFUL?

The responses of the working group consisting of the representatives of the Association of patients and informal providers (**Patients/Informal caregivers**) were presented by the representative of the Coalition of Association in Healthcare. As an outcome that should be followed related to the user alone and his family, as the basic criterion, they stated the quality of life for which determination is necessary to define the individual needs with user, to conduct measurement of the level of satisfaction of such needs and to involve all stakeholders in the process of meeting the needs. As outcomes associated with the system, they were pointed out unification and harmonization of legislation and clear and relevant sources of information. With regard to the organisation and implementation, they highlighted the importance of the local environment, the existence of coordinators in each area, mobile teams, teams for evaluation, conduction of analysis of economic efficiency and the importance of the electronic registry data. As an important component, they state the political will for cooperation at all levels, from the micro to the national level. They emphasized the willingness of involved professionals for collaboration, continuous communication and different roles during the implementation and respect for and promotion of good practices.

The answers for a group of professional service providers (**Professionals/Researchers**) were presented from the Head of the Department for Palliative Medicine, Clinical Hospital Rijeka. Measuring of health-social quality must be carried out according to the White Paper on standards and norms in hospice and palliative care. As a most important components were highlighted the Strategic Plan of palliative care 2017-2020, e-card and IT integration, training of trainers, so-called "Task shifting" from doctors to bachelors, national promotion of new, so-called "Point of care" technologies and the involvement of all interdisciplinary teams. It is emphasized measuring of social- health quality through nursing documentation, GeroS monitoring system, training in geriatrics, gerontology and geriatric health care, the need for further training of everyone involved in the health care of elderly and the involvement of interdisciplinary teams.

The answers for a group of health insurance holders (**Payers**) put forward a representative of the Croatian Health Insurance Fund. According to the presented concept, to determine what needs to be measured and to decide whether the programme is effective it is necessary to recognize the needs of two segments. The first is from the perspective of the patient, i.e., their families, where it is necessary to describe the present situation and then define the possibility of improvement. It is also necessary from the perspective of the system to describe the current situation and determine the features that the system offers; they can provide and what are the possibilities, to improve such health care delivery, to the patient. Regarding the segment of monitoring, from the perspective of the patient, proposal is to conduct a survey that would go in two directions: how are the patient's needs currently met and what are the priorities in meeting the patient's needs? Regarding the monitoring of indicators related to the perspective of the system, it is highlighted the monitoring of epidemiological indicators, health care quality indicators, patient safety and financial indicators. It is necessary to carry out a survey between health professionals with regard to how much their need are being met and how much power they have to extend the patient's needs satisfaction. It was emphasized that it is important that models and interventions should extend the life expectancy of that group of patients and improve the quality of life of patients. It is necessary to decide on those interventions that are most effective, i.e., that which provide most from the invested funds. It is important to identify priorities and based on them to achieve a model that will give you the best outcome.

Answers for decision (regulatory) makers group (**Policy makers**) the representative of the Ministry of Social Policy and Youth was presented. It was emphasized the importance of root base definition: who is the target group, how many members the target group has, which parameters will be monitored. Based on the above, after an analysis of costs and benefits, it is necessary to make a professional basis (What programme offers? What would be the savings, what would be the advantages and disadvantages?). It was emphasized that it is necessary to consider the normative regulation – would it be better to implement programme through a policy or law, and regardless which way will be chosen, to make an action plan that will further define the provisions of the law or strategy, on the way that all processes will be named, defined, separate, that will be determinate in what period of time they will be carry out, who will be a holder and which indicators will be monitored.

Norway, April 13th 2016

The first Norwegian stakeholder workshop was held at University of Bergen on 13th April 2016. A total of 11 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- Two stakeholders representing the **patients**;
- No stakeholder representing the **partners** (informal caregivers);
- Seven stakeholders representing the **professionals**;
- Two stakeholders representing the **policy makers** (and **payer**);

Patients

- A project is successful when the patient experiences increased coping and increased quality of life; is the patient doing better than before the treatment started?
- Programme participation depends on its usefulness, e.g., that other patients will benefit from project experiences.

Professionals (researchers)

- Projects may be interesting from a research perspective although they do not succeed.
- A project is successful when there is documented positive effect with respect to important outcomes such as improved functional ability and coping (considered most important outcome – 60%?), improved patient pathways (10%?), learning/increased competence among patients, professionals and partners (10%?), cost-effectiveness (20%?).
- With respect to the learning network it was suggested to ask patients to rank their objectives so that researchers performing the evaluation can weigh the objectives when deciding the degree of goal attainment.

Professionals (health care providers [GPs, nurse])

- A project is successful when the patient experiences lasting improvement of functional ability within a certain time span, e.g., that 80 per cent of the patients attain their goals within a month after being discharged from the hospital. PSFS (patient-specific functioning scale) is a good tool for measuring changes.
- Professionals must also see the project as successful (e.g., fill out questionnaires), and be asked how they evaluate that patients have benefitted from the project.
- Cost-effectiveness is another important measure.
- Follow-up of patients over time should be included.

Policy makers

- A programme must meet a current challenge and have transfer value to other groups of patients than those participating in the project (e.g., MAR Bergen), alternatively concern a substantial number of care recipients (large volume).
- Important outcome measures are survival, hospitalisation admission for intoxication, the relationship between health impact and patient satisfaction.
- To implement the program, policy makers would have to be convinced that factors such as patient satisfaction, health impact and resources (economic evaluation) were attended to

England, April 26th 2016

The first English stakeholder workshop was held at Manchester on 26th April 2016. A total of 5 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- One stakeholder representing the **patients**.
- No stakeholder representing the **partners** (informal caregivers);

- One stakeholder representing the **p**rofessionals;
- No stakeholder representing the **p**ayers;
- Three stakeholders representing the **p**olicy makers;

There was no representation of the partner or payer perspectives, as no representatives from these groups were able to attend.

Patients

- There is loose evidence for self-management, and it is not always a positive thing. For example, in a survey of diabetes type 1 patients the overriding concern was that of fear of complications.
- Can self-management capabilities be evaluable?
- Could look for any questionnaires that include whether patients feel that care feels coordinated. (We have example questions from our FP7 MUNROS project)
- Analyse unscheduled instances of care.
- Is there some EU survey data for this, e.g SHARE?

Partners

Measure the burden on informal carers

Professionals

- Negative instances might be better to look at – more memorable for person – could ask about experiences of communication breakdowns for example.
- Areas with hubs (e.g., South Somerset) will be helpful as there is a central office with all this info
- Existing data might be found in the GP Workforce Survey or MUNROS questionnaires (both held by MCHE)
- Examples of content in the GP Workforce Survey
 - “I am consulted about changes that affect my work”
 - “relationships at work are strained”
 - “how do you think the intro of CCGs has affected integration of primary and secondary care”
 - “I feel informed about what the CCG is trying to achieve” – not sure if relevant but there you go

Germany, June 3th 2016

The first German stakeholder workshop was held at TUB, Berlin on 3th June 2016. A total of 11 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- Three stakeholders representing the **p**atients.
- One stakeholder representing the **p**artners (informal caregivers);
- Three stakeholders representing the **p**rofessionals;
- Three stakeholders representing the **p**ayers;
- One stakeholder representing the **p**olicy makers;

Patients / Partners

- See the patient in his environment (living situation, partner), wishes, needs and individual treatment goals at the core of each health related communication. A first comprehensive needs assessment should be done as early as possible, as the deterioration of health status can happen suddenly, consequently diminishes the patients capabilities to communicate this complex situation.
- Agreeing on one competent contact person for the patient in the beginning of the care process. Patient's experiences show that services at health insurance funds or the long-term care eligibility scheme are often not tailored to the patient. Patient perceived themselves as numbers which are causing costs.
- Adequate health literacy is important also at health care institutions
- Lack of information and time: no time to discuss open questions, no communication on possible choices, and a "sensitive" communication on diagnoses that helps understanding and coping with the situation, Internet is not the best option to substitute this lack.
- Health providers need to communicate among each other: Electronic medical records or shared databases, flagging risk for patient in polypharmacy
- Need for educated medical personnel as a first contact point for patients, need for a comprehensive education of contact persons, i.e., case manager, in a wider scope than now delivered (+ long-term care counselling, + treatment possibilities+ polypharmacy, +help to mobilize additional financing,...)

Professionals / policy-makers

- Integrated care is a solution to a concrete problem of local health providers and need to reconcile with a lack of coordination "What can I do for my patients". Medication as a big problem in the daily routine of health professionals.
- It is also a cultural change needed to perceive a patient not any longer as a case, but as an individual with health goals, individual needs and expectations
- The concrete shape of integrated care varies among three represented types: (1) regional population focused: fully integrated into regional setting, including MM patients. Step by Step building of a network with a broad range of health services from primary prevention to psychiatric care. (2) Case management across Germany. Offers guidance and coaching by telephone and home visits for eligible patients. One concrete contact person that is competent to answer to a broad range of topics+ doctoral team+ polypharmacy. (3) Integrated Care Ambulance. Integration across sectors, employing a concept of positive health of patients. Starting with prevention and offering a health coaching hour+ eHealth.
- There is a cultural change taking place right now (it is at least beginning). Doctors start to change the understanding of their profession, due to the (1) feminization of health workforce, (2) patient information status, empowering them to communicate needs and expectations, (3) development of IT possibility and (4) changes in health perception by medical doctors and that working in a team is a real advantage and creates a more valuable working atmosphere and can lift off work load from medical doctors by a multi-disciplinary team.

Payers

- Integrated care as solution to a currently imperfect health provision (over-or under supply of health services or, not according to clinical guidelines or other not optimal treatment)
- To generate efficiency gains and improve effectiveness of health provision within the statutory health insurance system
- To improve structural quality of health provision (to avoid dual diagnoses and tests, to improve communication between providers and patients, institutionalize a local network and care regionally for patients living in this region)
- To secure patient safety (polypharmacy, secure for hygiene standards and care pathways)
- Based on valid data about patients, professionals and health services. Which patients are eligible to participate in the programme?, How qualified is the medical personnel within the integrated care programme, collect data to provided health services and quality (i.e., user experience by patients and how this reflects on the participating health insurance fund)
- Clear responsibility of contact persons and ensure transparency throughout the process

Austria, June 8th 2016

The first Austrian stakeholder workshop was held at TUB, Berlin on 8th June 2016. A total of 11 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- Three stakeholders representing the **p**atients.
- One stakeholder representing the **p**artners (informal caregivers);
- Three stakeholders representing the **p**rofessionals;
- Three stakeholders representing the **p**ayers;
- One stakeholder representing the **p**olicy makers;

We asked the participants what makes a programme for the care of patients with multiple chronic conditions successful. They answered:

- Acceptance of the programme by target group
- Institutions need to work together sufficiently and exchange information
- Interfaces between service providers are closed
- Duplication of work is prevented
- Reduction of the number of service points for patients
- The occurrence, length and readmission rate for hospital stays
- Administrative simplification of patient records, e.g., in form of electronic records
- Polypharmacy: counteracting adverse effects and drug interaction
- Continuous care and stable relationships with medical and social staff
- Project leader who motivates all persons involved

They proposed to measure success through outcomes on:

- Increase in quality of life
- Patient surveys concerning their increased satisfaction and welfare
- Patient outcomes are hard to measure. A project is regarded as successful if the people concerned with it are satisfied. Especially for employees it is important to have a feeling to achieve something.
- It should be possible to objectively measure advancements, the project should be cheaper, better, faster than existing solutions.
- The geographical scope and expansion of the programme
- Duration and sustainability of the programme

- Easing the burden of relatives who care for the patient
- Decrease of informal carers who become ill due to caring
- Increased number of patients who can be cared for at home while reducing institutional care
- The extent of utilisation of services

Spain

The first Spanish stakeholder workshop was held at the headquarters of AQuAS (Catal Agency for Assessment of Quality of Health Services), Barcelona on 11th July 2016. A total of 20 stakeholders participated the brainstorm about outcomes, which can be divided into the 5Ps:

- One stakeholder representing the **p**atients.
- No stakeholder representing the **p**artners (informal caregivers);
- Twelve stakeholders representing the **p**rofessionals;
- Three stakeholders representing the **p**ayers;
- Four stakeholders representing the **p**olicy makers;

All participants agreed on SELFIE's orientations as well as on the specifics of the design of the project in Catalonia. They stressed, however, the interest for generating a two-level evaluation for the empirical study. They advised to consider both: (i) the target programmes (AISBE and BSA); and, (ii) the general deployment of integrated care at regional level.

The participants also stressed the interest of looking for synergies among the ongoing projects and programmes and they identified several areas for synergy specifically in following domains:

- Standardisation of service workflows;
- Risk assessment and stratifications (interplay between population-based risk and clinical assessment & stratification);
- Evaluation methodologies;
- ICT developments identified in Nextcare;
- Integration between social support and healthcare services (PIAISS);
- Explore novel business models and incentive for care coordination.

There was a strong consensus among participants without identifiable biases associated with specific profiles of the attendees.

8.2. Appendix 2. Focus group procedure

General introduction (5-10 minutes)

- Welcome (introduce researchers), including:
 - Why you're here: to discuss with us about what is important from the perspective of an individual with multiple health- and social problems in health and in care.
 - Aim: the results of the discussion will be used to improve the care for persons with multiple health- and social problems.
- Explanation of the agenda:
 - Practical details (when is the break, restrooms etc.)
 - Introduction of participants
 - Part 1 – discussion on what's important to you in health and care, i.e., complete the statements "For me, being in great health means....." and "I'd be really satisfied with all of the care / the overall care that I receive, if....."
 - Break
 - Part 2 – discussion on what's *most* important to you in health and care, i.e., discussion about prioritization
 - Concluding remarks and time for feedback
- Rules during the focus group:
 - No right / wrong answers, only differing points of view
 - You don't need to agree with others, but you must listen respectfully as others share their views
 - Talk to each other, role as moderator is to guide the discussion
 - Privacy / anonymity
 - The discussion will be recorded, and notes will be made
 - We ask you to turn off your phones
- Participants have time to read/fill in informed consent
- **Recorder turned on.*

Introduction of participants (10-15 minutes)

- Name, age
- Current health situation (multi-morbidities).
- **Try to keep the introduction short.*

Part 1: What's important in health and in care? (45 minutes)

Health and well-being

- Step 1: When you think about your **health and well-being**: try to complete this sentence / thought:
"For me, being in great health means..." (**Write this question on a large white board / flip-over*)
 - Provide examples if participants are having trouble understanding what you mean:
 - ...being able to work full-time.
 - ...being able to spend time with family and friends.

- ...being able to live for many more years.
 - ...not going to the doctor so often.
 - **The researcher needs to ask triggering and thought-provoking questions here.*
 - **The discussion should be about health and well-being in general, not about care specifically (yet).*
 - **Be careful not to provide too many examples and to steer the answers in one direction.*
 - **The researcher leading the discussion will be writing these thoughts out on a white board / flip-over (with assistance from the second researcher).*
 - **The researchers need to allow the participants to reflect on one-another's ideas.*
 - **Close the discussion with a final question: i.e., have we missed anything?*
- **Step 2:** Once it seems as though all participants have said what's important to them, the researcher will go through the points on the board, and with the help of the participants try to extrapolate what these things mean, in order to go from **specific** examples to **general** outcomes. For example:
 - "For me, being in good health means being able to work full-time", does this mean:
 - **Participating** in society?
 - Being able to support one-self financially? → **Self-sufficiency**
 - Having **social contacts**?
 - Having a daily **structure**?
 - "For me, being in good health means not going to the doctor so often", does this mean:
 - Having **no acute** health problems?
 - Having the **ability to deal** with minor health problems on your own? (**self-management**)
 - **The researcher needs to write **key words** (such as the ones highlighted green above) that come forth on large notecards and place them in the center of the table for all participants to be able to see.*
 - **The researcher needs to ask triggering and thought-provoking questions here – what do the points mentioned in step 1 really mean? What does it come down to? What would it mean for the person sitting next to you? How can you expand this so that it 'counts' for everyone in the room? Try to distinguish between individual opinions and actual group consensus.*
 - **In asking further questions, try to focus on multi-morbidity – how is this specific to you as a person with multiple health- and/or social problems, would this be different if you had a single disease?*
 - **For each initial statement, multiple cards can be made.*
 - **Close the discussion with a final question: i.e., have we covered all elements?*

Care

- Now we repeat the exercise, but for **care**. As you are all persons that deal with multiple health problems, it is likely that you also deal with multiple health and care professionals.
- We are interested in how these persons work together and how care can be integrated.
- **Step 1:** When you think about the **care** that you receive, have received, or may receive in the future, try to complete this sentence / thought:

"I'd be really satisfied with all of the care / the overall care that I receive, if..." (**Write this on a large white board / flip-over*)

- Provide examples if participants are having trouble understanding what you mean:
 - ...my doctor took more time to explain things to me.
 - ...my partner would always be allowed to join me and discuss with the doctors as well.
 - ...my care plan was discussed with me.
 - ...I had one overall written care plan.
 - ...I always knew I could contact one person in case of questions.
- **Be careful not to provide too many examples and to steer the answers in one direction.*
- **Step 2:** Once it seems as though all participants have listed what's important to them, the researcher will go through the points on the board, and with the help of the participants try to extrapolate what these things mean, and again go from **specific** to **general**. For example:
 - "I'd be really satisfied with all of the care / the overall care that I receive, if my doctor took more time to explain things to me", does this mean:
 - Good **communication**?
 - **Shared-decision making**?
 - More/**enough time**?
 - "I'd be really satisfied with all of the care / the overall care that I receive, if my partner could always be allowed to join me and discuss with the doctors as well.", does this mean:
 - **Understanding** your personal situation?
 - **Involvement** of the **informal caregiver**?
 - Good **communication**?
 - **The researcher needs to write **key words** (such as the ones highlighted green above) that come forth on large notecards and place them in the center of the table for all participants to be able to see.*
 - **The researcher needs to ask triggering and thought-provoking questions here – what do the points mentioned in step 1 really mean? What does it come down to? What would it mean for the person sitting next to you? What does it mean for your environment? How can you expand this so that it 'counts' for everyone in the room? Try to distinguish between individual opinions and actual group consensus.*
 - **In asking further questions, try to focus on multi-morbidity – how is this specific to you as a person with multiple health- and/or social problems, would this be different if you had a single disease?*
 - **For each initial statement, multiple cards can be made.*

BREAK (15 minutes)

- **During the break one of the researchers needs to assemble the notecards so that these are all arranged in a legible way- and so that there is an open space on the table for the next exercise.*
- **Please add concepts from the concept-list that the EUR provides you with (by May 15th), that are not on table yet. These should be on a different color card.*

Part 2: What's *most* important in health and in care? (30 minutes)

- Instructions: In the discussion during part 1 you've come up with points that are important for you when it comes to defining health and care. As you saw, we've been trying to write this into more general terms on these cards.
- In our research team we've also been looking at concepts that are often mentioned in research/literature as being important, we've added these to the table as well. **Explain the new concepts in case anything is unclear.*
- We'd like to ask each of you to look at all of these cards and write down for yourself which 5-10 are most important to you.
- Now we'd like you all to use the empty space on the table to place the 'top' 10 cards, *as a group*. You do not need to reach consensus about the 'order' of these 10, but try to decide which 10 should be on this side of the table. **Ask a participant to first put his/hers down, through discussion see whether some kind of consensus can be reached.*

Conclusion (10 minutes)

- Short summary of the discussion.
- Ask if there are any remaining questions.
- Have we missed anything?
- Thank the participants for coming.
- Ask them if they would like to be notified of the report that comes forth from the focus groups being held in all partner countries (email address list).

8.3. Appendix 3. Outcomes on cards for focus groups

Health / well-being

Outcome on card
Biomedical outcomes <i>e.g., bloodsugar, bloodpressure, lung function, kidney function</i>
Life expectancy
Maintaining independence
Activities of daily living <i>e.g., eating, bathing</i>
Independence on medical aids <i>e.g., wheelchair, oxygen</i>
Energy and fatigue
Pain and discomfort
Disability
Physical mobility <i>e.g., being able to walk</i>
Work ability <i>being physically and mentally able to work</i>
Cognitive functioning <i>e.g., thinking, memory, concentration and learning</i>
Anxiety and depression
Stress
Worrying
Listless <i>no spirit, apathetic, indifferent</i>
Self-esteem <i>a good feeling of one-self, self-respect</i>
Respect from others
Social relationships <i>staying in contact with family/friends/acquaintances</i>
Maintaining social status <i>in terms of 'societal class', 'occupation', how you think others look at you in society.</i>
Societal participation <i>e.g., volunteer work, club memberships, community activities</i>

Social support <i>emotional, instrumental and financial assistance from the social network</i>
Loneliness
<i>Investing in future</i> health and well-being
Self-efficacy <i>Belief in one's capacity to follow a needed or desired course of action</i>
Positive frame of mind, resilience <i>ability to maintain a positive perspective regarding the future, despite setbacks or change</i>
Coping <i>Being able to deal with problems, losses, adverse events in an effective manner</i>
Health literacy <i>capacity to obtain, process, and understand information about illness and health</i>
Compliance/adherence to treatment
Lifestyle <i>e.g., smoking, nutrition, physical activity, alcohol and drug use</i>
Feeling safe
Enjoyment of life
Maintaining dignity
Living comfortably
Caregiver burden

Experience of care

Outcome on card
Holistic assessment
Shared decision-making
Tailored care
Individualized care planning
Pro-active, prevention-oriented care
Clear responsibilities and accountability

Named coordinator
Team work and collaboration between professionals
Good communication
Shared information between professionals and providers
Continuity of care <i>pertains to continuity (e.g., follow-up, monitoring, stability, transfer) throughout time and between professionals and organisations</i>
Confidence in knowledge and skills in professionals
Respectful interaction between provider-patient <i>feeling of being treated with respect and being 'heard'</i>
Geographical access <i>e.g., facilities close to home</i>
Physical access <i>e.g., building is wheelchair accessible</i>
Timely access <i>e.g., no/short waiting lists</i>
Satisfaction with care process

Cost

Outcome on card
Service and support coverage: <i>co-payments/deductible and financial access to services</i>
Travel and parking costs
Loss of income - patient
Loss of income - informal caregiver



SELFIE

Questionnaire

Instructions

This questionnaire asks questions about your health and wellbeing, your experience with care and your health care use.

We are interested in your opinion and your experience. There are no right or wrong answers. Choose the answer that best applies to your situation. Mark an X in the box of your choice.

Example

1. *Are you male or female?*

☐ *male*

☒ *female (you indicated that you are female)*

If you accidentally mark the wrong box, you can make the box black and mark the correct box.

2. *Are you male or female?*

☒ *male (you have now indicated that you are male)*

☐ *female*

For our research, it is important that you answer all questions, even if you find them difficult. Your answers will remain strictly confidential, will not be shared with your careproviders, and will not influence the care you receive.

Completion of the questionnaire will take approximately 25 minutes.

Many thanks in advance for completing the questionnaire.

Part I: Health and well-being

A. Physical functioning

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? Please mark one box for each question.

	Yes, limited a lot	Yes, limited a little	No, not limited at all
A1. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A3. Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A4. Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A5. Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A6. Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A7. Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A8. Walking several blocks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A9. Walking one block	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A10. Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. How you feel

These questions are about how you feel and how you have been doing the past month. For each question, please mark the box that best applies to you. Please mark one box for each question.

How much of the time during the past month...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
B1. Were you a happy person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B2. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B3. Have you been a very nervous person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B4. Have you felt downhearted and blue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B5. Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Enjoyment of life

Please indicate which statement fits your current situation best by marking ONE box.

Enjoyment and pleasure

- ☐ I can have all of the enjoyment and pleasure that I want
- ☐ I can have a lot of the enjoyment and pleasure that I want
- ☐ I can have a little of the enjoyment and pleasure that I want
- ☐ I cannot have any of the enjoyment and pleasure that I want

D. Social relationships

The next questions are about the quality and frequency of your social relationships. Please mark one box per question.

	Very good	Good	Fair	Poor	Very Poor
D1. My chances of talking to people close to me on equal terms are	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D2. The quality of my relationships with people who are close to me are	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D3. The respect I receive from people who are close to me is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D4. My relationships with acquaintances are	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D5. The respect I receive from acquaintances is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D6. My chances of having an intimate relationship are	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D7. My chances of seeing people as often as I want are	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E. Resilience

Below are some statements. Please mark one box per statement.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
E1. I tend to bounce back quickly after hard times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E2. I have a hard time making it through stressful events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E3. It does not take me long to recover from a stressful event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E4. It is hard for me to snap back when something bad happens	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E5. I usually come through difficult times with little trouble	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E6. I tend to take a long time to get over set-backs in my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

F. Activation & engagement

Below are some statements. For each statement, please mark the box that best describes how much you agree or whether the statement is not applicable. Please mark one box per statement.

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
F1. When all is said and done, I am the person who is responsible for managing my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F2. Taking an active role in my own health care is the most important factor in determining my health and ability to function	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F4. I know what each of my prescribed medications does	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F6. I am confident I can tell my health care provider concerns I have even when he or she does not ask	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly agree</i>	<i>N/A</i>
F7. I am confident that I can follow through on medical treatments I need to do at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F8. I understand the nature and causes of my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F9. I know the different medical treatment options available for my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J10. I have been able to maintain the lifestyle changes for my health that I have made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J11. I know how to prevent further problems with my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J12. I am confident I can figure out solutions when new situations or problems arise with my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G. Your health today

Under each heading, please mark the ONE box that best describes your health TODAY.

G1. Mobility

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

G2. Self-care

- ☐ I have no problems washing and dressing myself
- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

G3. Usual activities (e.g., work, family or leisure activities)

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

G4. Pain/discomfort

- ☐ I have no pain or discomfort
- ☐ I have slight pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have severe pain or discomfort
- ☐ I have extreme pain or discomfort

G5. Anxiety/depression

- ☐ I am not anxious or depressed
- ☐ I am slightly anxious or depressed
- ☐ I am moderate anxious or depressed
- ☐ I am severely anxious or depressed
- ☐ I am extremely anxious or depressed

Part II: Experience of care

H. Person-centeredness

The next questions are about your experience and understanding of the care you have received from your health and social care providers in the last month. 'Care' could be any treatment or support you received in relation to your health and well-being. Please provide a response based on your overall experience if you have received care from more than one service.

	Not at all	To some extent	More often than not	Always
H1. Did you discuss what was most important for YOU in managing your own health and well-being?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H2. Were you involved as much as you wanted to be in decisions about your care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H3. Were you considered as a 'whole person' rather than just a disease/condition in relation to your care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H4. Did your care team / providers involve your family/friends/carers as much as you wanted them to be in decisions about your care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H5. Have you had enough support from your care team / providers to help YOU to manage your own health and well-being?				
<input type="checkbox"/> I have had no support				
<input type="checkbox"/> I have not had enough support				
<input type="checkbox"/> I have had enough support				
<input type="checkbox"/> I have had a lot of support				
H6. To what extent did you receive useful information at the time you needed it to help you manage your health and well-being?				
<input type="checkbox"/> I do not receive any information				
<input type="checkbox"/> I rarely receive enough information				
<input type="checkbox"/> I sometimes receive enough information				
<input type="checkbox"/> I always receive enough information				
<input type="checkbox"/> I receive too much information				

I. Continuity of care

The following statements are about the collaboration between caregivers (for example between your general practitioner and the medical specialist in the hospital). For each statement, please mark the box that best describes how much you agree or whether the statement is not applicable (N/A). Please mark one box per statement.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A
I1. My care providers transfer information very well to one-another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I2. My care providers work together very well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I3. My care providers are very well connected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I4. My care providers always know what one-another is doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I5. I have to wait too long for an appointment or treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part III: Costs

J. Health and social care costs

The net questions are about your care utilisation in the last three months. Please add up all control visits, appointments, home visits, and consultations by telephone in the last three months. Telephone calls for making an appointment should not be counted. Please fill in how many consultations you have had approximately if you are unsure about the exact number of consultations.

During the last 3 months, did you visit		
J1.your general practitioner?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J2.a primary care nurse (e.g., practice nurse, nurse practitioner)	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J3.a GP assistant?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J4.a physiotherapist?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J5.an occupational therapist?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J6.a speech therapist?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J7.a dietician?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J8.a podiatrist?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J9.a medical specialist (e.g., geriatrician, lung specialist, cardiologist, eye specialist, rheumatologist, neurologist, elderly care physician) Add up all appointments.	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J10.a psychologist, psychiatrist or psychotherapist? Add up all appointments.	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J11.a district nurse or community nurse? Add up all appointments.	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J12.a social worker?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J13.a welfare worker?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)

J14.a homoeopathist or an acupuncturist? Add up all appointments.	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J15.dentist?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J16.optician?	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J17.other, namely: <input type="text"/>	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J18.other, namely: <input type="text"/>	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J19.other, namely: <input type="text"/>	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)

<i>During the last 3 months did you visit any of the following services below, and if so, how often? Please only fill in day-visits (outpatient), and not overnight stays (inpatient)</i>		
J20.residential care or nursing home	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J21.rehabilitation center	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)
J22.other, namely: <input type="text"/>	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> visit(s)

J23. During the last 3 months, did you visit a hospital emergency room?

- ☐ No
☐ Yes, namely time(s)

J24. Have you been admitted to a hospital in the past 3 months?

- ☐ No
☐ Yes, namely days in total (add up all days in case of more admissions).

J25. Were you admitted elsewhere because of your health during the last 3 months? For example you stayed in a home for residential care or a nursing home, in a psychiatric hospital or rehabilitation center.

- ☐ No → Go to question J29
☐ Yes

During the last 3 months, I have been admitted to a...		
J26.residential care or nursing home	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> three <input type="text"/> days in the past months
J27.rehabilitation center	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> three <input type="text"/> days in the past months
J28.psychiatric hospital	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> three <input type="text"/> days in the past months

J29. Did you receive home care in the last 3 months?

- ☐ No → Go to question J33
☐ Yes

During the last 3 months (13 weeks), did you receive the following home care services...		
J30.housekeeping and home help (e.g., vacuum cleaning, doing the laundry, making up your bed, going for daily groceries)	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> hours a week <input type="text"/> weeks during the last 3 months
J31.personal care (e.g., help for bathing or help to get dressed)	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> hours a week <input type="text"/> weeks during the last 3 months
J32.nursing (e.g., put on a bandage, administer medicines, measure blood pressure)	<input type="checkbox"/> No <input type="checkbox"/> Yes, namely <input type="text"/> hours a week <input type="text"/> weeks during the last 3 months

J33. Did you take any medication during the last 3 months?

- ☐ Yes
☐ No → Go to question K1

J34. What medication did you take during the last 3 months?

With medication we mean all drugs that were prescribed and medication that you have bought at the pharmacy or a drugstore. We have given 2 examples.

Note: Filling in the questions below will be much easier if you look at your medication boxes. You'll find the dose you have to take per time. And how often you have to do so per day. **Did you take more or less?** Please fill in the dose that you have actually taken.

What is the medication name?	How much did you take per time? <i>See the box or the package.</i>	How many times did you take this per day? <i>See the box or the package.</i>	How many days during the past 3 months did you take the medication?
<i>example 1</i> Metoprolol (blood pressure)	<i>example</i> 100mg	<i>example</i> 1 time	<i>example</i> 90 days
<i>example 2</i> Furosemide (diuretic)	<i>example</i> 40 mg	<i>example</i> 1 time	<i>example</i> 26 days (2 times a week; 13 weeks)

Part IV: Demographics

K1. What is the date today?

D	D	M	M	Y	Y	Y	Y

K2. What is your date of birth?

D	D	M	M	Y	Y	Y	Y

K3. What is your gender?

- ☐ Male
☐ Female

K4. What is the highest degree or level of school that you have completed?

- ☐ Early childhood education
☐ Primary education
☐ Lower secondary education
☐ Upper secondary education
☐ Post-secondary non-tertiary education
☐ Tertiary education
☐ Short-cycle tertiary education
☐ Bachelor's or equivalent level
☐ Master's or equivalent level
☐ Doctoral or equivalent level.

K5. What is your marital status:

- ☐ Single (never married)
☐ Married / long-term relationship
☐ Widow / widower
☐ Divorced

K6. What is your living situation:

- ☐ Independent, alone
☐ With others (partner, children, etc.)
☐ Care home / residential care centre since / / (DD/MM/YY)
☐ Nursing home since / / (DD/MM/YY)

K7. Which of the following statements about occupational status apply to you? (multiple answers allowed)

- ☐ I have a paid job
☐ I do volunteer work
☐ I am retired or on pre-pension
☐ I am work disabled, for %
☐ I am looking for a job
☐ I have a paid job
☐ I am a housewife / househusband
☐ I am a student

K8. What is your smoking status?

- ☐ Current smoker
☐ Former smoker
☐ Never smoker

Health conditions

The following is a list of common health problems. Please indicate for each condition if you have this or not. At the bottom there is space to list health problems not already presented.

Do you have this condition?	No	Yes
K9. Asthma	<input type="checkbox"/>	<input type="checkbox"/>
K10.Cancer during the past five years (not including small skin cancers)	<input type="checkbox"/>	<input type="checkbox"/>
K11.Chronic back pain or sciatica	<input type="checkbox"/>	<input type="checkbox"/>
K12.Chronic bronchitis, COPD or emphysema	<input type="checkbox"/>	<input type="checkbox"/>
K13.Chronic kidney disease	<input type="checkbox"/>	<input type="checkbox"/>
K14.Cognitive problems, memory loss, dementia, Alzheimer	<input type="checkbox"/>	<input type="checkbox"/>
K15.Colon problem, irritable bowel or colitis	<input type="checkbox"/>	<input type="checkbox"/>
K16.Congestive heart failure	<input type="checkbox"/>	<input type="checkbox"/>
K17.Depression, anxiety or emotional difficulties	<input type="checkbox"/>	<input type="checkbox"/>
K18.Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
K19.Hard of hearing	<input type="checkbox"/>	<input type="checkbox"/>
K20.Heart disease, angina (chest pain from heart problem), heart attack, bypass surgery or angioplasty	<input type="checkbox"/>	<input type="checkbox"/>
K21.High blood pressure	<input type="checkbox"/>	<input type="checkbox"/>
K22.High cholesterol	<input type="checkbox"/>	<input type="checkbox"/>
K23.Osteoarthritis (not rheumatoid arthritis)	<input type="checkbox"/>	<input type="checkbox"/>
K24.Osteoporosis (thinning of the bones)	<input type="checkbox"/>	<input type="checkbox"/>
K25.Overweight	<input type="checkbox"/>	<input type="checkbox"/>
K26.Poor circulation in your legs	<input type="checkbox"/>	<input type="checkbox"/>
K27.Rheumatoid arthritis	<input type="checkbox"/>	<input type="checkbox"/>
K28.Rheumatic disease, fibromyalgia or lupus	<input type="checkbox"/>	<input type="checkbox"/>
K29.Stomach problem, ulcer, gastritis or reflux	<input type="checkbox"/>	<input type="checkbox"/>
K30.Stroke	<input type="checkbox"/>	<input type="checkbox"/>
K31.Thyroid disorder	<input type="checkbox"/>	<input type="checkbox"/>
K32.Vision problem	<input type="checkbox"/>	<input type="checkbox"/>
K33.Other (please write in)		

This is the end of the questionnaire.
Thank you for completing the questionnaire!!!

*****Information extracted from REGISTRATION data *****

Ambulatory care sensitive hospital admissions

Admission for	ICD-10 coders used to identify ACSC
Angina	I20, I24.0, I24.8, I24.9
Asthma	J45, J46
Congestive heart failure	I11.0, I50, J81
Convulsion and epilepsy	G40, G41, R56, O15
Chronic obstructive pulmonary disease	J20, J41, J42, J43, J47
Diabetes complications	E10.0–E10.8, E11.0–E11.8, E12.0–E12.8, E13.0–E13.8, E14.0–E14.8
Hypertension	I10, I11.9
Iron-deficiency anemia	D50.1, D50.8, D50.9
Cellulitis	L03, L04, L08.0, L08.8, L08.9, L88, L98.0
Dehydration	E86
Nonspecific gastroenteritis	K52.2, K52.8, K52.9
Kidney/urinary infection	N10, N11, N12, N13.6
Dental conditions	A69.0, K02, K03, K04, K05, K06, K08, K09.8, K09.9, K12, K13
Ear, nose and throat infections	H66, H67, J02, J03, J06, J31.2
Gangrene	R02
Nutritional deficiency	E40, E41, E42, E43, E55.0, E64.3
Pelvic inflammatory disease	N70, N73, N74
Perforated/bleeding ulcer	K25.0–K25.2, K25.4–K25.6, K26.0–K26.2, K26.4–K26.6, K27.0–K27.2, K27.4–K27.6, K280–282, K284–K286
Influenza and pneumonia	J10, J11, J13, J14, J15.3, J15.4, J15.7, J15.9, J16.8, J18.1, J18
Other vaccine-preventable diseases	A35, A36, A37, A80, B05, B06, B16.1, B16.9, B18.0, B18.1, B26, G00.0, M01.4
Alcohol-related diseases	F10
Atrial fibrillation and flutter	I47.1, I47.9, I49.5, I49.8, I49.9, R00.0, R002, R00.8
Constipation	K59.0
Fractured proximal femur	S72.0, S72.1, S72.2
Dyspepsia and other stomach function disorders	K30, K21
Hypokalemia	E87.6
Migraine/acute headache	G43, G44.0, G44.1, G44.3, G44.4, G44.8, R51x

Re-admissions

Re-admissions

“Proportion of people who are still at home 91 days after discharge from hospital”

9. References

1. Drummond M, Sculpher M, Torrance G, O'Brien B, Stoffart G. *Methods for the economic evaluation of health care programmes. third edition*. Third Edition ed. Oxford University Press; 2005.
2. Porter ME, Larsson S, Lee TH. Standardizing patient outcomes measurement. *N Engl J Med*. 2016;374(6):504-506.
3. Von Schirnding Y. Health in sustainable development planning: The role of indicators. *World Health Organization*. 2002;WHO/HDE/HID/02. 11.
4. Payne K, McAllister M, Davies LM. Valuing the economic benefits of complex interventions: When maximising health is not sufficient. *Health Econ*. 2013;22(3):258-271.
5. Berwick DM, Nolan TW, Whittington J. The triple aim: Care, health, and cost. *Health Aff (Millwood)*. 2008;27(3):759-769.
6. Whittington JW, Nolan K, Lewis N, Torres T. Pursuing the triple aim: The first 7 years. *Milbank Q*. 2015;93(2):263-300.
7. Tsiachristas A, Rutten- van Mölken M. Chapter 4.1 evaluating complex interventions. In: Volker A, Stein K, Goodwin N, Balicer R, Nolte E, Suter E, eds. *Handbook of integrated care*. Berlin: Springer; (in press).
8. Stiefel M, Nolan K. A guide to measuring the triple aim: Population health, experience of care and per capita cost. *IHI Innovation Series white paper Cambridge, Massachusetts: Institute for Healthcare Improvement*. 2012.
9. Hendrikx RJ, Drewes HW, Spreeuwenberg M, Ruwaard D, Struijs JN, Baan CA. Which triple aim related measures are being used to evaluate population management initiatives? an international comparative analysis. *Health Policy*. 2016;120(5):471-485.
10. Verbeek NA, Franken M, Tsiachristas A, Koopmanschap MA, Rutten-van Molken MP. A triple aim framework for the performance assessment of disease management programs. *Value Health*. 2015;18(7):A400.
11. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346:f167.
12. Porter ME. What is value in health care? *N Engl J Med*. 2010;363(26):2477-2481.

13. Struckmann V, Leijten F, Van Ginneken E, et al. Results of a scoping review on integrated care for persons with multi-morbidity. *(submitted)*.
14. Leijten F, Struckmann V, van Ginneken E, et al. The SELFIE framework for integrated care for multi-morbidity: Development and description. *(submitted)*.
15. Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ*. 2011;343:d4163.
16. Huber M, van Vliet M, Giezenberg M, et al. Towards a 'patient-centred' operationalisation of the new dynamic concept of health: A mixed methods study. *BMJ Open*. 2016;6(1):e010091-2015-010091.
17. Linton MJ, Dieppe P, Medina-Lara A. Review of 99 self-report measures for assessing well-being in adults: Exploring dimensions of well-being and developments over time. *BMJ Open*. 2016;6(7):e010641-2015-010641.
18. OECD. Health at a glance 2015: OECD indicators. *OECD Publishing, Paris* http://dx.doi.org/10.1787/health_glance-2015-en. 2015.
19. Raleigh V, Bardsley M, Smith P, et al. Integrated care and support pioneers: Indicators for measuring the quality of integrated care. final report. *Policy Innovation Research Unit*. 2014;8.
20. World Health Organization. People-centred and integrated health services: An overview of the evidence. interim report. *WHO Press*. 2015;WHO/HIS/SDS/2015.7.
21. Guézennec M. Integrated care in europe: What is measured and how? identification of indicators and measures used in practice. *(submitted)*.
22. SUSTAIN. Sustainable tailored integrated care for older people in europe. <http://www.sustain-eu.org/>.
23. ACT@Scale. Advancing care coordination and telehealth deployment at scale. <https://www.act-at-scale.eu/>.
24. Topics-MDS. The older persons and informal caregivers survey minimum DataSet. <http://topics-mds.eu/>.
25. World Health Organization. WHO definition of health. <http://www.who.int/about/definition/en/print.html>. Updated 1948.
26. Carinci F, Van Gool K, Mainz J, et al. Towards actionable international comparisons of health system performance: Expert revision of the OECD framework and quality indicators. *Int J Qual Health Care*. 2015;27(2):137-146.

27. Evans RG, Stoddart GL. Producing health, consuming health care. *Soc Sci Med*. 1990;31(12):1347-1363.
28. Boorsma M, Frijters DH, Knol DL, Ribbe ME, Nijpels G, van Hout HP. Effects of multidisciplinary integrated care on quality of care in residential care facilities for elderly people: A cluster randomized trial. *CMAJ*. 2011;183(11):E724-32.
29. Fabbriotti IN, Janse B, Looman WM, de Kuijper R, van Wijngaarden JD, Reijfers A. Integrated care for frail elderly compared to usual care: A study protocol of a quasi-experiment on the effects on the frail elderly, their caregivers, health professionals and health care costs. *BMC Geriatr*. 2013;13:31-2318-13-31.
30. Peters LL, Boter H, Buskens E, Slaets JP. Measurement properties of the groningen frailty indicator in home-dwelling and institutionalized elderly people. *J Am Med Dir Assoc*. 2012;13(6):546-551.
31. EuroQol Group. EuroQol--a new facility for the measurement of health-related quality of life. the EuroQol group. *Health Policy*. 1990;16(3):199-208.
32. Krabbe PF, Stouthard ME, Essink-Bot ML, Bonsel GJ. The effect of adding a cognitive dimension to the EuroQol multiattribute health-status classification system. *J Clin Epidemiol*. 1999;52(4):293-301.
33. Brazier JE, Harper R, Jones NM, et al. Validating the SF-36 health survey questionnaire: New outcome measure for primary care. *BMJ*. 1992;305(6846):160-164.
34. Muntinga ME, Hoogendijk EO, van Leeuwen KM, et al. Implementing the chronic care model for frail older adults in the netherlands: Study protocol of ACT (frail older adults: Care in transition). *BMC Geriatr*. 2012;12:19-2318-12-19.
35. Nederlands Trial Register. PIL: Polypharmacie intervention limburg, too much or too little? <http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2154>. Updated 2010. Accessed January, 2017.
36. Freund T, Peters-Klimm F, Rochon J, et al. Primary care practice-based care management for chronically ill patients (PraCMan): Study protocol for a cluster randomized controlled trial [ISRCTN56104508. *Trials*. 2011;12:163-6215-12-163.
37. Schmidt K, Thiel P, Mueller F, et al. Sepsis survivors monitoring and coordination in outpatient health care (SMOOTH): Study protocol for a randomized controlled trial. *Trials*. 2014;15:283-6215-15-283.

38. Muth C, Harder S, Uhlmann L, et al. Pilot study to test the feasibility of a trial design and complex intervention on PRIoritising MULtimedication in multimorbidity in general practices (PRIMUMpilot). *BMJ Open*. 2016;6(7):e011613-2016-011613.
39. Roland M, Lewis R, Steventon A, et al. Case management for at-risk elderly patients in the english integrated care pilots: Observational study of staff and patient experience and secondary care utilisation. *Int J Integr Care*. 2012;12:e130-Sep.
40. Coventry P, Lovell K, Dickens C, et al. Integrated primary care for patients with mental and physical multimorbidity: Cluster randomised controlled trial of collaborative care for patients with depression comorbid with diabetes or cardiovascular disease. *BMJ*. 2015;350:h638.
41. Allen KR, Hazelett SE, Radwany S, Ertle D, Fosnight SM, Moore PS. The promoting effective advance care for elders (PEACE) randomized pilot study: Theoretical framework and study design. *Popul Health Manag*. 2012;15(2):71-77.
42. Meret-Hanke LA. Effects of the program of all-inclusive care for the elderly on hospital use. *Gerontologist*. 2011;51(6):774-785.
43. Bielaszka-DuVernay C. The 'GRACE' model: In-home assessments lead to better care for dual eligibles. *Health Aff (Millwood)*. 2011;30(3):431-434.
44. Katon W, Lin EH, Von Korff M, et al. Integrating depression and chronic disease care among patients with diabetes and/or coronary heart disease: The design of the TEAMcare study. *Contemp Clin Trials*. 2010;31(4):312-322.
45. Tanio C, Chen C. Innovations at miami practice show promise for treating high-risk medicare patients. *Health Aff (Millwood)*. 2013;32(6):1078-1082.
46. KATZ S, FORD AB, MOSKOWITZ RW, JACKSON BA, JAFFE MW. Studies of illness in the aged. the index of adl: A standardized measure of biological and psychosocial function. *JAMA*. 1963;185:914-919.
47. World Health Organization. WHO centre for health development ageing and health technical report. . 2004;Volume 5:111.
48. Centers for Disease Control and Prevention (CDC). Behavioral risk factor surveillance system survey questionnaire. *Atlanta, Georgia: U S Department of Health and Human Services*. 2007.

49. Winefield H, Gill T, Taylor A, Pilkington R. Psychological well-being and psychological distress: Is it necessary to measure both? *Psychology of Well-Being: Theory, Research and Practice*. 2012;2:3.
50. Mars GM, Kempen GI, Post MW, Proot IM, Mesters I, van Eijk JT. The maastricht social participation profile: Development and clinimetric properties in older adults with a chronic physical illness. *Qual Life Res*. 2009;18(9):1207-1218.
51. Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with life scale. *J Pers Assess*. 1985;49(1):71-75.
52. Petros N, Opacka-Juffry J, Huber JH. Psychometric and neurobiological assessment of resilience in a non-clinical sample of adults. *Psychoneuroendocrinology*. 2013;38(10):2099-2108.
53. Uijen AA, Heinst CW, Schellevis FG, et al. Measurement properties of questionnaires measuring continuity of care: A systematic review. *PLoS One*. 2012;7(7):e42256.
54. World Health Organization. A glossary of terms for community health care and services for older persons. *World Health Organization*. 2011;A WHO Centre for Health Development Ageing and Health Technical Report Volume 5.
55. Ryan A, Wallace E, O'Hara P, Smith SM. Multimorbidity and functional decline in community-dwelling adults: A systematic review. *Health Qual Life Outcomes*. 2015;13:168-015-0355-9.
56. Laan W, Zuithoff NP, Drubbel I, et al. Validity and reliability of the katz-15 scale to measure unfavorable health outcomes in community-dwelling older people. *J Nutr Health Aging*. 2014;18(9):848-854.
57. MAHONEY FI, BARTHEL DW. Functional evaluation: The barthel index. *Md State Med J*. 1965;14:61-65.
58. Hindmarch I, Lehfeld H, de Jongh P, Erzigkeit H. The bayer activities of daily living scale (B-ADL). *Dement Geriatr Cogn Disord*. 1998;9 Suppl 2:20-26.
59. Johnson N, Barion A, Rademaker A, Rehkemper G, Weintraub S. The activities of daily living questionnaire: A validation study in patients with dementia. *Alzheimer Dis Assoc Disord*. 2004;18(4):223-230.
60. Joseph S, Maltby J. Positive functioning inventory: Initial validation of a 12-item self-report measure of well-being. *Psychology of Well-Being Theory, Research and Practice*. 2014:4-15.

61. Chassany O, Dimenäs E, Dubois D, Wu A, Dupuy H. The psychological general well-being index (PGWBI) user manual. *MAPI Research Institute*. 2004.
62. Vilagut G, Forero CG, Pinto-Meza A, et al. The mental component of the short-form 12 health survey (SF-12) as a measure of depressive disorders in the general population: Results with three alternative scoring methods. *Value Health*. 2013;16(4):564-573.
63. Friedman B, Heisel M, Delavan R. Validity of the SF-36 five-item mental health index for major depression in functionally impaired, community-dwelling elderly patients. *J Am Geriatr Soc*. 2005;53(11):1978-1985.
64. Warwick Medical School. Warwick-edinburgh mental wellbeing scale (WEMWBS). <http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/>. Accessed November, 2016.
65. Rose M, Devine J. Assessment of patient-reported symptoms of anxiety. *Dialogues Clin Neurosci*. 2014;16(2):197-211.
66. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67(6):361-370.
67. Kroenke K, Spitzer RL, Williams JB, Lowe B. An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*. 2009;50(6):613-621.
68. Dalemans R, de Witte LP, Lemmens J, van den Heuvel WJ, Wade DT. Measures for rating social participation in people with aphasia: A systematic review. *Clin Rehabil*. 2008;22(6):542-555.
69. Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ. The development of a handicap assessment questionnaire: The impact on participation and autonomy (IPA). *Clin Rehabil*. 1999;13(5):411-419.
70. van Brakel WH, Anderson AM, Mutatkar RK, et al. The participation scale: Measuring a key concept in public health. *Disabil Rehabil*. 2006;28(4):193-203.
71. Brown M, Dijkers MP, Gordon WA, Ashman T, Charatz H, Cheng Z. Participation objective, participation subjective: A measure of participation combining outsider and insider perspectives. *J Head Trauma Rehabil*. 2004;19(6):459-481.
72. Cardol M, de Haan RJ, de Jong BA, van den Bos GA, de Groot IJ. Psychometric properties of the impact on participation and autonomy questionnaire. *Arch Phys Med Rehabil*. 2001;82(2):210-216.

73. Sibley A, Kersten P, Ward CD, White B, Mehta R, George S. Measuring autonomy in disabled people: Validation of a new scale in a UK population. *Clin Rehabil.* 2006;20(9):793-803.
74. Kersten P, Cardol M, George S, Ward C, Sibley A, White B. Validity of the impact on participation and autonomy questionnaire: A comparison between two countries. *Disabil Rehabil.* 2007;29(19):1502-1509.
75. Lund ML, Fisher AG, Lexell J, Bernspang B. Impact on participation and autonomy questionnaire: Internal scale validity of the swedish version for use in people with spinal cord injury. *J Rehabil Med.* 2007;39(2):156-162.
76. Windle G, Bennett KM, Noyes J. A methodological review of resilience measurement scales. *Health Qual Life Outcomes.* 2011;9:8-7525-9-8.
77. Cosco TD, Kaushal A, Richards M, Kuh D, Stafford M. Resilience measurement in later life: A systematic review and psychometric analysis. *Health Qual Life Outcomes.* 2016;14:16-016-0418-6.
78. Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the connor-davidson resilience scale (CD-RISC): Validation of a 10-item measure of resilience. *J Trauma Stress.* 2007;20(6):1019-1028.
79. Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Bernard J. The brief resilience scale: Assessing the ability to bounce back. *Int J Behav Med.* 2008;15(3):194-200.
80. Von Eisenhart Rothe A, Zenger M, Lacruz ME, et al. Validation and development of a shorter version of the resilience scale RS-11: Results from the population-based KORA-age study. *BMC Psychol.* 2013;1(1):25-7283-1-25. eCollection 2013.
81. Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T. An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Qual Life Res.* 2008;17(7):967-976.
82. Fugl-Myer A, Braunholm I, Flugl-Myer K. Happiness and domain-specific life satisfaction in adult northern swedes. *Clinical rehabilitation.* 1991;5:25-33.
83. Endicott J, Nee J, Harrison W, Blumenthal R. Quality of life enjoyment and satisfaction questionnaire: A new measure. *Psychopharmacol Bull.* 1993;29(2):321-326.

84. Makai P, Koopmanschap MA, Brouwer WB, Nieboer AA. A validation of the ICECAP-O in a population of post-hospitalized older people in the netherlands. *Health Qual Life Outcomes*. 2013;11:57-7525-11-57.
85. Uittenbroek RJ, Reijneveld SA, Stewart RE, Spoorenberg SL, Kremer HP, Wynia K. Development and psychometric evaluation of a measure to evaluate the quality of integrated care: The patient assessment of integrated elderly care. *Health Expect*. 2016;19(4):962-972.
86. Measures for Person Centred Coordinated Care. Person centred coordinated experience questionnaire (formerly know as the modified long term conditions questionnaire 6). http://p3c.org.uk/prom-detail/29%20-%20ChildVerticalTab_11. Accessed November, 2016.
87. Uijen AA, Schellevis FG, van den Bosch WJ, Mookink HG, van Weel C, Schers HJ. Nijmegen continuity questionnaire: Development and testing of a questionnaire that measures continuity of care. *J Clin Epidemiol*. 2011;64(12):1391-1399.
88. McGuinness C, Sibthorpe B. Development and initial validation of a measure of coordination of health care. *Int J Qual Health Care*. 2003;15(4):309-318.
89. Sisler JJ, Taylor-Brown J, Nugent Z, et al. Continuity of care of colorectal cancer survivors at the end of treatment: The oncology-primary care interface. *J Cancer Surviv*. 2012;6(4):468-475.
90. Rutten-van Mölken M, Rutten F, Uyl-de Groot C. *Van kosten tot effecten. een handleiding voor evaluatiestudies in de gezondheidszorg*. Second Edition ed. Maarssen: Elsevier Gezondheidszorg.; 2010.
91. Tsiachristas A, Waters BH, Adams SA, Bal R, Molken MP. Identifying and explaining the variability in development and implementation costs of disease management programs in the netherlands. *BMC Health Serv Res*. 2014;14:518-014-0518-0.
92. Productivity and Health Research Group. iMTA medical consumption questionnaire. www.imta.nl.
93. Chisholm D, Knapp MR, Knudsen HC, Amaddeo F, Gaite L, van Wijngaarden B. Client socio-demographic and service receipt inventory--european version: Development of an instrument for international research. EPSILON study 5. european psychiatric services: Inputs linked to outcome domains and needs. *Br J Psychiatry Suppl*. 2000;(39)(39):s28-33.

94. Hoogendoorn M, van Wetering CR, Schols AM, Rutten-van Molken MP. Self-report versus care provider registration of healthcare utilization: Impact on cost and cost-utility. *Int J Technol Assess Health Care*. 2009;25(4):588-595.
95. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005;40(6 Pt 1):1918-1930.
96. Weeks WB, Ventelou B, Paraponaris A. Rates of admission for ambulatory care sensitive conditions in france in 2009-2010: Trends, geographic variation, costs, and an international comparison. *Eur J Health Econ*. 2016;17(4):453-470.
97. Pearlin LI, Schooler C. The structure of coping. *J Health Soc Behav*. 1978;19(1):2-21.
98. Krska J, Morecroft CW, Rowe PH, Poole H. Measuring the impact of long-term medicines use from the patient perspective. *Int J Clin Pharm*. 2014;36(4):675-678.
99. Hoefman R, Van Exel N, Brouwer W. iMTA valuation of informal care questionnaire (iVICQ). version 1.0. Rotterdam: iBMG / iMTA, 2011 [retrieved from www.bmg.eur.nl/english/imta/publications/manuals_questionnaires/]. 2011.
100. Groenvold M, Petersen MA, Aaronson NK, et al. The development of the EORTC QLQ-C15-PAL: A shortened questionnaire for cancer patients in palliative care. *Eur J Cancer*. 2006;42(1):55-64.
101. Lown BA, Muncer SJ, Chadwick R. Can compassionate healthcare be measured? the schwartz center compassionate care scale. *Patient Educ Couns*. 2015;98(8):1005-1010.
102. Pearce D. *The self-sufficiency standard*. Texas: Wider Opportunities for Woman; 1996.
103. Fassaert T, Lauriks S, van de Weerd S, et al. Psychometric properties of the dutch version of the self-sufficiency matrix (SSM-D). *Community Ment Health J*. 2014;50(5):583-590.