Innovative approaches to outcome measurement in EU-funded research projects on integrated care for people with complex needs

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Background

Roll out of numerous integrated care initiatives for people with complex needs

Strong belief in the benefits of integrated care:

- Tackle the challenge of delivering high-quality person-centered community-based care
  - Better coordination
  - Reduce service utilization
  - Improve healthcare utilization
- Independence and self-management
- Improve or maintain lifestyle at home
- “Tell my story only once”

Better experience

Better utilization

Better outcomes

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Scientific evidence

Policy-makers need process- and outcome-oriented, **evidence-based strategies**

- Research design problems
  - Sample sizes and recruitment
  - Evaluability
  - Counterfactual, before and after
  - Measurement: attribution and sensitivity
    - Reliance of service measures, quality of life, improvement in health and social status

- Evidence remains inconsistent
  - Impact and outcomes not obvious for complex patients
  - Five year evaluation of 30 initiatives: no reduction in emergency admissions and associated costs [Bardsley et al 2013]
  - Systematic reviews shed no light on what works

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Evidence from practice

Need to understand the implementation process and what works for whom, in what setting and with what outcome

- From practice we know the **important ingredients**

Organization	Professionals	User perspective
• Leadership & governance • Funding and contract agreements • Workforce strategies • IT infrastructure	• Defining objectives and roles • Shared documentation • Space • Active management • Autonomy	• Kindness and patience • Dignity • Independence • Contact with others • Stay in your own home

- Evidence grounded from practice
  - provides the best routes to achieving specific outcomes
  - avoids inappropriate data collection
  - highlights the relevance of ‘proxy’ measures
  - improves professional credibility and confidence

Appropriate outcomes for evaluation

- Often there is a strong focus on classical health outcomes
  - Examples: health status, physical functioning and quality of life
  - Whereas outcomes such as wellbeing, experience with care, social functioning, social participation and goal attainment might be more appropriate for vulnerable target groups such as frail older people and people with multimorbidity

- Often there is a strong focus on quantitative outcomes
  - Whereas mixed methods approaches might be more appropriate in evaluating **complex interventions** such as integrated care taking into account the **processes and contexts** in which these programs are implemented

Three different EU-funded research initiatives are taking place that take innovative approaches to measure the outcomes of integrated care practices for vulnerable populations with complex needs

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A short overview of the projects

- EU funded projects: ACT@Scale, SELFIE, SUSTAIN
- Evaluate existing integrated care initiatives
- Differences
  - Aim / Focus
  - Indicators
  - Instruments

Characteristics	ACT@Scale	SELFIE	SUSTAIN
Target population	Participants of an integrated care program	Multi-morbidity	Frail elderly
Focus	Scaling-up process	Evaluation and funding	Quality improvement
AIM	Structured methodology for assessment, benchmarking and exchange of good practices of scaling-up Transferability of good practices for scaling-up	Taxonomy of promising integrated care programmes and matching financing schemes Empirical evidence on impact of programmes & financing schemes on outcomes Develop implementation & transferability strategies	To improve established integrated care initiatives To ensure transferability of improvements to other EU health systems and regions

Process Indicators

ACT@Scale	SELFIE	SUSTAIN
Population coverage		**Person centeredness**
# Population stratified by the population tool # stratification levels # Population per risk stratum # Target population (size) # Population served (size) # Population diagnosed with target disease (size)	*Example frail elderly:* % patient with an individual care plan % patients discussed in a multi-disciplinary team meeting % patients actually present themselves during a multi-disciplinary team meeting % patients with a medication review	# users with needs assessment # care plans with activities (being) actioned # care plans shared across profs # care plans shared across orgs # carers with a needs assessment # carers with a care plan
		Prevention orientation
		# users receiving medication review # users receiving med adherence advice # users receiving self-man advice
		Safety
		# users receiving safety advice (eg falls) # users with falls recorded in care plan

Additional process indicators

- Change and stakeholder management
- Service selection
- Business models and sustainability
- Citizen empowerment

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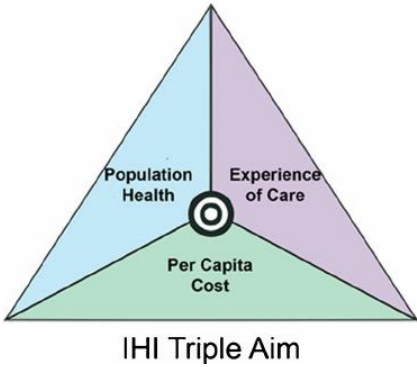
Core Outcomes – Experience of Care



IHI Triple Aim

Example program-specific:
(Frail Elderly) Autonomy

ACT@Scale	SELFIE	SUSTAIN
Experience with care	**Experience with care**	**Experience with care**
• Disease impact • Comfort with technology • Comfort in groups • Phenotype • Coping style • Patient activation • Ability for self-care • Social support • Psycho-social well-being	• person-centeredness • Continuity of care	• Patient perceptions of quality and coordination of care and support (P3CEQ) • Perceived control in care and support of older people (PCHC) • Perception and experiences of users, informal carers, professionals and managers with person-centredness, prevention, safety, and efficiency (interviews)
	Health and wellbeing	**Implementation progress**
	• Physical functioning • Psychological wellbeing • Social relationships & participation • Enjoyment of life • Resilience	• Team coherence of improvement team (professionals) (TCI) • Perception and experiences of professionals and managers (focus group interviews, minutes from steering group meetings, field notes)

	Programme-type specific outcomes			
	Population health management	Frail elderly	Palliative and oncology	Problems in multiple life domains
Health & well-being	Activation & engagement	Autonomy	Mortality	Financial independence
			Pain and other symptoms	
Experience		Burden of medication	Compassionate care	
		Burden of informal caregiving	Timely access to care	
			Preferred place of death	
			Burden of informal caregiving	
Costs	Ambulatory care sensitive hospital admission	Long-term institution admissions		Contacts with the ju system
	Hospital re-admissions	Falls leading to hospital admissions		

Examples Program specific:
(Frail Elderly) Burden of medication
(Frail Elderly) Burden of informal care giving

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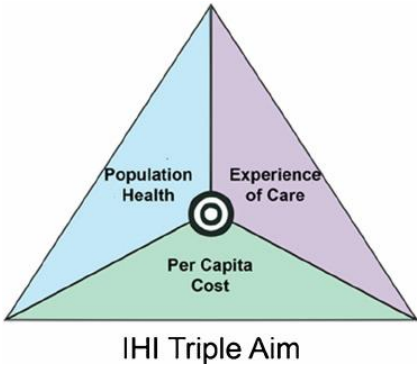
Core Outcomes – Per Capita Cost



IHI Triple Aim

ACT@Scale	SELFIE	SUSTAIN
Cost	Costs	Efficiency
• Cost per user • Cost per program	• Total health care costs pp • Total social care costs pp	# emergency hospital admissions LoS per emergency admission # hospital readmissions per user # hours dedicate to initiative, per member Cost related to equipment and technology

Program specific selections:
PC: home visit
PC: GP visit
PC: nurse visit
SC: ED visit
SC: specialist visit
SC: admissions
SC: admissions (30)
SC: hospitalization
SC: outpatient visit
CC: community care referrals
CC: home visit

Program specific frail elderly:
Long term institution admissions
Falls leading to hospital admissions

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Challenges - surveys

- **Harmonization between countries**
  - Questionnaires not available in all languages
  - Translations have not been validated
  - Sometimes inappropriate in a different culture

- **Harmonization between programs**
  - Mismatch with program population or program ambitions

- **Survey / research fatigue**
  - Use of shorter alternatives
  - Combine surveys

- **Additional challenges in vulnerable populations**
  - Organization and distribution difficult
  - Due to age of the population, surveys:
    - Difficult to understand and too long
    - Don't match experiences and perceptions of elderly
  - Reliability of the responses?
- **Consider: interviews, face-face administration of surveys, involve representative**

Challenges - measuring impact

- **Data inconsistency**
  - Quantitative: registries, local systems (regions, countries)
  - Qualitative: different instruments
    - **Flexible approach: concepts of core indicators, allowing multiple instruments**

- **Data availability**: issues preventing upload of data and/or to produce linked data for analysis

- **Changing environment**
  - Process improvement +
  - All sudden or gradual changes in organization, funding, processes, politics, technology, recruitment, staff engagement

- **Time pressure**
  - Quick results: produce outcomes versus the ability to create data
  - Project life cycles
    - Especially if also interventions are implemented within the programs
    - We expect to see impact on the process, but not see impact on outcomes

Dealing with variety

Expect differences due to program objectives, cultural differences, availability of validated surveys, access to data, or other pragmatic considerations

- **Operational setting**: running programs with existing measures
  - **Continuation of measurements used in the past is more important than comparability across programs**
  - **Where possible, harmonize the data with proposal for new data collection**

- **Harmonization between countries**
  - Data registries measure and report differently
  - Local systems measure and report differently

- **Harmonization between programs**
  - Wide scope of programs, difficult to get agreement on outcome indicators
  - **Layered approach: core set + program-specific outcomes**

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Summary

- Health and wellbeing indicators are perceived important
  - Recognized by all stakeholders
  - **interviews, face-face administration of surveys, involvement of representatives may be more appropriate for vulnerable populations**

- Process measures are important to understand quality improvement process
  - Different ways to do this: surveys, registries, interviews
  - **Mixed methods can help to understand the underlying mechanisms**

- Need to facilitate variety:
  - Program perspective
    - Value in continuation of existing measurements
    - Less focus on across program comparison
    - **Facilitate core + program-specific outcomes**
    - **Support multiple instruments to measure similar concepts**
  - Conflicts with research, policy makers and payers ambitions to unify and compare

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Discussion

- Which outcome measures are most relevant to evaluate health and wellbeing, patient experiences and reducing costs?
- Which practical issues should be taken into account when collecting data in vulnerable populations?
- Do we have the right indicators and instruments to measure outcomes in people with complex needs? Do we measure impact & changes?
- What challenges are to be expected when harmonising outcome measurement across and within countries;
- What does and does not work in evaluating integrated care?
- How can lessons learned from these projects collectively bring evaluation of integrated care practices forward?

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Questions?

Advancing Care Coordination and Telehealth deployment at Scale
ACT@Scale
https://www.act-at-scale.eu

Sustainable Tailored Integrated Care for Older People in Europe
SUSTAIN
www.sustain-eu.org

Sustainable Integrated Care Models for Multi-Morbidity: Delivery, Financing and Performance
SELFIE
http://www.selfie2020.eu/

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