SUSTAIN: what have we learned so far and how to move forward?

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ON BEHALF OF THE SUSTAIN CONSORTIUM
This presentation

1. Current status of the SUSTAIN project, aim, methodological approach and progression

2. SUSTAIN in Catalonia; a case example

3. SUSTAIN in Estonia; a case example

4. Development process of the roadmap to the improvement of existing integrated care initiatives

5. Your input on the roadmap; discussion!
Current status of the SUSTAIN project (2015-2019)
The SUSTAIN consortium
SUSTAIN aims

1. To **improve** established integrated care initiatives for older people living at home with multiple health and social care needs;

2. To ensure that improvements to the integrated care initiatives are **applicable** and **adaptable** to other health systems and regions in Europe.
SUSTAIN core domains

Person-centredness

Prevention-orientation

Efficiency

Safety
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<td>KV RegioMed Zentrum Templin (DE)</td>
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What have we done so far? April 2015 - May 2017

1. Working relationships
2. Initial assessments and workshops
3. Identification improvement areas
4. Design improvement projects
5. Roll-out improvement projects
6. First assessments

Methodological development and testing
Main deliverable Roadmap

Improved integrated care

Tips and tricks

Indicators/data collection tools

Good practices

Solutions for implementation issues

Instruments to develop improvement project
Improvement areas

Collaboration and coordination

Information exchange

More person-centred way of working
Improvement projects, some examples
Osona - Catalonia

https://www.youtube.com/watch?v=x3XXQcfj3FY
Improvement projects, some examples

- No joint assessment of needs
- Lack of standard exchange procedures
- Older people not actively involved in definition of care plan
Improvement projects, some examples
Improvement projects, some examples

**SELECTION CRITERIA**
- ≥ 65 years
- Living at home
- Health and social needs
- Cognitively capable

1. Pre-surveys
2. Selection of patients by health or social professionals in their settings (Primary Health Care, Social Services and the Geriatric service)
3. Patient recruitment by professionals & Informed consent signed
Improvement projects, some examples
Improvement projects, some examples
Improvement projects, some examples
Challenge  -  Solution

Lack of cooperation between healthcare and social systems

Lack on information sharing, partly due to strict medical data protection regulations.

Digital data sharing platform not feasible in the timeframe (legal issues and expensive development work)

A printed care and support plan (CSP) delivered to the patient that the multidisciplinary team fills in at each visit.

The intervention would actively involve patients in setting their own priorities and making decisions about how they want to be supported.

SUSTAIN in ESTONIA
What is the shared care and support plan (CSP)?

CSP is an overarching plan, designed to support the coordination of care across healthcare and social services.

CSP is developed together with the patient.

CSP captures key information about the person’s status, critical issues, needs, challenges, abilities and interests.

CSP provides the patient and the multidisciplinary staff with an overview of how the team works together.
Aim of the intervention

- To increase the engagement of the person, family, carers and other specialities into development of the goal directed common care plan.
- To provide person with personalized care in an efficient manner without any overlap or duplicating.
- To tailor the care services to the needs of the patient.
Benefits

• Shared understanding of key elements of effective goal setting and prevention-oriented care planning among the multiprofessional staff.

• Increased knowledge and awareness of staff supports the overall quality improvement and safety of the service and enhances the commitment of the staff delivering person-centered care.

• The project can be described as successful if the patient’s needs are satisfied, health is stable, frailty is not worsening and she is able to stay at home avoiding institutional care as long as possible.
Overall methodological approach and methodological challenges
SUSTAIN propositions

- Identified actions for improvement for integrated care will enhance patient-centredness, prevention orientation, safety, and efficiency in care delivery.
- Identified actions for improvement will ascertain what works for whom, in what context and with what outcomes.
- Explanations for (not) succeeding in improving existing integrated care initiatives will be identified.
- Factors necessary to guarantee impact and transferability and applicability of actions for improvement across the EU will be identified.
Implementation Science Evidence Integration Triangle (Glasgow 2013)

Intervention
Improvements to integrated care services

Evidence

Stakeholders

Participatory Implementation Process
Stakeholder engagement; cyclical evaluation

Practical Measures
Case study design with qualitative and quantitative indicators, process evaluation

Multi-Level Context (Macro, Meso, Micro)
- Interpersonal / person centeredness
- Social / Environment
- Policy
- Community
- Organisational
Case Study Design (Yin 2003)

**SUSTAIN UNIT OF ANALYSIS:**

**SET OF IMPROVEMENTS FOR INTEGRATED CARE INITIATIVE**

**Qualitative indicators:**
- Surveys to users (30: 840) and staff (10-20: 140-280)

**Quantitative indicators** (set of 16 per site)

**Dyad (6: 168) or single interviews with users (6: 84) and carers (6: 84)**

**Documents:**
- Care plans (6: 84) and steering group discussions (all)

**Interviews with managers (1: 14)**

**Focus groups:**
- Professionals/agency representatives (6-10: 84-140)**
Qualitative indicators

Perceived Control of Health Care (PCHC)(users)
- Control over organising health care, contacting and communicating workers, organising care in the future, managing help from family/friends

The Person Centred Coordinated Care Experiences (users)
- Goal setting, patient activation and empowerment, care coordination, involvement in decision making, information gathering and sharing

Team Climate Inventory (TCI-14) (professionals)
- Vision, task orientation, support for innovation
# Quantitative Indicators per SUSTAIN theme

*(GREY = care plan/clinical notes/other notes; ORANGE = carer demographic sheet; BLUE = service data)*

## PERSON-CENTREDNESS
- Number of users with a needs assessment
- Number of care plans with activities already actioned or being actioned
- Number of care plans shared across different professionals
- Number of care plans shared across different organisations
- Number of carers with a needs assessment
- Number of carers with a care plan

## PREVENTION-ORIENTATION
- Number of users receiving a medication review
- Number of users received or receiving advice on medication adherence
- Number of users received or receiving advice on self-management and how to maintain independence

## SAFETY
- Number of users received or receiving safety advice (home security, falls prevention)
- Number of users with falls recorded in the care plan

## EFFICIENCY
- Number of emergency hospital admissions of user (during 12 week evaluation period)
- Length of stay per emergency admission of user (during 12 week evaluation period)
- Number of hospital readmissions of the user (during 12 week evaluation period)
- Number of staff hours dedicated to initiative (per staff member)
- Costs related to equipment and technology for initiative
Overview of what is collected when

**Timeline**
- **0-6 months**
  - Team Climate Inventory (TCI)

- **6 months**
  - Discussion with steering group: Assessment and planning

- **6-12 months**
  - P3CEQ, PCHC, Quantitative indicators
  - User and carer interviews
  - Document analysis/care plans

- **12 months**
  - EIT: Evidence Feedback to steering group: Assessment and planning

- **12-18 months**
  - P3CEQ, PCHC, TCI
  - Quantitative indicators
  - Manager interview
  - Focus group
  - User/carer interview
  - Document analysis/care plans

- **18 months**
  - EIT: Evidence Feedback for final assessment and future planning
Challenges to methods

Accommodation to nature of improvement projects
- Length and intensity of intervention

Accommodation to the changing context of implementation
- Changes in project direction (new provider, resources, local policy)
- Overlapping of other new projects starting alongside
- Site withdrawal
- Analysis approach
  - Potential bias in variations in country data affecting overarching analysis
  - Conflict with role of researcher: participation in improvement project vs objective researcher in evaluation
Development process of the roadmap to the improvement of existing integrated care initiatives
1. Develop a **design tool** for decision-makers that:

(a) provides for a step-by-step guide to the necessary approaches and competencies required when planning services for older people living at home;

(b) enables a self-assessment of progress

(c) sets out guidance on how to manage, monitor, evaluate and improve
Purpose of the Roadmap - 2

Develop an **engagement tool** that:

(a) examines ‘how to’ develop a guiding coalition towards integrated care; build support for change from key stakeholders;

(b) provides guidance and support on the strategies required of leaders and managers
Principles in Developing the Roadmap

✓ Content *and* format to be co-designed with case sites and ‘end users’;

✓ To be tested out by policy-makers and decision-makers across the case sites and other integrated care programmes;

✓ To be an open-access resource available to all on-line;

✓ To support implementation through self-assessment
Roadmap Content Development

Phase 1 (May 2015 to November 2016)
➢ Non-systematic literature review of international approaches
➢ Web-based search to uncover existing tool-kits or strategies
➢ Review of frameworks on ‘what works’ for integrated care implementation
➢ Non-systematic review of issues related to change management
➢ Synthesis creates a ‘first version’ of the Roadmap

Phase 2 (December 2016 - present)
➢ ‘First version’ ‘tested out’ with consortium partners;
➢ Rounds of ‘testing’ with case sites and users
➢ Future steps
➢ ‘Second version’ to be developed as a prototype on-line version in the Autumn 2017
➢ Further iterations of development and testing
EMERGENT ROADMAP CONTENTS

**Design**
- Introduction
- Service Design Guide
- Self Assessment Guide

**Implementation**
- Introduction
- Implementing Integrated care
- Making Change Happen

**Engagement**
- Introduction
- Developing an Enabling Environment
- Guide to Leadership and Management

**Key Actions**

**Resources and Further Information**
**Introduction: Road Map Development**

- **Why?**
- **How?**
- **For whom?**
- **User guide**

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**Who Is This Roadmap For?**

It's our hope that a wide variety of stakeholders—individuals and organizations—will find the roadmap actionable and useful, including:

- People who care for patients and provide healthcare services
- Leaders of healthcare organizations
- Health-related professional and trade associations
- Patients, family members, and caregivers
- Individuals involved in health professions education
- Insurers
- Employers
- Researchers
- Funders
- Policymakers
- Consumer advocacy groups

This roadmap is for anyone interested in advancing work related to patient and family engagement—creating meaningful partnerships, increasing knowledge, developing and enhancing skills, and forging a path forward.

For many of these groups and individuals, the roadmap serves as a call to action. If you are interested in patient and family engagement, this roadmap has a range of strategies that you can use. For all groups, the roadmap highlights opportunities to create meaningful partnerships among and between stakeholder groups to foster healthcare changes that lead to better patient experiences of care, better population health, and lower costs.
**INTRO to Service Design**

When developing an integrated care approach, it is important to ask what works for who, where, how and with what outcomes. Guided by implementation science, we are not manipulating behaviour but seek to work with stakeholders through a participatory approach; (c) inclusion of the stakeholders is critical because of the dynamic and influential nature of context on the health and social care settings; and (d) boundaries between integrated care initiatives, their improvements and our settings are far from clear.

**Further Resources**

Introducing readers to further readings on the concept of service design in integrated care:
https://www.slideshare.net/pavan7soni/case-study-research-by-robert-yin-2003
### PERSON-CENTEREDNESS

Care that is patient-centered involves the and empowerment and engagement of service users. When care is centred around older people, carers and families, it can improve older people’s health and well-being.

### COMPONENTS OF PATIENT-CENTERED CARE

- Health literacy
- Access to health data
- Shared decision-making
- Coproduction of services
EXAMPLE: ROADMAP DESIGN
Domain: Person-Centred Care
Component: Co-production of Services

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<th>Patient-centeredness</th>
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<th>Functional integration</th>
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**ROADMAP DESIGN**

**Co-production of Services**

**The Evidence**
This section will provide rationales for patient-centered care as an element that supports integrated care through co-production of services. Links to further resources will also be provided.

**Further resources:**
http://integratedcarefoundation.org/about-ific

**CASE EXAMPLES**
This area will demonstrate case examples and illustrations for how the component element has been introduced into practice

**NAVIGATION TAB**
- Home
- Implementation tool
- Engagement tool

WP6 - roadmap
For integrated care for older people living at home:

• What key information would you include in a roadmap that seeks to guide *both* the design and effective implementation of integrated care?

• What characteristics should the roadmap have, so that you will definitely use, support and promote it?
How are we disseminating information?

Newsletter

WELCOME TO THE SUSTAIN NEWSLETTER

Dear Reader,

We are very excited to introduce the first issue of our newsletter about the SUSTAIN-project: SUSTAIN is a four-year initiative funded through the European Commission’s Horizon 2020 Work Programme 2014-2016. We are very proud and pleased to collaborate in a consortium of 13 partners from different European countries, experienced in integrated care and in the dissemination of knowledge in this area. We will use our newsletters to inform you about SUSTAIN and to keep you posted on news and developments within the project.

One of the aims of the project is to improve established integrated care initiatives for older people living at home with multiple health and social care needs. This issue features the participating integrated care sites in Estonia and how they aim to improve their current way of working during the course of the project. We intend to publish the newsletter three to four times a year. Each of the newsletters will contain information about the participating sites and how they make progress towards achieving their aims.

SUSTAIN European Baseline Report out now

Integrated care for older people living at home

The SUSTAIN consortium is pleased to introduce you to the SUSTAIN EU Report!

Built on the early findings of the project partners, the European Report presents the fourteen integrated care sites participating in the SUSTAIN project and their characteristics. It further describes their areas for potential improvement to move towards more person-centered, safe, efficient and prevention-oriented care for older people. Stakeholders from the sites and SUSTAIN partners are jointly working on improvement projects which will be implemented and evaluated in the next phases of SUSTAIN.

News from the sites: Sandgate Road Surgery

For the third release of the SUSTAIN newsletter, we will focus on the Kent’s based SUSTAIN site Sandgate Road Surgery ‘Over 75 Service’. Developed in the recent
How are we disseminating information?  
Community of Practice

What is a Community of Practice (CoP)?

The concept of a Community of Practice was first defined and described as "a group of people who engage in collective learning in a common area of interest" (Wenger: 1998). In general, they consist of a group of people with a common sense of purpose who agree to work together to share information, build knowledge, develop expertise and solve problems.

**Purposes of the CoP in SUSTAIN**

The CoP would be a safe platform for all SUSTAIN Partners to work as a core group to take forward the improvement initiatives within the SUSTAIN projects. The CoP will give partners the opportunity to virtually discuss daily issues with other SUSTAIN partners who perhaps face the same issues or learn from the partners who have perhaps solved similar issues. In other words, the CoP is a virtual platform that fulfills the purpose of information exchange.

For SUSTAIN, we aim to start up a CoP as a:

- Platform to exchange knowledge and experiences between SUSTAIN sites (patients, professionals, decision-makers etc.)
- Platform to link SUSTAIN sites with experts (eg from AGE, IFIC, EHMA networks)
- Platform to test out the roadmap (ask input from SUSTAIN sites, and potentially from stakeholders outside the SUSTAIN sites)
How are we disseminating information?

Please visit our website:

www.sustain-eu.org