Advancing Care Coordination and Telehealth Deployment at Scale: ACT@Scale

Deliverable 8.6:
Final Paper Report on citizen empowerment with lessons learned

This publication arises from the ACT@Scale (Advancing Care Coordination and Telehealth deployment at Scale) Programme which has received funding from the European Union, in the framework of the Health Programme under grant agreement 709770. The ACT@Scale programme is fully aligned with the European Innovation Partnership in Active and Healthy Ageing objectives to deploy integrated care for chronically ill patients.
### Short description of the Deliverable (as in the DoW):

Final Scale up using the citizen empowerment toolkit. Summary of results of patient surveys and final conclusions and recommendations.

### REVISION HISTORY

<table>
<thead>
<tr>
<th>REVISION</th>
<th>DATE</th>
<th>COMMENTS</th>
<th>AUTHOR (NAME AND ORGANISATION)</th>
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<td>Helen Schonenberg</td>
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<td>4 April 2019</td>
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<td>Cristina Bescos</td>
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</tbody>
</table>
Deliverable 8.6: Final Report on citizen empowerment

Content

Document Information ........................................................................................................... 2
Content ..................................................................................................................................... 3
1 Background of Deliverable 8.6 ...................................................................................... 5
2 Executive Summary ........................................................................................................ 7
3 Introduction ................................................................................................................... 9
3.1.1 Objectives of WP8 ..................................................................................................... 10
4 Programme overview .................................................................................................... 11
4.1 Programs with Citizen Empowerment interventions ............................................... 11
4.2 PDSA cycles ................................................................................................................ 11
4.2.1 Interventions .............................................................................................................. 11
4.2.2 Summary of results .................................................................................................. 12
5 Patient surveys ............................................................................................................. 14
5.1 Patient Survey: items ............................................................................................... 15
5.1.1 PAM (Patient Activation Measure) .......................................................................... 15
5.1.2 MAY 2.0 (More About You) ...................................................................................... 15
5.1.3 NPS (Net Promotor Score) ....................................................................................... 17
6 Results .......................................................................................................................... 18
6.1 Overall population characteristics ........................................................................... 19
6.2 Patient Activation 2018 ............................................................................................ 21
6.3 Patient Activation 2017–2018 .................................................................................. 23
6.4 Satisfaction 2018 ..................................................................................................... 24
6.5 Self-Care Behaviours 2018 ....................................................................................... 25
6.6 Clinician Activation 2017–2018 ............................................................................... 27
6.7 Program Results ........................................................................................................ 28
6.7.1 CATALONIA Chronic Care ....................................................................................... 29
6.7.2 CATALONIA Nursing Homes .................................................................................. 30
6.7.3 CATALONIA Frail Older Adults ............................................................................... 31
6.7.4 BASQUE COUNTRY CHF Telemonitoring ................................................................. 33
6.7.5 BASQUE COUNTRY Multimorbid Integration.......................................................... 35
6.7.6 SOUTHERN DENMARK Video Conferencing for relatives .......................................................37
6.7.7 SCOTLAND My Diabetes My Way ......................................................................................38
6.7.8 SCOTLAND My Diabetes Footcare ..................................................................................40
7 Conclusions ..........................................................................................................................41
  7.1 Recommendations ...........................................................................................................41
8 Discussion on citizens networks .........................................................................................42
9 References ............................................................................................................................43
1 Background of Deliverable 8.6

Work package 8 (WP8) Citizen empowerment, is one of the vertical work packages of the implementation research of ACT@Scale that encompasses the research, assessment and improvement activities performed in the area of citizen/patient empowerment in integrated care programs.

The specific objective of WP8 is to engage the consortium (and collaborating) regions in collecting the relevant data to measure citizen empowerment by use of agreed PROMs (Patient Report Outcome Measures) and support improvement actions through PDSA cycles (Plan Do Study Act).

WP8 has committed to produce at least one deliverable at the end of each phase of the project, as described in the table below:

<table>
<thead>
<tr>
<th>Baseline Phase</th>
<th>Learning Phase</th>
<th>Coaching Phase</th>
<th>Dissemination Phase</th>
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<td>M0–6</td>
<td>M7–18</td>
<td>M19–30</td>
<td>M31–36</td>
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</tbody>
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WP8: Citizen Empowerment

- D8.1 Touchpoint maps
- D8.2 Report on learning session I
- D8.3 Report on learning cycle
- D8.4 Report on learning session II
- D8.5 Report on coaching cycle
- D8.6 Final report on citizen empowerment
Deliverable 8.6 provides final results based on qualitative and quantitative data exploration and analysis. It presents results related to Citizen Empowerment of the selected ACT@Scale programmes, which were:

1. CATALONIA Chronic Care
2. CATALONIA Nursing Homes
3. CATALONIA Frail Older Adults
4. BASQUE COUNTRY CHF Telemonitoring
5. BASQUE COUNTRY Multimorbid Integration
6. SOUTHERN DENMARK Video Conferencing for relatives
7. SCOTLAND My Diabetes My Way
8. SCOTLAND My Diabetes Footcare

Disclaimer

The content of this report represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.
2 Executive Summary

The specific objective of Work package 8 (WP8) is to engage the consortium (and collaborating) regions in collecting the relevant data to measure citizen empowerment by using the “Plan Do Study Act” (PDSA) cycle (described in D3.1, p.15).

Deliverable 8.6 reviews the work done during the 3 preceding years in WP8.

Tackling all aspects of care coordination and telehealth is a vast challenge. ACT@Scale focused on 4 drivers; 4 areas that were considered to be the most essential to steer scaling-up and adoption of innovations. It is our view, both from the literature and extensive experience that improvements in these 4 areas largely contribute to extended coverage and sustainability of services.

The driver of citizen empowerment captures the need to establish patient-centered care. We focused on elements enabling significant engagement of users and on making the strategy self-sustaining, such as shared decision making, attention to patient journeys, development of empowerment skills, and citizens networks.

Citizen Empowerment, Citizen-centred care is essential to deliver integrated care. This driver focused on the elements that can achieve significant engagement of users and to make the strategy self-sustaining. These included shared decision making, attention to patient journeys, development of empowerment skills and citizens networks. Satisfaction (Net Promoter Score—NPS), Patient Activation Measure (PAM\(^1\)) in comparison to staff (Clinician Support for Patient Activation Measure – CSPAM\(^2\)), psycho-social profile and patient’s abilities were monitored in 500 patient surveys and more than 300 surveys for professionals.

Citizen and patient empowerment and participation are crucial elements for the promotion of sustainable health and wellbeing. It facilitates independence, self-management, and self-efficacy, supporting patients from diagnosis onwards enabling them to have the capacity to deal with their needs along the trajectory of their condition. Citizen empowerment is still not well-defined and there is no consensus on how to operationalise or measure it. The EIP on AHA is working intensively on reaching European consensus on definition, methods, with technology as enabler and assessment tools.

Most of the interventions reported by the partners addressed patients' needs at micro or meso level. In ACT@Scale, there appeared to be a predominance of interventions targeting the provision of information as a tool for empowerment. In addition, a majority of

1  https://www.insigniahealth.com/products/pam-survey
interventions focused on self-management, followed by education and health literacy, with shared-decision making being the least represented.

Clinicians have an important role both in supporting people to self-manage their conditions, and in helping to build their level of activation. Overall, we see a very high level of the clinician activation across all ACT@Scale programmes.

ACT@Scale programmes with focus on citizen empowerment in the PDSA cycles, showed better results in satisfaction (NPS score) and patient activation (PAM). Participants also reported significantly higher on self-care behaviours, were better in dealing with the impact of their condition, and were more comfortable using technology. We saw greater activation levels in participants with higher education level (university, post-graduate), and the opposite for participants that were divorced or widowed.

Online training provided regularly and/or when changes were introduced, helped ensure the programme remained a focus of all impacted staff. Having a local skilled leader and involving teams within the organisation was an excellent way to ensure that training was provided and that the continuation was independent of the scope of an individual project. It was important to train and deliver educational material and communication, which are adapted to the patient's coping styles. When dealing with improvement cycles, there may be some resistance from staff. Collaborative methodologies can help to manage differences in participants' status and help to promote openness to adjustments.

While there is no single best approach to engaging citizens in long-term decision-making, the ACT@Scale handbook presents several examples and recommendations of consumers willing to take ownership in managing their own condition.
3 Introduction

The specific objective of Work package 8 (WP8) is to engage the consortium (and collaborating) regions in collecting the relevant data to measure citizen empowerment by using the “Plan Do Study Act” (PDSA) cycle (described in D3.1, p.15).

Tackling all aspects of care coordination and telehealth is a vast challenge. ACT@Scale focused on 4 drivers; 4 areas that were considered to be the most essential to steer scaling-up and adoption of innovations. It is our view, both from the literature and extensive experience that improvements in these 4 areas largely contribute to extended coverage and sustainability of services.

In Europe, patient empowerment is supported by the EU through the European Patients Forum which aims to “…promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition…” (EPF Goal 4, n.d.). In the UK, “High quality care for all” committed the NHS to patient empowerment by (Rivett, n.d.):

- Giving patients more choice and control over their healthcare
- Making hospital funding contingent upon performance against a range of quality measures including patient reported outcomes measures (PROMs)
- Implementing use of personalized care plans and personal health budgets.

NHS England’s Five Year Forward View (NHS, 2014) reiterated a commitment to patient empowerment, to be enacted through shared decision-making and novel mechanisms such as “integrated personal commissioning”, a new approach involving blended health and social care funding for people with complex needs.

Deliverable 8.6 reviews the work done during the 3 preceding years in WP8. This report provides the final results based on qualitative and quantitative data exploration and analysis of the selected ACT@Scale programmes, which were:

1. CATALONIA Chronic Care
2. CATALONIA Nursing Homes
3. CATALONIA Frail Older Adults
4. BASQUE COUNTRY CHF Telemonitoring
5. BASQUE COUNTRY Multimorbid Integration
6. SOUTHERN DENMARK Video Conferencing for relatives
3.1.1 **Objectives of WP8**

- To identify, review, scale-up and transfer good practices on methods for citizen empowerment in the area of care coordination and telehealth.
- To enable rapid improvement cycles by adopting a collaborative methodology with annual do-plan-act-evaluate implementation cycles.
- To create a network of users/citizens that will make the strategy for citizen empowerment self-sustaining.
- To monitor the impact of the network of users/citizens on scaling-up.
4 Programme overview

Citizen empowerment captures the need to establish patient-centered care. We focused on elements enabling significant engagement of users and on making the strategy self-sustaining, such as shared decision making, attention to patient journeys, development of empowerment skills, and citizens networks.

4.1 Programs with Citizen Empowerment interventions

From the 15 programs in ACT@Scale, 8 chose to work in the area of citizen empowerment. Each programme participating in work package 8 has defined and identified the issues to be addressed in the area of citizen empowerment. Then they defined and implemented a change package with interventions and they evaluated the results.

4.2 PDSA cycles

ACT@Scale methodology is based on a collaborative methodology with Plan-Do-Study-Act (PDSA) cycles, as described in D 3.1 and D3.2. This methodology helps to apply multi-organisational structured collaborative quality improvement procedures and to adapt them to scale up integrated care experiences.

The different phases of the collaborative methodology of ACT@Scale are:
- Baseline phase
- Learning cycle
- Coaching cycle
- Dissemination phase

4.2.1 Interventions

The interventions were defined by the programs, addressing the most urgent issues in the area of citizen empowerment. The Video Consultation for Relatives program in the Region of Southern Denmark focused on empowering patients and their relatives. The program allowed relatives of haematology patients to remotely join the ward rounds through video conferencing.

The Basque Telemonitoring service for patients with Congestive Heart Failure supported their patients through remote clinical monitoring and enhanced self-management. It included personalized care plans, including patient and care giver viewpoints.

In the Multimorbid Integration Programme from the Basque Country, ICT-based platforms were used to improve treatment compliance, enhance self-management and increase patient and health care professionals understanding the issues in multimorbidity. Patients and healthcare professionals were well integrated in the implementation process.
The Catalan Healthcare Support Programme for Nursing Homes implemented improved care planning for elderly living in institutionalized homes and their families. The relationship between healthcare professionals, residents and families was improved through continuous (face to face) trainings and meetings. In the first meeting a multidimensional geriatric interview was included that improved the quality of the advanced care planning, respecting the decisions of the residents and their families.

Similarly, the Catalan Chronic Patient Programme used geriatric evaluation in the individual integrated care plans. In addition, it promotes independent living for patients while maintaining good quality of life and coordinates the work of the interdisciplinary teams doing interventions. The program focused on citizen empowerment to prevent and treat acute episodes. The program implemented an online tool (eConsulta) for communication between patients, care givers and primary care professionals. The program invested in training and material to educate patients how to use the tool.

The aim of the Catalan Integrated Care for Subacute and Frail Older Adults was to improve quality of care transitions led by Transitional Coaches shared with patients and caregivers, based on medication management, promoting healthy lifestyle and improving the care coordination after discharge. Focus groups were initiated to include citizens in the implementation process. As a result, the program has now adapted some of the guides, brochures and other program documentation. A discharge notification document was implemented and integrated into the daily routine of the programme.

In Scotland the programs have focused on raising awareness of the programs and increasing the numbers of active patients. My Diabetes My Way enables citizens with Diabetes to manage their condition more effectively, providing them access to their medical records online. The program achieved more citizen awareness by reaching out directly, making them aware of the service and organizing seminars and training sessions. They identified patients that were not registered in the service data and inactive users, they selected and contacted individuals that would benefit from the service and provided support to use the service.

### 4.2.2 Summary of results

Full description of the PDSA results can be found on deliverable 8.5. It can be seen from the results presented that all programs report satisfaction with the implemented changes and either adopt them or adopt after documented revisions (i.e. adapt). None of the programs has abandoned any of the planned interventions.

A few of the adoptions and adaptations deserve a little highlight in this section.

- The Basque Multimorbid Integration programme is successfully adopting online and APP–based communication channels. Part of their success of this technology
implementation lies in the integration into the total care-path: Multidisciplinary teams were created and trained. This integration of as many people responsible for the professional care seems of great importance. As, without it, uptake of the use of the services may phase difficulties that need (later) adaptation as seen in some regions. Promotional needs as stated by some regions also underline need for broad and thorough communication and inclusion of all care providers.

Sometimes more technological advancements can have unsolicited effects, as indicated by region of South Denmark. Here, inclusion of family via video communication during ward rounds led to distraction of patient focus for the attending physicians. It will be interesting to monitor how the region develops this type of support and how the sought balance will be found between inclusion of family, versus the right amount of patient care.
5 Patient surveys

This chapter describes the surveys used to measure patient satisfaction, activation and psycho-social context.

In Table 2: Response rates, we present the number of potential respondents, or population size (N). In most cases, it was not feasible to target the full population for the surveys. We present the feasible target number of responses (T) as well as the expected response rate (%T) for the target population. The surveys were distributed to T respondents. The number of expected responses was our objective for the data collection. The actual responses (R) give the number of responses collected. To indicate the success of our response prediction, we included response success (%R), and finally the response rate (%RR) was calculated based on actual responses and targeted responses for each program.

<table>
<thead>
<tr>
<th>Patients</th>
<th>N</th>
<th>T</th>
<th>%T</th>
<th>R</th>
<th>%R</th>
</tr>
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<td>Basque Country</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>BAS MM IC Multimorbid integration</td>
<td>6200</td>
<td>180</td>
<td>108</td>
<td>93</td>
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<tr>
<td>BAS CARD TH CHIP telemonitoring</td>
<td>150</td>
<td>20</td>
<td>12</td>
<td>6</td>
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<tr>
<td>Catalonia</td>
<td></td>
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<td>CAT IL SUP Nursing homes</td>
<td>3563</td>
<td>300</td>
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<td>CAT CHRON IC Chronic care</td>
<td>445</td>
<td>40</td>
<td>10</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>CAT CHRON CM Complex case management</td>
<td>500</td>
<td>50</td>
<td>13</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>CAT CHRON LS Physical activity</td>
<td>200</td>
<td>20</td>
<td>5</td>
<td>N/A</td>
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<tr>
<td>CAT IL IC Frail older adults</td>
<td>700</td>
<td>30</td>
<td>8</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>Northern Netherlands</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>NNIL RESP TH Asthma / COPD</td>
<td>11500</td>
<td>30</td>
<td>27</td>
<td>N/A</td>
<td>N/A</td>
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<td>NNIL ILIC Embrace</td>
<td>1500</td>
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<td>N/A</td>
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<td>18</td>
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<td>N/A</td>
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Table 2: Response rates
The Patient Survey consisted of 24 questions, which consisted of 68 items. For most regions, the survey was distributed as an online survey via the LimeSurvey Tool (LimeSurvey, 2017–2018). For the Effective Cardio Program, the survey was deployed onto the Telehealth System.

Demographics requested as part of the survey were limited to Marital Status (Single, never married; Married, or domestic partnership; Widowed; Divorced; Separated) and Educational Status (Other; Primary; Secondary; College; University/ Post graduate). Gender and age were not included as these were planned to be reported with the patient outcomes via the evaluation engine. Unfortunately, this approach was not feasible in the scope of the project, and population aggregates were reported without being able to link the gender and/or age categories.

5.1 Patient Survey: items

The Patient survey's main elements are the 13-item PAM (Patient Activation Measure) and the 12-question/54-item MAY (More About You). Additionally, one question to assess the level of satisfaction with the program was included: The Net Promotor Score (NPS). The decision was based on consortium agreement. Here we took into account not to overburden the patients with multiple separate and more extensive surveys.

5.1.1 PAM (Patient Activation Measure)

The Patient Activation Measure (PAM; (Hibbard, Stockard, Mahoney, & Tusler, 2004) is “a valid, highly reliable, unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation. Activation appears to involve four stages: (1) believing the patient role is important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one’s health, and (4) staying the course even under stress. The measure has good psychometric properties indicating that it can be used at the individual patient level to tailor intervention and assess changes.” (Hibbard, Stockard, Mahoney, & Tusler, 2004, p. 1005)

5.1.2 MAY 2.0 (More About You)

MAY is a complete and ready-to-use assessment tool that can be used to inform health professionals about the psychosocial context of their patients and guide them in providing psychosocial care to patients. While the MAY survey as such is not validated in a clinical trial, it is being applied for 2 years in Banner Health US, with over 600 participating patients. MAY 2.0 is the result of validation with the clinical staff at Banner Health (Banner Health, n.d.).
MAY includes the following dimensions:

1 Coping style
2 Comfort in groups
3 Disease impact
4 Comfort with technology
5 Ability for self-care
6 Phenotype
7 Social support
8 Psychosocial well-being

The developers of the original MAY (Van Genugten, Calo, Van Wissen, Vinkers, & Van Halteren, 2016) made use of validated shortened versions of existing questionnaires or 1-question items that were previously developed as part of a screening tool for self-management by IQHealthCare (a research institute of the Radboud University (Eikelenboom, Van Lieshout, Wensing, Smeele, & Jacobs, 2013). Leading to the 9 items included in “Coping style”, and 1 item indicating “Comfort in groups”. The item indication for the latter (i.e. “I function comfortably in groups (e.g., colleagues, friends, etc.)”) was not included in MAY2.0 version as used in this study.

For the psycho-social factors for which no adequate validated instruments exist for the present clinical context, they developed items that measure the construct in a psychometrically sound way. This applies to “Disease impact” (1 item, i.e. “How much does your medical condition limit you in your daily life and activities?”), “Comfort with technology” (1 item, i.e. “How comfortable are you with using devices such as a tablet or iPad, cell phone or computer?”), and “Ability for self-care” (13 items, e.g. “When all is said and done, I am the person who is responsible for taking care of my health”).

The psychosocial factor of phenotypes was based on a select-one-of-four statement that classifies the patient in one of four phenotypes (Janssen, J. H.; Lacroix, J P.W.; Tatousek, J., 2012). According to the Vinkers et al. (2014, p.27), the selection of one of the four statements is indicative for the “preference of manner of communication and focus of content”.

Social support items were selected from the modified Medical Outcomes Study Social Support Survey (mMOS-SS; (Moser, Stuck, Silliman, Ganz, & Clough–Gorr, 2012)). Two subscales were be computed as part of the MAY: “Instrumental Support” (also referred to as “Tangible Support”) and “Emotional Support”. The Emotional support subscale include three items labelled by Moser et al. (2012) as “Emotional Support”, and one item labelled as “Positive Social Interaction” (i.e. “...to have a good time with”).

For “Psychosocial well-being” the full 14-item Warwick-Edinburgh Mental Well-being Scale (WEMWBS; (Warwick Medical School, 2006–2013)is included in the MAY. The item
results are to be summed to provide a scale-score ranging from 14-70. WEMWBS provides extensive published psychometric properties and norm data is available.

More information about the More About You survey is in preparation for publication by the original authors, which will report a correlation between the MAY results and healthcare utilization (Van Halteren, personal communication, December 2018).

5.1.3 NPS (Net Promotor Score)
The final question of the patient survey, phrased to be able to determine the so-called “Net Promotor Score” (NPS): “On a scale from 0-10, how likely are you to recommend this program to a friend?”. 

- People responding with a 0-6 are called detractors
- People responding with a 7 or 8 are called passives
- People responding with a 9 or 10 are called promotors.

In line with NPS reasoning, detractors would be expected to inhibit successful continuation of the programme, because they would radiate negative opinions to other potential patients. Passives would be more neutral. And promotors might actively share positive attitudes about the programme and as such support an increase of participation for a programme with recurring intake moments. Hence, NPS is deemed a suitable methodology for programmes that have the aim to run over a longer period of time and aim to attract patients and/or family members on an ongoing basis.

The typical NPS-methodology would include open-ended follow-up questions based on the given answer in order to gain understanding of the reasoning behind the responses:

- (if NPS 9-10): “What is the main reason why our programme makes you likely recommend it to others?”, or
- (if NPS 0-6): “How can we improve our programme to make you more likely to recommend it to others?”

These were not included in this version of the survey. Nevertheless, the inclusion of NPS is a good way to (1) have an impression of the loyalty of the patients to the type of programme they experienced. And (2) learn from the data to assess which elements of the programme would need attention for improvement in order to increase loyalty. To improve the NPS score, focusing on improvement areas as identified by the PAM and MAY surveys for only participants that gave an 8 as NPS score would likely increase the number of promotors and hence the total score; focusing on respondents that gave a 6 would decrease the number of detractors. Such a strategy could increase overall loyalty with the program as measured by repeated NPS tracking.

6 Results

In this section we report results of the surveys related to patient empowerment. The table below presents the collected survey data. More than 500 patient responses and more than 350 staff responses were collected. For the staff survey we will only report the CS-PAM results.

![Table 3: 2017 regional participation](image)

<table>
<thead>
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<th>Program</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
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![Table 4: 2018 regional participation](image)

<table>
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<th>Program</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
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</tr>
<tr>
<td>CAT Complex case management</td>
<td>51</td>
<td>12.9</td>
<td>12.9</td>
<td>42.2</td>
</tr>
</tbody>
</table>
CAT Frail older adults & 22 & 5.6 & 5.6 & 47.7 \\
CAT Physical activity & 21 & 5.3 & 5.3 & 53.0 \\
GER Gesundes Kinzigtal & 19 & 4.8 & 4.8 & 57.8 \\
GER Promotion of physical activity & 13 & 3.3 & 3.3 & 61.1 \\
NNL Effective cardio & 70 & 17.7 & 17.7 & 78.8 \\
SCO My diabetes my way & 84 & 21.2 & 21.2 & 100.0 \\
**Total** & **396** & **100.0** & **100.0** & 

6.1 Overall population characteristics

No gender or age demographics are available of these samples. The marital status and educational level provide some insight into this population, 28 out of 128 (21%) stated ‘widowed’ as marital status (Error! Reference source not found.) and the reported level of education was low with 97 (75%) stating highest level was ‘primary’ (Figure 2). This gives the impression of an elderly population, which is in line with the said programmes. 15% (20) of the respondents in this sample took part in the Chronic Heart Failure Telemonitoring programme Distribution, and the remainder (108) were part of the Multimorbid Integration programme.

![Figure 2 2017 education level and marital status.](image)

The 2018 sample was more diverse from a participating programme perspective, nine programmes participated (}
Table 4); per programme participation was ranged from N=13 to N=96 participants. Like in the 2017 sample, we see almost a quarter (22%) of the 2018 sample reporting ‘widowed’ status, and an overall low level of education (45% primary). The marital status did not differ significantly by year, see **Error! Reference source not found.:** $x^2(4, N = 551) = 5.644, p = .227$. Chi-square test revealed that Educational status differed significantly between the 2017 and 2018 cohorts, at $x^2(4, N = 551) = 42.513, p = .000$.

**Figure 3** Marital status 2017 vs. 2018 ($x^2(4, N = 551) = 5.644, p = .227$)

**Figure 4**: Highest level of education, 2017 vs. 2018 ($x^2(4, N = 551) = 42.513, p = .000$)
6.2 Patient Activation 2018

In general, all the programs showed high levels of patient activation in their patient population. There is, nevertheless, a wide variation in scores between programs.
It is important to highlight that programs promoting citizen empowerment showed significantly better results in patient activation (PAM).

<table>
<thead>
<tr>
<th></th>
<th>CITIZENS EMPOWERMENT</th>
<th>NO CITIZEN EMPOWERMENT</th>
<th>COMPARISON (P-VALUE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPS</td>
<td>10 [8 - 10]</td>
<td>8 [6 - 9]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PAM score %</td>
<td>70.20 [58.10 - 77.70]</td>
<td>58.10 [51.00 - 70.20]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PAM sum</td>
<td>3 [3-4]</td>
<td>3 [2 - 3]</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
6.3 Patient Activation 2017-2018

Changes in patient activation (PAM) could be analysed in the Basque Country where the survey has been deployed in 2017 and 2018.

The multimorbid program showed significant improvement in the PAM scores between 2017 and 2018. Changes in the telemonitoring program were neither big nor significant.

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>N</th>
<th>2017</th>
<th>N</th>
<th>2018</th>
<th>P VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALL</td>
<td>55</td>
<td>65.50 [58.10 - 72.50]</td>
<td>80</td>
<td>72.50 [63.10 - 80.90]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>BAS_CARD_TH</td>
<td>12</td>
<td>58.10 [51.00 – 70.27]</td>
<td>16</td>
<td>58.10 [51.00 – 68.97]</td>
<td>ns</td>
</tr>
<tr>
<td>BAS_MM_PM</td>
<td>43</td>
<td>65.50 [60.60 - 72.50]</td>
<td>64</td>
<td>75.00 [65.50 - 84.80]</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Patients with university education have significant higher PAM scores in both years in both programs.
6.4 Satisfaction 2018
With regards to patient satisfaction (NPS), again programs promoting citizen empowerment showed significantly better results in NPS.

<table>
<thead>
<tr>
<th></th>
<th>CITIZENS EMPOWERMENT</th>
<th>NO CITIZEN EMPOWERMENT</th>
<th>COMPARISON(P-VALUE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPS</td>
<td>10 [8 - 10]</td>
<td>8 [6 - 9]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PAM score %</td>
<td>70.20 [58.10 - 77.70]</td>
<td>58.10 [51.00 - 70.20]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PAM sum</td>
<td>3 [3-4]</td>
<td>3 [2 - 3]</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
The major differences between programs in satisfaction levels are related the number of detractors and promoters within their patient population as shown in the graph above.

### 6.5 Self-Care Behaviours 2018

Participants in empowerment programs again reported significantly better behaviours for being able to manage their condition:

- higher on self-care behaviours,
- better in dealing with the impact of their condition, and
- more comfortable using technology
<table>
<thead>
<tr>
<th>MAY</th>
<th>EMPOWERMENT</th>
<th>NO EMPOWERMENT</th>
<th>COMPARISON</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMPACT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. LOW</td>
<td>59 (42.8%)</td>
<td>72 (26%)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>2. MODERATE</td>
<td>26 (18.8%)</td>
<td>86 (31%)</td>
<td></td>
</tr>
<tr>
<td>3. HIGH</td>
<td>53 (38.4%)</td>
<td>119 (43%)</td>
<td></td>
</tr>
<tr>
<td>TECHNOLOGY 1. LOW</td>
<td>121 (87.7%)</td>
<td>136 (49.1%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. MODERATE</td>
<td>017 (12.3%)</td>
<td>141 (50.9%)</td>
<td></td>
</tr>
<tr>
<td>3. HIGH</td>
<td>013 (12.3%)</td>
<td>196 (70.8%)</td>
<td></td>
</tr>
<tr>
<td>WELLBEING</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. LOW</td>
<td>5 (3.6%)</td>
<td>19 (6.9%)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>2. MODERATE</td>
<td>20 (14.5%)</td>
<td>62 (22.4%)</td>
<td></td>
</tr>
<tr>
<td>3. HIGH</td>
<td>113 (81.9%)</td>
<td>196 (70.8%)</td>
<td></td>
</tr>
<tr>
<td>COPING 1. BY SEEKING DISTRACTION</td>
<td>98 (71.0%)</td>
<td>139 (50.2%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. BY EXPRESSING EMOTIONS</td>
<td>16 (11.6%)</td>
<td>12 (4.3%)</td>
<td></td>
</tr>
<tr>
<td>3. BY SOLVING PROBLEMS</td>
<td>24 (17.4%)</td>
<td>126 (45.5%)</td>
<td></td>
</tr>
<tr>
<td>SOCIAL SUPPORT (PRACTICAL) 1. LOW</td>
<td>5 (3.6%)</td>
<td>15 (5.4%)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>2. MODERATE</td>
<td>7 (5.1%)</td>
<td>40 (14.4%)</td>
<td></td>
</tr>
<tr>
<td>3. HIGH</td>
<td>128 (91.3%)</td>
<td>222 (80.1%)</td>
<td></td>
</tr>
<tr>
<td>SOCIAL SUPPORT EMOTIONAL 1. LOW</td>
<td>3 (2.2%)</td>
<td>10 (3.6%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. MODERATE</td>
<td>7 (5.1%)</td>
<td>51 (18.4%)</td>
<td></td>
</tr>
<tr>
<td>3. HIGH</td>
<td>128 (92.8%)</td>
<td>216 (78.0%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE DIET 1. HIGH</td>
<td>12 (8.7%)</td>
<td>43 (15.5%)</td>
<td>&lt;0.1</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0126 (91.3%)</td>
<td>0234 (84.5%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE PHYSICAL ACTIVITY 1. HIGH</td>
<td>31 (22.5%)</td>
<td>88 (31.8%)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0107 (77.5%)</td>
<td>0189 (68.2%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE SYMPTOMS 1. HIGH</td>
<td>23 (16.7%)</td>
<td>64 (23.1%)</td>
<td>0.13</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0115 (83.3%)</td>
<td>0213 (76.9%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE HEALTH INFO 1. HIGH</td>
<td>15 (10.9%)</td>
<td>89 (32.1%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0123 (89.1%)</td>
<td>0188 (67.9%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE ENJOYMENT 1. HIGH</td>
<td>29 (21%)</td>
<td>109 (39.4%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0109 (79%)</td>
<td>0168 (60.6%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE FEELING BAD 1. HIGH</td>
<td>23 (16.7%)</td>
<td>92 (33.2%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0115 (83.3%)</td>
<td>0185 (66.8%)</td>
<td></td>
</tr>
<tr>
<td>SELF CARE SMOKING 1. HIGH</td>
<td>4 (2.9%)</td>
<td>18 (6.5%)</td>
<td>0.12</td>
</tr>
<tr>
<td>2. LOW</td>
<td>0134 (97.1%)</td>
<td>0259 (93.5%)</td>
<td></td>
</tr>
</tbody>
</table>
6.6 Clinician Activation 2017-2018

Perception of the clinician on patient activations (CS-PAM) showed very high involvement of staff in the ACT@Scale programs. The variations in staff population activation scores between programs is very small and much smaller than the variation in the patient population. Programs reporting both years showed a slight improvement (non-significant) in staff CSPAM scores.

In general scores of staff are higher than the patients, with the exception of the BAS multimorbid program where patients showed even higher levels of engagement than staff.

Comparison between PAM and CSPAM in 2018
6.7 Program Results

Citizen and patient empowerment and participation are crucial elements for the promotion of sustainable health and wellbeing. It facilitates independence, self-management, and self-efficacy, supporting patients from diagnosis onwards enabling them to have the capacity to deal with their needs along the trajectory of their condition. Citizen empowerment is still not well-defined and there is no consensus on how to operationalise or measure it. The EIP on AHA is working intensively on reaching European consensus on definition, methods, and technology as enabler and assessment tools.

Most of the interventions reported by the partners addressed patients’ needs at micro or meso level. In ACT@Scale, there appeared to be a predominance of interventions targeting the provision of information as a tool for empowerment.

In addition, a majority of interventions focused on self-management, followed by education and health literacy, with shared-decision making being the least represented.

Clinicians have an important role both in supporting people to self-manage their conditions, and in helping to build their level of activation. Overall, we see a very high level of the clinician activation across all ACT@Scale programmes.

ACT@Scale programmes with focus on citizen empowerment showed better results in satisfaction (NPS score) and patient activation (PAM). Participants also reported significantly higher on self-care behaviours, were better in dealing with the impact of their condition and were more comfortable using technology. We saw greater activation levels in participants with higher education level (university, post-graduate), and the opposite for participants that were divorced or widowed.

Online training, provided regularly and/or when changes were introduced, helped ensure the programme remained a focus of all impacted staff. Having a local skilled leader and involving teams within the organisation was an excellent way to ensure that training was provided and that the continuation was independent of the scope of an individual project. It was important to train and deliver educational material and communication, which are adapted to the patient’s coping styles.

When dealing with improvement cycles, there may be some resistance from staff. Collaborative methodologies can help to manage differences in participants’ status and help to promote openness to adjustments.
6.7.1 CATALONIA Chronic Care
No patient surveys were collected for this program. A very high level of clinician engagement was achieved and maintained during scaling.
6.7.2 CATALONIA Nursing Homes

No patient surveys were collected for this program. A high and increasing level of clinician engagement was achieved during scaling.
6.7.3 CATALONIA Frail Older Adults

This program has a high (55) NPS. Clinical activation is high and increasing. The patients are mostly in the higher activation levels (level 3 and 4). Patients experience issues with understanding healthcare information, mainly they struggle with the skills, but also motivation and confidence are reported as issues.
Figure 5 Demographics for CAT Frail Older Adults.
6.7.4 BASQUE COUNTRY CHF Telemonitoring

Patients of the program are satisfied with the program (NPS 35). Clinical activation is very high and increasing. The program managed to shift the patient activation levels to the higher levels of engagement. Noticing symptom changes is a motivation issue for the patients of this program.
Figure 6 Demographics for BAS CHF Telemonitoring.
6.7.5 **BASQUE COUNTRY Multimorbid Integration**

Patients of the Multimorbid program are very satisfied (NPS 75). Clinical activation is very high and increasing. Patient activation is shifting towards the higher activation levels. Skills for physical activity and motivation to notice symptom changes are challenges for these patients.
Deliverable 8.6: Final Report on citizen empowerment

Figure 7 Demographics for BAS Multimorbid Integration.
6.7.6 SOUTHERN DENMARK Video Conferencing for relatives
This program joined as second wave program. This program is more targeted at the relatives and due to the disease severity of the patients, no patient surveys were issued. Clinical activation is good.
6.7.7 **SCOTLAND My Diabetes My Way**

This program joined as second wave program. The satisfaction levels of the patients were low due to a large group of detractors. Clinical activation is high and patient activation levels vary across all levels with a big portion of the patients being highly engaged (level 3 and 4). Patients struggle with physical activity (confidence, motivation) and social enjoyment (motivation and confidence).
Figure 8 Demographics for SCO My Diabetes My Way.
6.7.8 SCOTLAND My Diabetes Footcare
This is a very new second wave program that recruited the professionals during ACT@Scale. The program is now ready to enrol the first patients. Clinician activation is very high.
7 Conclusions

Citizen-centred care is essential to deliver integrated care. This driver focused on the elements that can achieve significant engagement of users and to make the strategy self-sustaining. These included shared decision making, attention to patient journeys, and development of empowerment skills and citizens networks. Satisfaction (Net Promoter Score-NPS), Patient Activation Measure (PAM) in comparison to staff (Clinician Support for Patient Activation Measure - CSPAM), psycho-social profile and patient’s abilities were monitored in 870 surveys. In addition, surveys to managers were completed to provide an overview of the strategy and operational plans.

While there is no single best approach to engaging citizens in long-term decision-making, ACT@Scale presents several examples and recommendations of consumers willing to take ownership in managing their own condition.

7.1 Recommendations

- Embed a method to collect patient-related outcomes and experience measures. These should be adapted to the capabilities of the target population and embedded in the workflow of the professionals. Ensure knowledge is fed back to those in practice. Collecting patient information outside a standard clinical process requires ethical approval, consent management, licenses, supporting technology for collection, storage and analysis.
- Regularly collect indicators on patient activation and/or engagement, including caregiver and informal caregiver, in order to identify those that require empowerment interventions. The findings suggest that the Patient Activation Measurement (PAM) survey might be a useful instrument for clinical practices to identify patients that are most in need of support and education.
- Define and review guidelines and perform a regular review and validation of standardised training materials for patients and professionals. There is no single best approach to engaging the public in long-term decision-making activities such as networks need to be tailored to suit specific arrangements in regions and programmes.
- Clinicians have an important role both in supporting people to self-manage their conditions, and in helping to build their level of activation. Overall, we see a very high level of the clinician activation across all ACT@Scale programmes.

- ACT@Scale programmes with focus on citizen empowerment showed better results in satisfaction (NPS score) and patient activation (PAM). Participants also reported significantly higher on self-care behaviours, were better in dealing with the impact of their condition, and were more comfortable using technology. We saw greater activation levels in participants with higher education level (university, post-graduate), and the opposite for participants that were divorced or widowed.
- Decision makers need to be much clearer about the purpose of any specific engagement exercise and how they ‘frame’ the engagement activity to ensure that expectations are not misplaced. Dedicated resource and sustained governance are key enablers to citizen engagement activity.
8 Discussion on citizens networks

Below a direct copy of the results of the Citizen Network Survey as was reported by Ms. C. Buchner of the NIRE region; former Work Package 8 leader. The full report is attached as Annex B of deliverable 8.5.

“Public engagement in the health and social sector is an evolving area. Over the last decade, the increasing interest in engagement, in particular for health, has largely been driven by the desire to see more ‘customer centric’ services that deliver the outcomes that patients, clients and their carers value. Engagement has also, however, been used to give all consumers (current, future), citizens and stakeholders a voice in helping to shape key decisions and so make these more ‘legitimate.’ This is particularly important given resource and financial challenges faced by the sector at this time.

Engagement is also increasingly been used as a vehicle for cultural change in health and social care providers, to support a shift from commodity to service provision. This is part of the move from passive to more active patients and clients and the development of the demand-side role. The potential for engagement to lead to new partnerships and collaboration is being actively explored by all ACT@Scale partners.

There are differences in engagement practice and opportunity between the regions and programs included in this survey, with programs being at different stages in their respective networking cycles and facing different pressures. There is no single best approach to engaging the public in long-term decision-making – activities need to be tailored to suit specific arrangements in each region and program. What works well in one context won’t necessarily work well in another. Decision makers do, however, need to be much clearer about the purpose of any specific engagement exercise and how they ‘frame’ the engagement activity to ensure that expectations aren’t misplaced.

As seen from the results the resources available can be a significant potential barrier to engagement. Funding pressures across the sector and in local government, there are questions about how best to ensure that consumer, citizen and other stakeholder representatives have adequate capacity to be able to fulfil the breadth of engagement roles envisaged for them in a sustained way over time. If these issues are not addressed through dedicated funding – plus suitable governance – engagement could be set up to fail or at risk of being exposed to undue pressure from vested interests.

To maximise the value of citizen engagement, it is worth understanding key enablers and barriers. Ensuring a high-level ‘vision’ – from providers of care, regulators and policy makers – as to what engagement can and cannot be expected to achieve would seem important to help manage public expectations. Finding effective ways to measure the impact of engagement can help all interested stakeholders judge what works and what is proportionate. Providers of care need to articulate how their own procedures and processes may need to adapt to get the most out of engagement activity.”

(Citizen Networks, p31–32)
9 References


