



Advancing Care Coordination
and Telehealth Deployment

ACT Programme

Annex I to Deliverable 3:

WP6: PATIENT ADHERENCE. PATIENT SURVEY

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I. Summary

Aims and objectives

This element of the ACT project aimed to provide an insight into the participation of patients in telehealth and coordinated care programmes. This report looks specifically at the views of interviewed patients in relation to their perceptions of their engagement.

Methods

Surveys for patients were developed and made available online/paper or telephone, depending on the program. The survey comprised Likert-style items. Once completed, the survey findings were collated within the ACT evaluation engine.

Outcome

In view of the current limitations in coverage, the analysis of the outcomes has been postponed for the next deliverable.

Conclusion

Despite the commitment of the regions and program managers with ACT, the access to direct information from the patients involved in the CC&TH programs is a challenge. Items like data privacy, ethics, involvement of local practitioners, and access to patients/caregivers... require additional administrative workload that limits the ability to collect data from a 3-year program like ACT.

The combination of quantitative and qualitative approaches in ACT will ensure the adequate capture of the voice of the users/patients in the assessment of the programs and in the selection of good practices for the ACT project.



2. Assessment Approach: Patient Questionnaire

Measuring adherence accurately is a complicated process. There are many different methods to assess adherence. Some regions already assess patient adherence indicators by using several outcome measures. Since patients can improve for reasons other than following the prescribed regimen and a person's condition can deteriorate or remain stable even when the patient is adherent and the medications are taken as prescribed, they may tell us not enough about adherence.

Due to the complexity of patient adherence, a mixed methods approach and an exploratory sequential design employing both qualitative and quantitative designs was chosen. The responsibility for adherence must be shared between patients, the health care provider and the health care system. To get a deep insight data about adherence are merged from different sources.

A systematic literature review was performed in order to obtain a better insight into the different methodologies that have been employed to address and measure patient adherence and to identify potential role models for the best approach within the ACT project. The search strategy was carried out in the Cochrane Library, PubMed and PsycInfo by using the search terms: adherence, compliance, medication, chronic disease, intervention, telehealth.

Based on this literature review but also experience from the investigators, the knowledge base was established allowing to derive the indicators for patient adherence. The selection of these indicators was an iterative process consisting of several sessions joined by all participants involved. The indicators were structured into domains and subdomains and arranged according to their relevance for WP6. Of note, the group regarded it important to differentiate between “drivers” and “outcomes” of patient adherence. Finally, after careful consideration, the group decided that – for the purpose of the project – it may not be necessary to focus on all aspects of adherence. Therefore, the number of domains and subdomains was reduced selecting only the elements with both the highest relevance/pertinence for the project and the greatest feasibility.

The domains identified and prioritised in relation to patient adherence are summarised graphically in the diagrams below. The selection ranges from factors linked to patient adherence to specific influences and environmental factors.

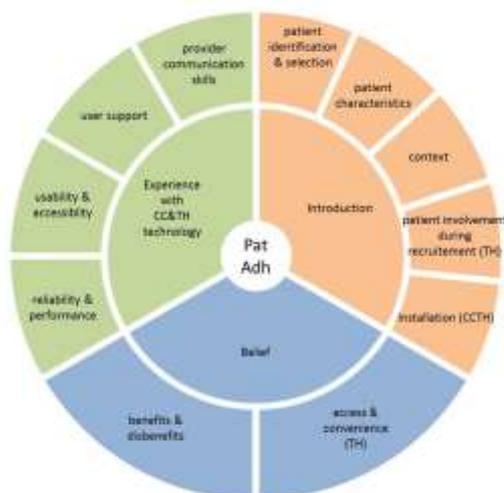


Figure 1: Patient Adherence Driver Indicators selected for the ACT-WP6 project

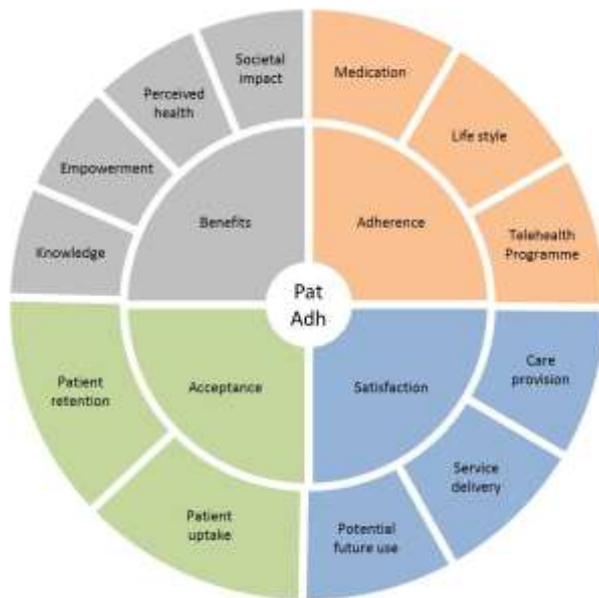


Figure 2: Patient Adherence Outcome Indicators selected for the ACT-WP6 project

2.1 Purpose and Objectives

The aim of this questionnaire is to collect patient-derived informations in order to explore different aspects of adherence. The objective of the use of a self-report questionnaire is to identify the level of adherence and to identify different types of non-adherence.

In order to produce a high level of evidence as many participants as possible should be reached.

2.2 Implementation

In order to ease implementation and reach the highest possible number of participants several modalities were offered to the participating regions how to distribute the questionnaire and collect the information: a) paper-based version; b) online tool filled in by participants themselves; c) telephone-based version filled in by dedicated staff. The regions were allowed to select the most appropriate and feasible approach for their program.

Most regions chose the telephone-based version. The majority of programmes integrated the Patient Questionnaire in pre-existing patient-interviewing algorithms.

2.3 Methods and Means

An indirect measurement was chosen to assess patient adherence. Using a patient questionnaire subjective measures should be assessed. These measures have the potential to identify reasons for a patient's adherence or non-adherence.

The draft patient questionnaire was circulated to all ACT members for review and critical feedback. After finalization the survey has been translated into the respective languages of the region.



The questionnaire contains two parts: the first section concerns all participants, the second part concerns only participants using TH in their program.

The questionnaire aims to address as specific as possible the chosen domains and subdomains. The domains “Introduction”, “Belief” and “Experiences with TH technology” were defined as drivers. Driver indicators capture the enablers and determinants for patient adherence.

“Introduction”

The Introduction domain considers how the CC&TH service is introduced to patients and care givers. A solid introduction program that selects the appropriate patients and enhances staff engagement is required for better patient adherence. The survey should assess how patients are introduced and contracted for the programs. Good matching between patients and the CCTH service is necessary for engaging the patient.

Lower adherence levels and health outcomes may be expected when the patient is not able to use the CC&TH service. Additionally, lower adherence levels and health outcomes are associated with a lower education level (1). It is therefore interesting and important to measure how well the patient is capable of using the CC&TH services in relation to various aspects:

- Ability to utilize the intervention, based on education level, cognitive and physical ability
- Motivation to engage with the intervention, based on attitude, personality, condition concerns, confidence with technology and extrinsic factors
- Knowledge of the condition, self-care recommendations and knowledge and experience.

Involving the patient as an active participant in treatment decisions is important for good adherence (1). Individuals assume greater responsibility for themselves and their health, if they actively participate in decisions about their health care.

Good explanations during recruitment are another component for involvement of the participant. Patients become frustrated with health care providers when misunderstandings occur or treatment becomes overly complex. Thus, questions regarding the domain “Explanation during recruitment” consider how the explanation on the aims and implications of the programme participation during recruitment is perceived by the patient. Sufficient information about the program and involvement of the patient is required for high patient adherence. If a patient feels forced into a programme, poorer adherence and empowerment may be the result.

Context factors can influence the behaviour of a participant. These environmental factors can include economic, agricultural, political, health care, geographical, ecological or cultural systems. The patient questionnaire addresses the perceived quality of care before participating in the program. If satisfaction with the current service and the support available from spouse/family/informal care giver is high the person may be less inclined to get involved in a program which may stop them interacting with that trusted service. If it is poor, then the patient may see the program as a means to access care more readily. Moreover social support, i.e. informal or formal support received by patients from other members of their community, has been consistently reported as an important factor affecting health outcomes and behaviors (1).

“Belief”

Patients must believe that they are vulnerable or susceptible to the disease or its consequences, that they actually suffer from this very condition, and that consequences of



the disease on their well-being could be serious. They must believe that by following a particular set of health recommendations the threat or severity of the condition will be abolished or reduced (1).

Patients believing that the consequences of non-adherence are severe are more likely to be adherent than those believing that consequences are less serious. Patients' attitudes and beliefs about medication and about medicine in general also affect adherence. Patients' knowledge, ideas and experiences, as well as those of family members and friends, have been shown to relate to adherence (2).

“Experiences with CC Programs and TH technology”

Experiences with CC Programs and TH technology indicators capture the perception of the patient with respect to the technology and the program.

The questionnaire addresses several aspects of TH usability including satisfaction with the performance of the equipment, technical problem solving and repair/and maintenance. It is conceivable that the degree of satisfaction with the TH equipment and ease of use are associated with adherence.

In this domain patients' beliefs play an important role, too. As described above, belief domain indicators consider the belief patients have in the programs. Patients who are not convinced of the programme benefits are less likely to use the tools or to participate.

Adherence is likely to be determined also by the knowledge and attitudes of a patient (1). The responsibility for adherence must be shared between the patients, the health care provider and the health care system. Good relationships between the patients and their health care providers are therefore imperative for good adherence. Greater physician-patient collaboration is associated with better adherence (shared-decision-making) (2). The literature contains sufficient evidence on the relationship between aspects of communication and the outcomes of patient satisfaction, recall and adherence for positive correlations to be made (3).

The domains “Adherence”, “Satisfaction”, “Acceptance”¹ and “Benefits” were defined as indicators of patient adherence outcome. These indicators capture aspects of patient adherence to CC&TH services.

“Adherence”

Adherence domain indicators capture how well patients comply with the management of their disease. Self reported indicators on understanding of the condition, self-management requirements, medication and life style aim to examine the progress achieved with CC&TH services. The “Medication” and the “Life style” subdomains aim to assess the extent to which a patient follows the medication plan. The questionnaire intends to assess the patient perspective on his medication behaviour and the extent he is following the life style plan.

“Satisfaction”

“Satisfaction” domain indicators capture the level at which the CC&TH service meets or surpasses the expectations of the patient. Service satisfaction is needed to keep patients engaged for future use. The opinion of patients complaining or agreeing with this type of service should be systematically assessed.

¹ Since data can not satisfactorily be observed in a patient survey, the domain “Acceptance” is not taken into account in the questionnaire.



“Care provision” indicators capture current experiences with respect to the care received by the CC&TH services.

“Benefits”

“Benefit” domain indicators capture the benefits for the patient due to use of service.

The “Empowerment” indicator in the questionnaire captures how well patients are able to manage their health by using the TH equipment.

Failure to adhere to treatment plans consequences frequently mentioned in reduced quality of life. The “Perceived patient health” indicator captures how the patient perceives his quality of life.

2.4 Execution

The survey has been distributed to the regions at the end of June 2014. Informations are collected until January 2015.



3. Outcomes

3.1 Population size

Table 1 Population size in the regions and covered in the programs

Program	“Region” Total population (N)	“Program” Potential patients in the org. Unit (N)	Patients in the programme (N)
Basque Country (Spain)	938,847	66540	7,002
Active patient program			200
PIP COPD	312,949	22,180	1,417
PIP DM	312,949	22,180	3,342
PIP HF	312,949	22,180	2,043
PIP PP			NA
Telehealth HF			
Catalonia (Spain)	1,137,784	34.660	2,163
AISBE – Postdischarge HF/COPD	180,000	170	70
AISBE – Diabetes	112,000	402	191
AISBE – Diabetes Follow-up	300,000	1,200	600
AISBE - Validation Oxygen Prescription	300,000	288	216
Chronic Care Model – AP	454	2,600	257
Chronic Care Model – BSA	88,330		329
Chronic Care Model – SISO	157,000	30,000	500
Groningen (Netherlands)	1,120,198	19,148	13,069
Asthma / COPD	700,000	1,400	11,473
eDiabetes	217,022	15,972	NA
Effective Cardio	130,000	312	118
Embrace	73,176	1,464	1,478
Lombardy (Italy)	100,000	65,000	36,000
CreG	100,000	65,000	36,000
Expert Patient			40
Telemonitor		1,800	100
West-Lothian (Scotland)	176,000	82,000	7,848
Home Safety Service	176,000	36,000	4,500**
Rapid Elderly Assessment Care Team	176,000	10,000	1,098
Reablement and Crisis Care	176,000	36,000	2,250*



3.2 Coverage of the patient surveys

The ideal target of the patient surveys is 50%

Three of the five regions already approached some patients (Lombardy, Catalonia, and Groningen) during Iteration 2. The Basque Country is pending on the approval of the Ethics committee in October 2014.

- Multimorbid program
- Telehealth program

Table 2 Iteration 2 response at August 14 2014, 13:00.

Program	Patient adherence		
	R	T	%T
	244	9,177	2.7
Lombardy (Italy)	18	1,645	1,1
LOM_ExpertPatient	18	45	40
LOM_Telemonitor	0	100	0
LOM_CREG	0	1,500	0
Basque Country (Spain)	0	1,000	0
BAS_ActivePatient	0	200	0
BAS_PIP HF	0	200	0
BAS_PIP DM	0	200	0
BAS_PIP COPD	0	200	0
BAS_PIP MM	0	200	0
BAS_TelehealthHF	NA	NA	NA
Groningen (Netherlands)	32	5,857	0.5
GRO_EffectCardio	0	120	0
GRO_eDiabetes	NA	NA	NA
GRO_Embrace	T0: 1,478 T1: 1,136	1,478	T0: 100% T1: 76.9%
GRO_Asthma COPD	32	5,737	0.6
Catalonia (Spain)	194	642	30.2
CAT_OXYGEN_AISBE	97	100	97
CAT_Diabetes_AISBE	0	50	0
CAT_Diabetes FU_AISBE	0	50	0
CAT_postdischarge HF/COPD_AISBE	36	50	72
CAT_PPAC_BSA	61	164	37.2
CAT_PPAC_AP	0	128	0
CAT_PPAC_SISO	0	100	0
West-Lothian (Scotland)	0	33	0
SCO_Reablement	0	10	0
SCO_HSS	0	20	0
SCO_REACT	0	3	0



3.3 Findings

The survey has been distributed to the regions at the end of June 2014. Informations are collected until January 2015.



4. References

- (1) World Health Organisation (2003): Adherence to long-term therapies: evidence for action. Online verfügbar unter <http://www.who.int>
- (2) DiMatteo MR, Haskard-Zolnierok KB, Martin LR. Improving patient adherence: a three-factor model to guide practice. *Health Psychology Review*. 2012;6:74–91.
- (3) Vermeire E, Hearnshaw H, van Royen P, Denekens J. Patient adherence to treatment: three decades of research. A comprehensive review. *J Clin Pharm Ther*. 2001;26:331–342.



5. Conclusions and next steps

The responsibility for adherence must be shared between patients, the health care provider and the health care system. To get a deeper insight, data informing on adherence are merged from different sources. Due to the complexity of the concept of patient adherence, a mixed methods approach and an exploratory sequential design employing both qualitative and quantitative designs was chosen. Both informations assessed by frontline staff and outcome measurements assessed by the regions as part of their individual programs were incorporated to gain a summary of patient adherence as precisely and valid as possible. The sampling procedure for the questionnaire is run in two phases. Collection and analysis of quantitative data is followed by a qualitative phase building on the results of the quantitative phase aiming to explain the initial quantitative results and to obtain a more detailed knowledge on drivers and outcomes of patients. The questionnaire was devised in the framework of work circles and meetings building on the identified domains, subdomains, and key indicators, as specified above. Further, semi-structured group interviews with 8 to 10 participants per programme will take place in order to collect qualitative data. The local teams will then synthesise the responses for each main category with the help of guidance notes provided by the WP6 team. The results will be summarized and discussed in an Empowerment and Compliance Report in February 2015.



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Patient questionnaire

Participants using telehealth in their program

	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
I had a choice whether the program will include a telehealth solution.	<input type="radio"/>				
The staff clearly explained the purpose of the telehealth equipment and how to use it.	<input type="radio"/>				
I was satisfied with the installation of the telehealth equipment.	<input type="radio"/>				
The technical equipment works well.	<input type="radio"/>				
If the telehealth equipment malfunctions, the problem is quickly resolved.	<input type="radio"/>				
I feel that the telehealth equipment enables me to access quicker care/information.	<input type="radio"/>				
Use of the telehealth equipment has improved my health knowledge.	<input type="radio"/>				
Use of the telehealth equipment has enabled me to manage my health better/more effectively.	<input type="radio"/>				
I feel safer with my health because I had the opportunity to use the telehealth equipment.	<input type="radio"/>				
I telehealth equipment is easy to use.	<input type="radio"/>				
I felt comfortable using the telehealth equipment.	<input type="radio"/>				
I would recommend telehealth to a friend.	<input type="radio"/>				