

Recommendations for Promoting Patient Engagement in Chronic Care: A Consensus Conference Statement

Guendalina Graffigna^{1,2}, Serena Barelo^{1,2}, Giuseppe Riva¹, Massimo Corbo³, Gianfranco Damiani⁴,
Primiano Iannone⁵, Albino Claudio Bosio^{1,2}, Walter Ricciardi⁴

1. EngageMinds Hub – Consumer, Food & Health Research Center, Università Cattolica del Sacro Cuore (Italy);
2. Department of Psychology, Catholic University of Milan (Italy);
3. Casa di Cura Privata del Policlinico, Milan (Italy);
4. Department of Public Health, Università Cattolica del Sacro Cuore, Fondazione Policlinico ‘Agostino Gemelli’, Rome (Italy)
5. Higher Institute of Health, Rome (Italy).

CORRESPONDING AUTHOR AT

Dr. Serena Barelo
EngageMinds Hub – Consumer, Food & Health Research Center
Università Cattolica del Sacro Cuore
L.go Gemelli 1, 20123 Milano (Italy)
Mail: serena.barelo@unicatt.it
Phone: +390272343863

ABSTRACT

Patient engagement is receiving a growing attention in the healthcare context. However, although worldwide healthcare stakeholders agree that patient engagement is a priority for quality and effective care, no shared recommendations on how to promote patient engagement are currently available. Based on these premises, a Consensus Conference (CC) was promoted to address four main issues: What is the definition of Patient Engagement? How measuring Patient Engagement? What are the most recommended methodologies and the tools to promote Patient Engagement? What is the role of new technologies in promoting of Patient Engagement?

The consensus was obtained through an iterative process that began with a systematic synthesis of the available literature in each domain followed by plenary expert discussions.

This CC - including the systematic analysis of international scientific evidences (2749 sources across the major international scientific databases) together with experiences of a multi-disciplinary consortium of investigators and key stakeholders - attempted to provide the first evidence-based Expert Consensus Statement for the promotion of Patient Engagement in chronic care.

These recommendations should be envisaged as inspirational principles to promote a real eco-system of engagement and might orient health services research and interventions.

Key words: patient engagement; consumer health; recommendation; consensus conference; guidelines; health services research

1. Introduction

The occurrence of new environmental risk factors, as well as ones regarding the population's lifestyle, in parallel to deep demographic changes (as for example the increase of the elderly population) brought the contemporary health systems to face increasingly complex scenarios characterized by the growth of care requests in face of a worrisome scarcity of economical and human resources(1). Chronicity is therefore the new scenario that professionals and institutions have to deal with in order to develop effective and sustainable care responses. Dealing with chronicity means coming to terms with a long-term management of the patient as well as with the resulting costs(2,3). Consequently, the promotion of an effective integration between healthcare organizations and territorial services and the optimization of the patient's therapeutic journey, which today are even more complex and articulated, becomes a priority(4). In light of this scenario, the concept of Patient Engagement gained more and more attention in healthcare both in the clinical and research fields (5,6,15–20,7–14). The last decades, in fact, have witnessed a profound turning of care models towards a growing and increasing valorisation of the role of the individual, who is seen as an active and "expert" subject within the clinical care process willing to co-create his/her own health (21–25). Furthermore, the care system finds itself involved with people that express their desire to have a more active role in all the phases of their healthcare journey and feel their illness experience valued(26–33). People wish to be more involved in the decision-making process related to their healthcare, they wish to be aware and thoroughly know all the possible treatment options, and the relative pros and cons(34–40). Even if researchers and clinicians agree with the ethical and pragmatic priority of Patient Engagement promotion, to this day there is no consensus regarding the definition of this concept and the more appropriate strategies and instruments to reach this objective. Patients and healthcare professionals' perspectives on the factors that could support or obstruct Patient Engagement have not yet been sufficiently studied and, to this day, there are no recommendations on the interventions that are more effective in reaching the goal of Patient Engagement.

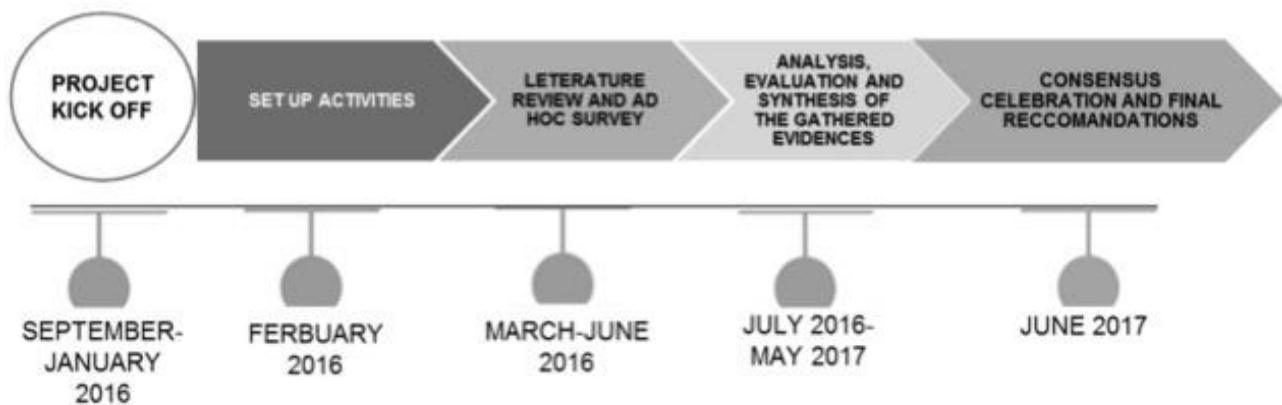
2. Methods

Based on these premises, the Università Cattolica del Sacro Cuore (Milan, Italy) in collaboration with the Welfare General Directorate of Lombardy Region (Northern Italy), under the methodological supervision of the National Institute of Health (ISS), promoted a Consensus Conference to define shared recommendations for Patient Engagement. The Consensus Conference represented the occasion to promote a multidisciplinary and cross-disease discussion among scholars, healthcare professionals, national patient advocacy groups and policy makers to seek answers to the following issues:

1. What is the definition of Patient Engagement?
2. How measuring Patient Engagement?
3. What are the most recommended methodologies and the tools to promote Patient Engagement?

4. What is the role of new technologies in promoting of Patient Engagement?

The methodological procedure adopted by this Consensus Conference (later described) followed the standard procedure defined by the Consensus Development Program of the United States' NIH (<https://consensus.nih.gov/>). The Consensus Conference Process developed over the years 2016-2017 following the process showed in figure 1 and detailed in the next paragraphs. Particularly, the traditional approach of Consensus Conference was combined with an extensive analysis of evidence based international scientific literature on these topics (see table 1) and an extensive survey of best practices and experiences to promote Patient Engagement. 3) The process of consensus development was formalized among experts based on the conduction of working groups with experts under the final supervision of a panel of jury to collate, analyse, discuss and rate existing clinical evidences about Patient Engagement and to share final recommendations. The Consensus Conference involved 104 experts in patient engagement promotion from diverse disciplinary backgrounds (i.e. medicine, psychology, sociology, nursing, management, public health, policy making, health engineering) in order to promote a trans-disciplinary and cross disease debate and to reach a broader consensus. Furthermore the Consensus Conference included representative from 14 patients and voluntary associations to speak for their community and on behalf of their direct care needs and illness experience.



The entire methodological procedure was conducted under the supervision of the National Health Institute in order to guarantee its rigor and compliance with the NIH Consensus Developmental Standards. The methodological features of each phase of the Consensus Development are detailed in the next paragraphs.

2.1 Review of scientific evidences

A systematic revision of the international scientific literature published in English was conducted for the topic areas object of the CC using the following databases: Cochrane Library, Isi Web of Science, PubMed, Scopus, CINAHL, PsychInfo. The literature review was executed with the creation of 2 search

strings that corresponded with the areas of interest (definition and measurement; promotion of patient Engagement with/without technologies) following two different methods given the different nature of the queries and the relative bibliographical material (see table 1). The assessment of the methodological quality was conducted by a group of methodologist experts in scientific literature analysis. Here below is the methodology and the search strings used to analyse the scientific evidence in response to the queries raised by the CC.

Table 1 Methodological process of the analysis of the literature

Analysis of the scientific evidence related to queries 1 and 2	
<i>Method:</i>	For queries 1 and 2 (related to the first search string), the experts were asked to do a narrative review of literature given the nature of the object of interest and the analysed literature. The goal of this literature analysis was, in fact, to further explore the nature and characteristics of concepts, theories and definitions of the phenomena of Patient Engagement. It seemed appropriate to analyse the literature that, even when inspired by systematic criteria, allowed a deeper and more critical analysis of the theoretical and conceptual components of the analysed studies, as well and their empirical characteristics. Particularly, the analysis followed the principles of Conceptual Analysis, widely spread in both social sciences and in welfare (12,41,42).
<i>Key words used in the search strategy</i>	the databases listed above were subject to a systematic search according to the following keywords search string: ["patient engag*" OR "consumer engag*" OR "client engag*" OR "citizen engag*"] AND ["definition" OR "conceptualization" OR measure OR "questionnaire"]. No restriction was applied regarding the year, the language or the document type. The search was integrated on the basis of an accurate analysis of the bibliographical references reported in the studies found.
<i>Inclusion criteria of the studies</i>	In the analysis, only the manuscripts that reported a conceptual definition or a modelling theory of the concept of patient engagement were included. The manuscripts were considered as "conceptual" if they discussed in depth the epistemology roots of the analysis construct and that specified the theoretical and implementing components. Careful attention was given to the modality of operationalizing and measurement of the theoretical constructs proposed in the analyzed studies. The ones included were: Clinical Trial, Meta-Analysis, Practice Guideline, Randomized Controlled Trial, Review, Clinical Trial, Controlled Clinical Trial, Guideline, Multicenter Study, Survey, Case-Control Study OR Protocol, Retrospective Study, Cohort Analysis OR Cohort Study, Longitudinal Study, Follow up OR Prospective Study, Observational Study, Qualitative studies, Quantitative studies, Expert Opinion (Literature OR Analysis).
<i>Selection process:</i>	First, the database duplicates that generated from the systematic search were eliminated. At a later stage, all the titles and abstracts found were read and analyzed with the aim of excluding sources irrelevant and incoherent with the study inclusion criteria. Finally, the full texts of the sources left were read and thoroughly analyzed to understand how they conceptualized, described and operationalized the concept of Patient Engagement. The process of analysis of the sources was ongoing up until conceptual saturation was reached.
<i>Process of analysis of the evidence</i>	The conceptual analysis conducted was inspired by Walker & Avant's(42) methodological principles. In particular, a thorough qualitative analysis of the sources found was conducted through an iterative process of comparison between the definitions found and the continuous critical validation of the concepts emerging during the analysis process itself. This iterative and interpretative process of analysis allowed to clear the theoretical roots of the conceptualizations of Patient Engagement thanks to the continuous comparison and differentiation process between the definitions found in literature, the description of their characteristics and peculiarities, the definition of their main attributes, as well as the overlapping areas with other concepts. More in detail, the analysis was finalized by highlighting and classifying the attributes, the conceptual antecedents and consequences as well as means of empirical operationalization of the concept of Patient Engagement as proposed by the definitions and the theoretical models found in literature(12). The analytical process was recursive and articulated in the following phases: 1) Patient Engagement definitions were coded and articulated in units of significance. The codes given – in reference to the main analysis goals- were: the terminology of the concept definition; the main attributes of Patient Engagement reported in the definition; the antecedents of Patient Engagement; the consequences of Patient Engagement; the empirical operationalization proposed for the concept of Patient Engagement. 2) The codes defined and given to each source/article were schematically reported in a coding grid. The grid was constantly reviewed, corrected and broadened as new insights emerged from the analytical process. Furthermore, the codes that were given initially were revised and categorized in broader thematic categories which in turn were merged in themes with the aim of systematizing and synthesizing the main insights emerging from the analysis. 3)The coding grids obtained were then compared with the aim of highlighting eventual recurrences in meanings and in conceptualizations or diversions between the definitions of Patient Engagement found in literature that were object of analysis. 4) The final phase that followed consisted in the interpretation and abstraction starting from the

	comparative literature and the different analysis grids obtained. This final phase of the process allowed us to synthesize the main conceptual characteristics of the definitions found, and build a final taxonomy able to account for the conceptual attributes and the definition of Patient Engagement.
Analysis of the scientific evidence related to queries 3 and 4:	
<i>Method:</i>	for queries 3 and 4, the experts were asked to do a systematic literature review according to the methodological principles of PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses(43). Below the methodological characteristics are detailed.
<i>Key words used in the search strategy:</i>	With the aim of answering queries 3 and 4, the databases listed above were the object of a systematic research conducted with the following search string: (“patient* engag*”) AND [“plan*” OR “practice*” OR “intervention*” OR “program*” OR “protocol*” OR “trial*”]. No restriction was applied regarding the year, the language or the type of document. The search was integrated on the basis of an accurate analysis of the bibliographical references reported in the studies found.
<i>Inclusion criteria of the studies:</i>	the studies that were included in the analysis were coherent with the following inclusion criteria: (1) Years covered by the research: all the literature produced until the year 2016; (2) Population: studies that explicitly discussed the concept of Patient Engagement in the context of chronic illnesses; (3) Types of studies: with the aim of focusing the analysis on the most significant scientific evidence, only studies with Randomized Controlled Trial were included.
<i>Selection process:</i>	the identified studies underwent another selection through the analysis of the titles and abstracts, to which followed an exclusion of those that were clearly unsuitable for the queries and inclusion criteria previously described. Of all the selected abstracts the full texts were then obtained and divided per topic area (in reference to the CC queries) and types of study. The systematic search of the sources was purposefully initially broad, in order to include all of the potentially relevant studies for the study objectives. The articles found were then skimmed down and selected using a funnel process. Specifically, during an initial selection phase all the sources found were analyzed with regard to their title and abstract. This analysis allowed for the selection of only the relevant studies according to the following criteria: (1) being a Randomized Controlled Trial; (2) referring to chronic patients; (3) presenting measurement data of the impact of the intervention finalized to increase Patient Engagement; (4) being a peer-reviewed article with full text availability.
<i>Process of analysis of the evidence</i>	the selected sources underwent systematic analysis with the aim of extracting the following information in a structured analysis grid: (1) methodological characteristics of the study (country of the first author, study design, number of branches of the study, type of control group, n. of participants in the experimental and control group) (2) participants' characteristics (diagnosis, average age, % per gender); (3) characteristics of the intervention (number and duration of the sessions, type of treatment, strategies and instruments used both for groups and single individuals, theoretical foundations of the intervention); (4) obtained results (measured outcomes, methods of evaluation of the results, results achieved overall). The data extracted was then qualitatively analysed. <i>Evaluation of the quality of the studies:</i> The quality of the RCT studies was evaluated following the Downs and Black checklist, a solid instrument with good psychometric property (44) that has high levels of correlation with other instruments of studies' quality assessment(45). This checklist allows to attribute a complex score of the methodological quality of the considered studies (with a maximum score of 27) as well as a score on the quality of the evidence reported (with a maximum score of 11), external validity (maximum score of 3), internal validity (maximum score of 7), internal validity regarding the intervening variables (maximum score of 6). A final area of the checklist allows us to give a score related to the adequacy of the sample size. The score relative to this item will be simplified as follows: 0=70% (or impossible to determine), 1=80%, 2=85%, 3=90%, 4=95%, 5=99%.

2.2 Analysis of best practices from the clinical field

An ad hoc investigation was conducted regarding the good practices, instruments and methodologies used for the promotion of Patient Engagement. The investigation, coordinated by the Organization Committee, was done on a sample that was not statistically significant, but representative based on the research goals, and was formed by healthcare professionals that were selected in order to guarantee the multidisciplinary requirement. Data collection was executed through the diffusion of an online qualitative questionnaire in order to gather the experience gained by the experts on the initiatives and practices of the promotion of Patient Engagement, on the main targets of intervention and on the

different instruments and methodologies that they use for the promotion of Patient Engagement. The investigation provided face-to-face workshops with experts. The investigation took place between March and April in 2016. All the collected questionnaires underwent normal quality checks before proceeding with data analysis. The data was analysed with the use of thematic analysis.

2.3 Process of Consensus Development

The experts involved in the Consensus were purposively selected on the basis of their previous renowned commitment and experience on patient engagement promotion both attested by previously published work, or due to generated outcomes during their work in the field (i.e. empirical research, patient engagement promotion initiatives; development of patient engagement tools or strategies). In order to guarantee the scientific standards of the process all members of the Consensus had to undersign a Conflict of Interest statement and the Consensus Conference Regulation. Particularly, in relation to this according to the methodology of the of the United States' NIH, an organizational structure for the whole Consensus Process was defined, as described in table 2.

Table 2 The role in the Consensus Conference

ROLE	RESPONSIBILITIES	MEMBERS
Organizing Committee	<p>Was responsible for:</p> <ul style="list-style-type: none"> – defining the aims of the conference; – finding financers; – identifying members of the Technical-Scientific Committee (TSC); – writing the protocol with the TSC; – promoting the conference; – organizing the different phases of the program; – identifying members of the Panel Jury; – formulating, in agreement with the Technical-Scientific Committee, the queries for the Panel Jury; – giving directions and methodological support to the Experts for the preparation of the reports to present to the Panel Jury; – defining the distribution and measuring strategies of the impact of the recommendations produced 	<p>G. Graffigna, Università Cattolica del Sacro Cuore, Milano; A.C. Bosio, Università Cattolica del Sacro Cuore, Milano; S. Barello, Università Cattolica del Sacro Cuore, Milano; G. Castelnuovo, Università Cattolica del Sacro Cuore, Milano; M. Corbo, Casa di Cura Privata del Policlinico, Milano; G. Riva, Università Cattolica del Sacro Cuore, Milano</p>
Technical-Scientific Committee	<p>Was composed of members with recognized experience and representativeness identified and invited by the Organizing Committee and was responsible for:</p> <ul style="list-style-type: none"> – collaborating with the Organizing Committee for the writing of the Consensus Conference protocol; – formulating the queries for the Panel Jury, in accord with the Organizing Committee; – internally designating its Experts and the eventual work groups needed to prepare and present to the Jury the reports of the single queries during the conference; – providing the Experts and the work groups with the necessary methodological directions to write the assigned reports and make sure that a common method is used to analyse data and present it to the Jury. 	<p>E. Anessi Pessina, CERISMAS (Centro di ricerche e studi in management sanitario), Università Cattolica del Sacro Cuore, Milano; R. Bellantone, Università Cattolica del Sacro Cuore, Roma; R. Borgatti, IRCCS Istituto Eugenio Medea, Bosisio Parini, Lecco; A. Celano, APMAR (Associazione Persone con Malattie Reumatiche); A. Cicchetti, ALTEMS (Alta Scuola di Economia e Management dei Sistemi Sanitari), Università Cattolica del Sacro Cuore, Roma; F. Consorti, SIPeM (Società Italiana di Pedagogia Medica); L. Coppola, DG Welfare Regione Lombardia; R. D'Elia, Ministero della Salute, Direzione Generale della Prevenzione; D. D'Ugo, SICO (Società Italiana Chirurgia Oncologica), Università Cattolica del Sacro Cuore, Roma; F. De Lorenzo, European Cancer Patients Coalition, FAVO (Federazione Italiana Associazioni di Volontariato in Oncologia); F. Donatelli, Università degli Studi di Milano, Istituto Clinico Sant'Ambrogio Gruppo San Donato; A. Fauci, Istituto Superiore di Sanità; F. Giardina, CNOP (Consiglio Nazionale Ordine degli Psicologi); P. Iannone, Istituto Superiore di Sanità; D. Mannino, AMD (Associazione Medici</p>

		Diabetologi); D. Mari, Fondazione IRCCS Ca'Grande - Ospedale Maggiore Policlinico, Università degli Studi di Milano; V. Mastrilli, Ministero della Salute, Direzione Generale della Prevenzione; P. Mocarelli, IRCCS Fondazione Don Gnocchi; E. Molinari, Università Cattolica del Sacro Cuore, Milano, Istituto Auxologico Italiano; F. Molteni, Villa Beretta - Presidio di Riabilitazione dell'Ospedale Valduce; A. Muratore, SICO (Società Italiana Chirurgia Oncologica); G. Muttillio, IPASVI (Infermieri Professionali, Assistenti Sanitari e Vigilatrici di Infanzia); G. Perseghin, SID (Società Italiana Diabetologia); G. Pintori, Inversa Onlus (associazione italiana per i pazienti affetti da idrosadenite suppurativa-acne inversa-); E. Previtali, AMICI Onlus (Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino); W. Ricciardi, Istituto Superiore di Sanità; E. Rizzato, Fondazione SPP (Scuola di Sanità Pubblica); E. Santoro, IRCCS - Istituto di Ricerche Farmacologiche "Mario Negri"; G. Spata, FNMCEO (Federazione Italiana Ordine dei Medici); M. Tessarollo, Residenze Anni Azzurri (Gruppo KOS); R. Valdagni, IRCCS Istituto Nazionale dei Tumori.
Panel Jury	<p>Had the authority to:</p> <ul style="list-style-type: none"> - write a regulation of discussion in which the methods and procedures that the Jury will apply internally are defined a priori, including the composition of the Writing Committee; - read and evaluate the documents produced from the work groups; - assist to the presentation and discussion of the reports during the meetings of the Consensus Conference; - discuss, review and approve the preliminary consensus document to present at during closing time of the conference; - review and approve the final consensus document according to the modalities and times provided by the regulation. 	A. Aglione, FAVO (Federazione Italiana Associazioni di Volontariato in Oncologia); G. Artioli, Arcispedale Santa Maria Nuova - IRCCS di Reggio Emilia; F. Avolio, Agenzia Regionale Sanitaria della Puglia; European Innovative Partnership for Active Healthy Ageing; C. Colombo, IRCCS Istituto di Ricerche Farmacologiche Mario Negri, Milano; S. Leone, A.M.I.C.I. Italia Onlus (Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino); M.C. Ghiotto, Regione del Veneto; B. Mazzoleni, Commissione Nazionale Ipasvi (Infermieri professionali, assistenti sanitari e vigilatrici di infanzia); R. Mete, Istituto Superiore di Studi Sanitari, Giuseppe Cannarella; P. Mosconi, IRCCS Istituto di Ricerche Farmacologiche Mario Negri, Milano; S. Nardi, Coordinamento nazionale delle Associazioni di Malati Cronici (CnAMC); C. Pinto, AIOM (Associazione Italiana Oncologia Medica); P. Quintaliani, SIN (Società Italiana Nefrologia), FIR (Fondazione Italiana Rene); G. Sanna, METIS FIMMG (Federazione italiana medici di medicina generale); S. Tonolo, ANMAR (Associazione Nazionale Malati Reumatici); A. Virzi, Società di Medicina Narrativa
President of the Jury	<p>Had the authority to:</p> <ul style="list-style-type: none"> - write the work regulation and get the Jury's members to approve it; - verify that all the members of the Jury promptly receive the materials produced by the experts and work groups; - coordinate the Jury and the Writing Committee until the writing of the final consensus document; - regulate the unfolding of the Jury's discussions, ascertain the poll results and countersign the meeting's reports; - maintain the relationships with the Organization Committee and act as a conduit for communications directed to the Jury; - take part in the celebration of the Consensus Conference; - publicly communicate, at the end of the Jury's discussion, the conclusions reported in the approved preliminary consensus document. 	G. Damiani, Policlinico Universitario Agostino Gemelli, Università Cattolica del Sacro Cuore, Roma
Writing Committee	Formed by members selected from the Jury, this Committee reflects the competences and characteristics of the Panel's multidisciplinary, provided the newsroom with the final consensus document, following the modalities established and described in the Jury	F. Avolio, Agenzia Regionale Sanitaria della Puglia; European Innovative Partnership for Active Healthy Ageing; G. Artioli, IPASVI Emilia Romagna (Infermieri professionali, assistenti sanitari e vigilatrici di infanzia), Università degli studi di Parma; S. Leone, A.M.I.C.I. Italia Onlus

	regulation. This document is an integration of the preliminary document that the Jury will produce in the hours following the Consensus Conference with a synthesis of the tasks that the Panel based itself on to formulate the recommendations. Moreover, the Writing Committee verified the coherence between the conclusions and the accompanying texts.	(Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino); P. Mosconi, IRCSS Istituto di Ricerche Farmacologiche Mario Negri, Milano
Scientific Secretariat	coordinated the collected and exchanged material and information between the different participants involved	G. Graffigna, Università Cattolica del Sacro Cuore, Milano; S. Barello, Università Cattolica del Sacro Cuore, Milano
Organizational Secretariat	coordinated the operative organization of the conference	J. Menichetti, Università Cattolica del Sacro Cuore, Milano; M. Savarese, Università Cattolica del Sacro Cuore, Milano
Members of the Expert Meetings	<p>Held the role of assessing and synthesizing the evidence present in literature that were pertinent to the queries of the Consensus Conference. Particularly, they had the following jobs:</p> <ul style="list-style-type: none"> – preparing a synthesis of the scientific evidence available on the subject; – preparing a synthesis of the information available to the public that comes from different sources, regarding the subjects of interest in the conference; – handing the reports made to the Jury, within the stipulated times; – presenting the data collected during the celebration of the conference and participate in the discussion. 	<p><i>Working Group on the definition of Patient Engagement:</i> A. Bertoni, Università Cattolica del Sacro Cuore, Milano; S. Donato, Università Cattolica del Sacro Cuore, Milano; S. Gilardi, Università degli studi di Milano; C. Guglielmetti, Università degli studi di Milano; M. Lastretti, Ordine degli Psicologi del Lazio; L. Lombi, Università Cattolica del Sacro Cuore, Milano; S. Ostuzzi, ALOMAR (Associazione Lombarda Malati Reumatici); G. Pitacco, ASUIT (Azienda Sanitaria Universitaria Integrata di Trieste); M. Savarese, Università Cattolica del Sacro Cuore, Milano; E. Vegni, Università degli Studi di Milano; N. Visalli, AMD (Associazione Medici Diabetologi)</p> <p><i>Working group on the measurement of patient engagement:</i> S. Barello, Università Cattolica del Sacro Cuore, Milan; D. Bettega, Fatebenefratelli Ospedale Sacra Famiglia Erba (Como); F. Lucchi, Azienda Ospedaliera Spedali Civili Brescia; M. Magri, IPASVI Milano, Lodi, Monza e Brianza (Infermieri professionali, assistenti sanitari e vigilatrici di infanzia); M. Pozzi, Fatebenefratelli Ospedale Sacra Famiglia Erba (Como); L. Provenzi, IRCSS Istituto Eugenio Medea, Bosisio Parini, Lecco</p> <p><i>Working group on the promotion of patient engagement:</i> M. Annoni, Fondazione Umberto Veronesi; M. P. Arnaboldi, IEO (Istituto Europeo Oncologico); L. Bellardita, IRCSS Istituto Nazionale Tumori ; C. Carzaniga, GITIC (Gruppo Italiano Infermieri di Area Cardiovascolare); A. Castaldo IRCSS Istituto Piccolo Cottolengo Don Orione</p> <p>L. Garrino, SIPeM (Società Italiana di Pedagogia Medica); M. Gorli, Università Cattolica del Sacro Cuore, Milano; M. Gulizia, ANMCO (Associazione Nazionale Medici Cardiologi Ospedalieri)</p> <p>A. Lotti, SIPeM (Società Italiana di Pedagogia Medica); J. Menichetti, Università Cattolica del Sacro Cuore, Milano; M.L. Mottes, Diabete Forum; A.D.P.Mi Onlus (Associazione Diabetici della Provincia di Milano); N. Piana, Università degli Studi di Perugia; G. Quaglini, Parkinson Italia Onlus</p> <p>G. Scaratti, Università Cattolica del Sacro Cuore, Milano; M. Tettamanti, GITIC (Gruppo Italiano Infermieri di Area Cardiovascolare); P. Varese, FAVO (Federazione Italiana Associazioni di Volontariato in Oncologia).</p> <p><i>Working group on the use of new technologies for patient engagement:</i> S. Bigi, Università Cattolica del Sacro Cuore, Milano ; D. Bruttomesso, SID (Società Italiana di Diabetologia); L. Del Campo, FAVO (Federazione Italiana Associazioni di Volontariato in Oncologia) ; S. Franco, Istituto Superiore di Studi Sanitari, Giuseppe Cannarella; A. Mazzone, FADOI (Federazione delle Associazioni dei</p>

		<p>Medici Internisti Ospedalieri) ; G. Palumbo Villa Beretta - Presidio di Riabilitazione dell'Ospedale Valduce; D. Pero AIMAC (Associazione Italiana Malati di Cancro); G. Pintori, Inversa Onlus; G. Polvani, Università degli Studi di Milano, IRCSS Centro Cardiologico Monzino</p> <p>E. Santoro, IRCCS - Istituto di Ricerche Farmacologiche "Mario Negri" ; S. Triberti, Università Cattolica del Sacro Cuore, Milano; A. Tzannis, Università Cattolica del Sacro Cuore, Milano</p>
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An Organizational Committee together with the Technical-Scientific Committee supervised the whole process to guarantee its methodological standard. Further experts were involved in four thematic working group which had to synthetize, discuss and report on the scientific evidences in response to the four questions of the project. Experts meetings were held to assess, discuss and synthesize the evidences produced in the previous literature analysis and ad hoc survey. Four Working Groups were organized: one to respond to each of the Consensus Conference questions, as described below:

(1) Working Group on the definition of Patient Engagement, to evaluate, select and synthesize all the available evidence regarding the main definitions of Patient Engagement available and the conceptual boundaries between Patient Engagement and other related concepts (e.g. Patient empowerment, Patient Activation, Health literacy, Patient Adherence). Finally they had to discuss and define the main obstacles and the main enablers of Patient Engagement.

(2) Working Group on the measurement of Patient Engagement to evaluate, select and synthesize all the available evidence regarding the main instruments used for the measurement of Patient Engagement, of Caregiver/Family Engagement and of the healthcare professionals attitudes to promote Patient Engagement.

(3) Expert Meetings on the promotion of Patient Engagement to evaluate, select and synthesized the available evidence regarding the main methods and instruments for the promotion of Patient Engagement.

(4) Expert Meetings on the role of new technologies for Patient Engagement to evaluate, select and synthesize the available evidence regarding the types of technologies more effective in the promotion of Patient Engagement and the main barriers or facilitators to the adoption of new technologies for the promotion of Patient Engagement.

Finally a Panel of Jury had to revise and rate the evidences produced by the experts to finalize the final consensus document with shared recommendations. The Panel of Jury was composed of members selected from the Organizing Committee on the base of intellectual autonomy criteria, representativeness, authority in the scientific field and moral and cultural intellect, in order to guarantee multi-disciplinarily and multi-professionality. It met at the end of the consensus process to read and evaluate the documents produced from the experts meeting. The Panel of Jury also discussed, drafted and approved the consensus document.

3. Results

The final Consensus report (extensively reported elsewhere (46)) was prepared by the Panel of Jury on the basis of the deep consideration, evaluation and rating of all the evidences reported by experts in the documentation provided. The main recommendations reported in the final Consensus Statement are summarized in the following paragraphs.

3.1 Query 1 – What is the definition of Patient Engagement?

It was decided to avoid the term “patient” because conceptually too passivizing and not coherent with the goal of encouraging the individual’s active role. The word patient comes from the Latin word *patiens*, the present participle of the deponent verb, *patior*, meaning ‘I am suffering’ and akin to the Greek verb *πάσχειν* (= *paskhein*, to suffer) and its cognate noun *πάθος* (= *pathos*). The use of the word patient thus, implicitly evokes a negative an asymmetric relationship between an “expert” (i.e. the healthcare professionals) and a “lay” person who have to be changed in some extent. Thus, rather than of “patients” it appears preferable to refer to “persons” with a demand of health or care. Furthermore, the Consensus Conference recommends adopting the term “Engagement” without pinning it to a specific actor (i.e. the patient) to underline the relational nature of this concept. “Engagement”, indeed, is a concept which identifies and qualifies the possible relationships that a person may entertain with the healthcare system in its whole: namely with its health and/or care condition (i.e. individual’s level of psychological adjustment to the disease); with his/her informal caregiver (the family in particular); with his/her healthcare professionals; with society and so on. Thus, “Engagement” has to be conceived as a systemic and organizational phenomenon since it results from a combination of multilevel factors of individual, relational, organizational, social and political nature. On these basis, “Engagement” needs to be considered as an umbrella concept that articulates, systemizes and includes other such as adherence, compliance, empowerment, activation, health literacy, shared decision making, and activation as described in Supplementary file 1.

3.2 Query 2 - How measuring Patient Engagement?

Individual differences of how people react and respond to their own health’s management needs are important to consider for a better personalization of social and healthcare services. Furthermore, the assumption that people of the same clinical or socio-cultural characteristics necessarily respond in the same manner to the proposal of taking a proactive role in their health managements is misleading and risky. Assessing the degree of emotional elaboration and adaptation to the illness and its management is key to support patients’ motivation in the involvement in the clinical care journey. At the same time, the needs and aptitudes of the professionals and the team towards the development of Engagement are aspects that need just as much monitoring. According to the Consensus Conference, a cultural and

organizational reconfiguration of the social/health and welfare services in favour of the inclusion of non-extemporary opportunities of assessment and monitoring of Engagement is very desirable. The integrated assessment, as an inspiring principle and value within the organizational and social healthcare system, is to be considered the *primo movens* of the promotion of Engagement. The assessment implies the monitoring across time, of different operational levels (micro-meso-macro) of the actors and the social and health care system and requires multiple scientifically validated methods and instruments. Furthermore the assessment of Engagement should not be addressed only to the “receivers of care”, but also to their families and even to the healthcare professionals. Assessing the level of Engagement of individuals with chronic illness and their informal/family caregivers in the clinical care process should become a routine operation within clinic practice. It’s necessary to adopt assessment measures that are validated and reliable in order to evaluate the efficacy/efficiency of the interventions done, and to orient and personalise them based on the characteristics of the recipients and the complexity of their clinical care case. Just as important is the evaluation of the aptitude (difficulty/resistance) and the behaviours of the professionals and team towards the active role of the individual with chronic illness and his formal/informal caregivers. Healthcare professionals skills/knowledge for the efficient promotion of Engagement need to be assessed and trained too. Furthermore, the adoption of Engagement assessment tools should be seen as a way to guarantee that the voices of all the key stakeholders of a healthcare system are listened in the goal of realising a really value base healthcare.

For a broader vision of the instruments available for the assessment of Engagement refer to Table 3. It appears necessary to adopt articulated devices to monitor the system of activities/practices that occur in the organization context such as, for example, the Change Laboratories or the instruments of organizational ethnography.

Table 3 Instruments for Engagement assessment

Scale name	Characteristics	Pros	Cons
Patient Engagement assessment scales			
<i>Altarum Consumer Engagement (ACE)</i> (47)	15 item scale that assesses the individual’s behaviour in managing his health and his decision-making regarding health care. The instrument is formed by four sub-scales (commitment, informed choice, navigation, ownership) each indicative of a specific aspect of Engagement.	The scale is very articulated and detailed and allows for a good assessment of the individual’s self-management skill.	The scale is quite long and complicated in its clinical application. The scale does not measure the emotional-motivational component of Engagement.
<i>Patient Activation Measure (PAM)</i> (48)	Scale formed by 13 items that assesses the person’s current behavioural abilities in managing the illness and the treatment prescriptions.	The scale is broadly used and has validation in several languages	It focuses on the behavioral and cognitive components of Engagement, and does not analyze the emotional-motivational component of Engagement
<i>Patient Health Engagement Scale (PHE-s)</i> (49)	5 item scale developed based on a solid conceptual evidence-based model of the individual with chronic illness’ experience of Engagement (PHE-model). The scale assesses the ability to reconfigure ones’ identity from passive receiver to co-author of the health service.	The scale is easy and fast to use in the clinical context. The scale is well reliable in measuring the psychological attitude of patients towards Engagement	The scale does not measure behavioural components of the individual’s self-management.

Family and Caregiver Engagement assessment scales			
<i>Preparedness for caregiving scale</i> (50)	An 8 item questionnaire (validated on a psychometric level) created to assess how much the caregiver perceives himself as prepared to deal with the assistive role on various levels (physical care, emotional support, stress management).	The scale is articulated and complete and offers an adequate measurement of the caregiver's competences in care-taking as well as his psychological adjustment in having this role.	The scale was developed and validated for the neurological and oncological field and was never used in other therapeutic areas.
<i>Parent-Patient activation measure</i> (51)	It's the caregiver version of the 13 item scale that measures the individual's activation in self-managing his healthcare. Particularly, this scale assesses the level of the caregiver's activation, evaluating his knowledge, his perceived self-efficacy and his desire to take an active role in managing the healthcare of his loved one.	The scale allows to assess the caregiver's activation in a way specular to the one of the person with chronic illness.	The scale is specific for the paediatric area.
Scales for the assessment of the healthcare professional's aptitudes for Patient & Caregiver Engagement			
<i>Clinician Support for Patient Activation Measure – CS-PAM</i> (52)	Instrument that allows assessing the attitudes and value orientation of the clinicians towards the activation of the person with chronic illness.	It is proposed as a measure of activation specular to the measurements of the person and caregiver's activation and allows for a triangulation of this data.	It's an aptitude assessment scale that does not evaluate the actual clinician's Engagement abilities.
<i>Self-Management Support (SMS) Scale</i> (53)	Behavioural scale that seeks to measure how much clinicians use strategies to improve the individual's self-management competences.	Offers a list of prototypical behaviours that characterize the clinician's abilities to motivate and educate the person in self-management.	It doesn't assess the clinician's attitudes and his value orientation for Engagement.
<i>Clinicians Competence in Patient Engagement Strategies (CC-PES)</i> (54)	The scale is articulated in 9 items and assesses the clinician's self-efficacy perceptions concerning the different fundamental strategies for the promotion of the person's Engagement.	The scale was created and validated specifically to measure the clinician's Engagement competences and perceived Engagement efficacy	It's based on the clinician's self-evaluation.

3.3. Query 3 - What are the most recommended methodologies and the tools to promote Patient Engagement?

It's necessary to avoid a simplistic approach to the promotion of Engagement, by limiting it to matters concerning just the individual patient. Therefore the Consensus Conference recommends to develop an "eco-system" of actions of Engagement promotion on different levels: individual, interpersonal, organizational, social-community, and political/institutional, as detailed described in Supplementary file 2.

1) At the level of individuals, it is necessary to support their engagement skills and their sense of ownership over the healthcare course. Interventions designed and structured on the basis of a scientific framework of Engagement and personalized based on the assessment of individuals' needs and availability to take ownership over their health management. To achieve this goal, the following are recommended: 1) Therapeutic education and peer education; 2) Motivational strategies and counselling; 3) Implementing psychology counselling interventions to increase motivation and self-awareness. In this direction the following strategies should be considered: Health Coaching(55–57), Motivational Interviews(58), Goal Setting(59,60), Medical Humanities(61–64), and Mindfulness(65,66).

2) The healthcare professional's participation within this cultural shift and the support to their knowledge and skill acquisition for Engagement promotion is crucial in order to avoid psychological resistances and to have them "on board". To sensitise, train and involve healthcare professionals and the healthcare unit team, it's necessary to promote an "Engagement culture" through concrete actions such as: 1) Providing, starting from the university health professionals' educational curricula as well as in continuous training, knowledge and specific skills for the promotion of Engagement in the daily clinical practice; 2) Promote the health professional's well-being and Engagement and motivate him towards initiatives of Engagement promotion; 3) Promote healthcare unit teams that are multi-professional and multi-disciplinary is a prerequisite. To achieve these goals recommended strategies are: Inter-professional Education(67–69), Problem Based Learning(70,71), appeal to Expert Patient(21,22,72) such as sensitizers and educators; multidisciplinary and inter-professional consulting for a better care of the individual(73,74); technologies as facilitators for the communication and sharing of clinical data between among health practitioners (75,76).

3) Promoting Engagement of family members and informal caregivers, through specific intervention of education and sensitization, is an important resource to strengthen the efficacy of the preventive or therapeutic intervention. Focusing only on the people with illness is reductive and imprecise, as more often than not the person with chronic illness is not alone in his encounter with the healthcare professionals, nor in taking charge of the management of his health. When the caregiver becomes an active part of the healthcare team and gains knowledge regarding the value of his role, he contributes to the increase of the potential of therapeutic success of the interventions both in short and long term. The malaise or hyper-protective ways he uses with the assisted person, moreover, could jeopardize the person with chronic illness' abilities to actively participate in the healthcare journey. In relation to the informal/family caregivers, there is a need for: 1) resources that guarantee efficacy, sustainability and continuity of the interventions in the long run; 2) emotional support and counselling; 3) caregiver education and improvement of health literacy. To achieve these goals recommended strategies are: Therapeutic Education(34) and Peer Education(79,80) and Psychology Counselling(81) to increase motivation and self-awareness of the informal caregivers.

4) Models, processes, and practices of the social and healthcare organization should be reconfigured in order to truly achieve the goal of Engagement. To opt for a personalized care intervention and a better continuity of social welfare services are conceived as fundamental precursor of patient engagement. In this direction the following priorities are recommended: 1) Integration of assistive, social and care services; 2) the establishments of Case Managers(82), the continuity and personalization of social welfare and care interventions; 3) systematic stakeholders' involvement in the co-design and co-production of care services(83,84);

5) Association formed by people with chronic illness, caregivers and volunteers can act as glue of the different functions and organizations that are responsible for the management of the person with chronic illness. They are a priceless source of education, information, practical and especially emotional support for the assisted and their families(85,86). The valorisation and support of the role of Associations of people with chronic illnesses or citizen's organisations within the "eco-system" for the promotion of Engagement benefits the assisted, his informal/family caregiver and the social and healthcare system itself, both in terms of protection of their rights and of promotion of the knowledge and exercise of the duties of the people thanks to their irreplaceable contribution in the realization of their health plan.

6) Finally, the promotion of initiatives of social and public opinion information and sensitisation on the value of Engagement is to be considered. Society, in particular peer networks, can have a crucial role in the promotion of Engagement for the individual and his informal caregiver. Social sensitisation and informative initiatives on the value of engagement as well as a transparent analysis of the challenges encountered by individuals in the Engagement process are desirable. Sensitisation and informative campaigns, even with a social marketing approach, can be useful in the achievement of this goal(87,88).

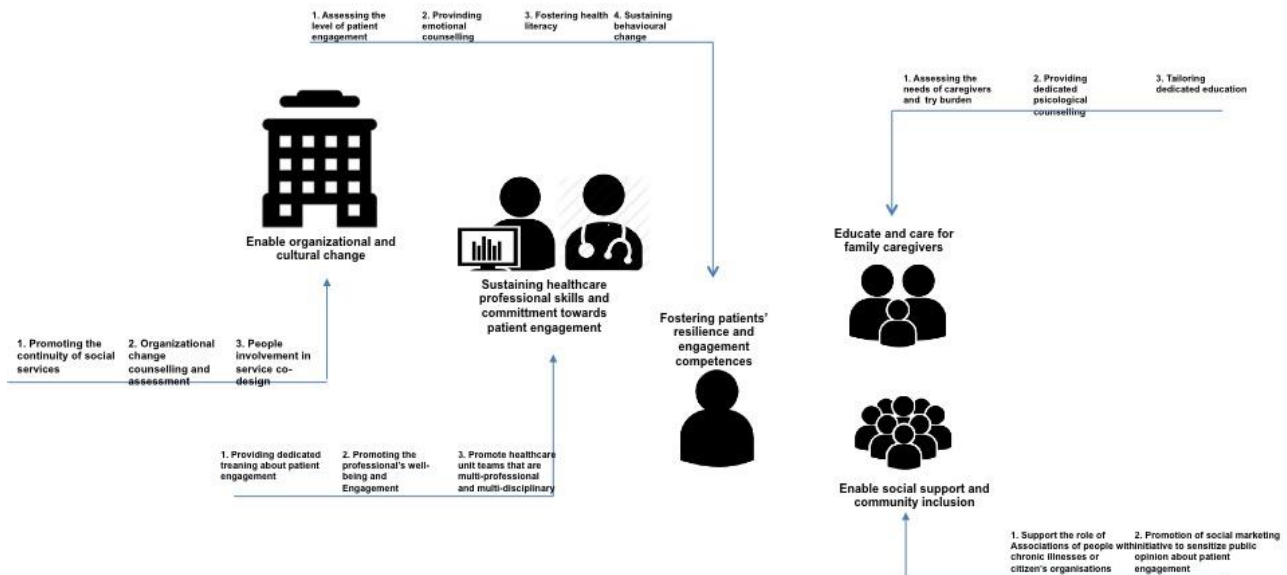
3.4 Query 4 - What is the role of the new technologies in the promotion of Patient Engagement?

Technology can be considered as a facilitator of Engagement and could be integration to other types intervention strategies. Technological intervention supports Engagement, and it is not substitutive of the relationship between the individual and his assisting team. Technologies should be considered as one of the possible means of intervention to promote Engagement, and not an end in itself. Technological interventions for the promotion of Engagement should be perceived as integrative and complementary and not substitutive to the traditional strategies and interventions for the education and support of the individual. The efficacy of technological intervention is in function of the assistive and cure relationship. Moreover, it's necessary to avoid the risk that these are developed and used exclusively as something "imposed from above" (i.e. the welfare system) for the person with chronic illness. Technologies should be designed as customizable based on the specific level of Engagement previously measured with adequate and scientific instruments, derived from an analysis of the Engagement needs of the different actors, to improve the personalization of the technological intervention(89). It's important to involve the

final users (people with chronic illness and their caregivers) in the design and implementation of the technology to allow it to be able to respond to the specific needs of the different phases of Engagement. It's also crucial to develop technologies that act in a systemic way on the diverse drivers of Engagement (to allow for the integration and connection of the different actors of the welfare ecosystem) and acculturate and sensitize the health facilities and professionals in the adoption of new technologies for the promotion of Engagement (training initiatives...)(90). Furthermore, the project and implementation of technological initiatives for the promotion of Engagement should be perceived/created in collaboration with the healthcare structure and the professionals in order to guarantee the best possible alignment of healthcare models and practices, with the information systems and with the routines/procedures currently in use. The health facility, in turn has to promote the definition of policies, principles and criteria aimed at regulating the design and implementation of initiatives for the promotion of Engagement, that are able to guarantee and safeguard people's health. However, efficacy assessment, feasibility as well as regulatory mechanisms and certification criteria must be provided for an appropriate use of these instruments.

4. Discussion

Engagement promoting strategies can vary depending on clinical conditions and the seriousness of symptoms: it's important to adopt a systemic approach that takes into account the potential obstacles that may be present at different levels. A systematic view of interventions can counter more efficiently to the complexity of Engagement, avoiding a reductive view with subsequent supply of interventions that are fragmented and badly coordinated. Engagement should become an integrating part of organizational models that call for the realization of care continuity in the treatment of chronic illnesses with the empowerment of "out of office" actions, meaning in alternative contexts, linked to the person's life circumstances and situations, to his/her sensibility and his/her interests which appear to be functional when integrated with Engagement promoting strategies. Furthermore, the adoption of instruments for the assessment of the level of engagement of a person with chronic illness and/or his informal caregiver, represents a crucial strategy to overcome the "one size fits all" logic, and instead move in the direction of modular actions, that can be tuned in progress throughout the person's clinical care journey. Finally, the "patient" is not the unique actor that needs to be considered and support to achieve the Engagement goal; on the contrary an eco-system of actions should be enacted at the different levels (i.e. micro-meso-macro) and addressed to the different stakeholders (i.e. patients, family caregivers, healthcare professionals, society, organizations and peer networks) (Figure 2).



5. Conclusions

This consensus conference was established in response to concerns about the rapid increase in the number of patient engagement initiatives that were being developed around the world. The Consensus Conference prioritised the need for a set of criteria to guide the quality appraisal of patient engagement interventions. The purpose of this work is to enhance the quality and effectiveness of patient engagement strategies by establishing a shared evidence framework for the content, development, implementation and evaluation of them.

The recommendations drafted from the Consensus Conference should not be conceived as strict guidelines to practice, rather a scientific systematization of best practices often fragmented and jeopardized in the medical sector. These recommendations should be envisaged as inspirational principles to promote a real eco-system of engagement, against a reductive and unrealistic approach to this issue. Finally, although the Consensus Meeting took place in Italy, the expert involved have a renowned international scientific and clinical expertise on the topic of the conference and they based their recommendation on international scientific evidences. However, a further cross-national validation of the recommendation provided by this consensus conference statement is advisable and is currently planned by the Authors.

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Figure legend

Figure 1 The Consensus Conference phases

Figure 2 The patient engagement eco-system