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The Determinants of Online Collective Action in Patients' Virtual Communities : a Multimethod Approach

Raphaëlle Laubie

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THÈSE DE DOCTORAT

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PSL Research University

Préparée à l'Université Paris-Dauphine

Les Déterminants de l'Action Collective en Ligne dans les Communautés Virtuelles de Patients : une Approche Multi-Méthodes

École Doctorale de Dauphine — ED 543

Spécialité **Sciences de gestion**

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“There is no unique picture of reality.”

- Stephen Hawking

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Résumé

Au cours des dernières années, les communautés virtuelles de patients se sont énormément développées sur l'Internet. Ces communautés permettent des échanges fréquents entre les patients, qui peuvent partager des informations liées à la santé dans un environnement interactif. Alors que beaucoup s'accordent sur l'opportunité représentée par ces communautés pour ses utilisateurs, les connaissances sur ce qui détermine l'action collective en ligne des patients ainsi que sur les fondamentaux de l'action collective en ligne dans ces espaces virtuels sont relativement peu développées. En conséquence, ce travail doctoral examine les raisons pour lesquelles les patients interagissent entre eux et comment ils procèdent. En nous appuyant sur le modèle du comportement orienté vers un but, la théorie de la valeur de l'attente, la théorie des forces du champ, les concepts de dons et les interviews menées, nous avons développé un modèle qui examine les interactions en ligne des patients dans un contexte d'action collective en ligne. Une approche multi-méthode, qualitative et quantitative, permet d'explorer les interactions des patients et de mesurer les déterminants de l'action collective en ligne sur ces espaces virtuels. L'analyse qualitative de 54 entretiens menés avec des patients, des proches de patients, des professionnels de la santé 2.0, des médecins et des soignants permet d'affiner le modèle de recherche, qui a ensuite été testé au travers d'une enquête quantitative auprès de 269 patients. Cette recherche contribue à la recherche en systèmes d'information en augmentant nos connaissances sur la dynamique individuelle et les interactions qui entourent les communautés de patients en ligne.

Mots Clés

Patients 2.0, Santé 2.0, Communautés Virtuelles, Action Collective en Ligne, Concepts de Dons, Théorie des Forces de Terrain, Théorie de la Valeur de l'Attente, Modèle de Comportement Orienté vers un But, Émotions, Systèmes d'Information en Santé, Adoption, Médias sociaux, Réalisme Critique

Thesis Abstract

Over the last few years, virtual patients' communities have been developing tremendously over the Internet. These Web 2.0 communities allow frequent interactions among patients, who can share health-related information within an interactive environment. While many agree on the opportunity represented by those communities for its users, we know very little about what determines patients' online collective action, specifically on virtual communities as well as the fundamentals of online collective action in these virtual spaces. Accordingly, this doctoral work examines why patients interact with others and how they interact on topics related to their disease through these virtual communities. Drawing on the goal-directed behavior (MGB), the expectancy-value (EVT) theories, the field force theory, gift concepts and field interviews, we have developed a model for examining patients' online interactions and identified gift-giving behaviors in the context of online collective action. A multi-method, qualitative and quantitative approaches, enables us to explore patients' interactions and measures the determinants of online collective action on these virtual spaces. The qualitative analysis of 54 interviews conducted with patients, patient's relatives, Health 2.0 professionals, doctors and caregivers allows refining the research model, which has then been tested through a survey handled with 269 patients, members of patient's communities. This research contributes to IS research by increasing our knowledge regarding the individual dynamics and interactions that surround online patients' communities.

Keywords: Patients 2.0, Health 2.0, Virtual Communities, Online Collective Action, Gift Concepts, Field Theory, Expectancy Value Theory, Model of Goal-Directed Behavior, Emotions, Health Information Systems, IT Adoption, Social Media, Critical Realist

1 - INTRODUCTION

1 INTRODUCTION

Le comportement des patients face aux informations relatives à la santé a évolué significativement avec les nouvelles technologies (Eysenbach 2008; Frost and Massagli 2008). Bien que les praticiens de santé restent les interlocuteurs de référence (Dedding et al. 2010), de nombreux patients considèrent que les sites traitant des questions de santé offrent une alternative pertinente en cas d'isolement ou de manque d'information pour eux-mêmes ou leurs familles (White and Dorman 2001; Smith and Christakis 2008). Ces mêmes patients regrettent souvent de ne pas être assez bien informés par leurs praticiens, déplorant que ce même système de santé ne prenne pas assez en compte leurs besoins (Bos et al. 2008). Des réponses à ces besoins sont en partie offertes par des plateformes web qui permettent aux patients d'interagir sur des sujets relatifs aux questions de santé et de devenir acteurs de leur santé (Ajoulat 2007). Les patients y trouvent ainsi le moyen de se libérer d'une dépendance qu'ils pourraient développer vis-à-vis des professionnels de santé pour mieux vivre avec leur maladie (Gagnayre and d'Ivernois 1995). Toutefois, ces plateformes se sont le plus souvent développées sans la prise en compte d'indications précises relatives aux besoins des patients ou à leurs motivations à rejoindre ces dernières.

1.1 Systèmes d'Information et le Contexte du Web 2.0

1.1.1 Théories et Modèles Existants

Dans le domaine des Systèmes d'Information, des modèles antérieurs ont été utilisés pour examiner l'adoption de la technologie dans différents contextes, qu'il s'agisse du

Web 1.0 ou du Web 2.0, autour de la notion de l'utilisation du système (Hofmann 2002; Bokhari 2005; Straub and Burton-Jones 2007; Burton-Jones and Gallivan 2007; Usluel and Mazman 2009).

Par exemple, le modèle d'acceptation de la technologie (TAM) (Davis 1989) a été considéré comme un cadre de référence pertinent pour mieux comprendre l'adoption d'outils informatisés, reliant les comportements aux attitudes et aux croyances, notamment en termes de facilité d'utilisation et d'utilité perçue de la technologie. Dans ce modèle, ces déterminants du comportement d'usage sont cohérents avec ce dernier en termes de temporalité, de cible et de contexte (Wixom and Todd 2005).

La théorie unifiée de l'acceptation et l'utilisation de la technologie (UTAUT) (Venkatesh et al. 2003) modifie le TAM, identifiant quatre déterminants (l'espérance de performance, l'espérance de l'effort, l'influence sociale, et les conditions de facilitation) de l'intention comportementale d'utiliser la technologie, elle-même déterminant de l'utilisation. Le sexe, l'âge, l'expérience, et le caractère volontaire de l'utilisation modèrent l'influence de ces facteurs susmentionnés sur l'intention comportementale.

Puis, sur la base du travail de (Shannon and Weaver 1963) et Mason (1978) ainsi que des recherches sur les systèmes d'information de gestion empiriques (SIG) opérées de 1981 à 1987, la mise à jour du modèle de succès des systèmes d'information (ISM) de DeLone et McLean (2003) reconnaît que le rôle des systèmes d'information a changé et progressé pendant cette durée de dix ans et dresse un modèle multidimensionnel de succès des systèmes d'information.

Néanmoins, s'agissant du TAM (Davis 1989), Burton-Jones and Straub (2006) expliquent qu'ils doutent que les intentions d'utilisation et les variables dépendantes de

comportement d'utilisation du modèle recouvrent la notion même d'acceptation, et invitent les chercheurs à « fournir la preuve systématique que les mesures d'usage retenues, le cas échéant, sont de bons indicateurs des construits qu'elles sont censées mesurer et de déterminer quels autres construits, le cas échéant, seraient de bons indicateurs de l'usage de la technologie » (Burton-Jones and Straub 2006, p.241). Bokhari (2005) souligne en outre que la recherche ne propose pas de conclusions congruentes reliant l'utilisation du système et la satisfaction des utilisateurs. De même, en ce qui concerne le modèle de succès (ISM) (DeLone and McLean 2003), Hofmann (2002) met en garde contre les conséquences de phénomènes collectifs ajoutant un caractère à plusieurs niveaux pour l'utilisation du système.

1.1.2 Lacunes Identifiées concernant le Web 2 .0

Certaines recherches se sont appuyées sur plusieurs des modèles tels que TAM ou ISM pour expliquer l'adoption des utilisateurs en termes de facilité d'utilisation et l'utilité dans le contexte du Web 2.0. Elles ont démontré que certaines variables pouvaient contribuer à motiver une masse critique d'utilisateurs s'agissant de l'adoption des systèmes (Shin and Kim 2008; Shin 2008; Wu et al. 2008). Cependant, lorsque ces phénomènes sont analysés dans des univers connectés, l'ISM, selon la mise à jour de DeLone et McLean (2003), nécessiterait que d'autres dimensions soient prises compte pour comprendre les déterminants de l'adoption des utilisateurs. Par exemple, dans le cas des organisations, le fait de prendre en compte la culture d'entreprise, le soutien de l'encadrement dirigeant, un bon leadership, la communication, la motivation et la formation des utilisateurs finaux devraient être plus étudiés lorsqu'il s'agit de l'action collective en ligne sur le Web (Trkman and Trkman 2009).

En outre et concernant la théorie unifiée d'acceptation et d'utilisation de la technologie (UTAUT) (Venkatesh et al. 2003), Burton-Jones et Gallivan (2007) soulignent l'absence de prise en compte de plusieurs niveaux, les construits étant conceptualisés au niveau individuel. En conséquence, et en dépit de la force conceptuelle de tous ces modèles pour comprendre l'utilisation des systèmes, nous croyons que, seuls, ils ne fournissent pas une base suffisante pour examiner l'action collective en ligne, qui est liée à l'utilisation des technologies de l'information et de la communication (TIC) dans un contexte Web 2.0.

En somme, ces modèles ne parviennent pas à répondre à quatre principales lacunes.

Tout d'abord, ils se concentrent sur l'utilisation des systèmes et restent silencieux sur la nature fondamentalement collective de l'utilisation et des avantages des technologies offertes par le Web 2.0. Contrairement au Web 1.0, l'utilisation du Web 2.0 sous-tend l'action collective. Pour cela, la conceptualisation de l'utilisation des systèmes dans un contexte Web 2.0 ne peut se faire par les conceptualisations classiques car ses principes et avantages résident dans l'usage collectif de la technologie (Burton-Jones and Gallivan 2007; Rheingold 2003). En cela, comme évoqué par Lamb and Kling (2003), les utilisateurs sont fondamentalement des acteurs sociaux qui interagissent grâce à des technologies et doivent être considérés comme tels.

Deuxièmement, ces modèles ne prennent pas ou peu en compte le rôle des émotions dans le cadre des interactions individuelles avec la technologie. Or, ces émotions jouent un rôle, qu'elles soient positives ou négatives (Beaudry and Pinsonneault 2010). Sans doute, parce qu'elles impliquent des interactions fréquentes entre les personnes, les technologies du Web 2.0 offrent de fréquentes occasions pour les processus émotionnels

de se développer. Cela semble particulièrement pertinent pour les patients 2.0 puisque les individus sont à la recherche d'informations sur leurs - parfois graves - problèmes de santé (Arnst 2008). En négligeant les émotions, les modèles «traditionnels» d'adoption, tels que TAM, UTAUT, ou ISM, sont insuffisants pour fournir une compréhension en profondeur relatives aux interactions des patients avec la technologie. En revanche, comme il comprend les émotions, en le complétant des composantes affectives du désir orientées vers un objectif, nous croyons que le modèle du comportement orienté vers un but (model of goal oriented behavior - MGB) est plus adapté. Ce modèle fournit des indications supplémentaires par rapport à des modèles tels que TAM pour prédire le comportement des utilisateurs en ligne (Dholakia et al. 2004).

Troisièmement, ces modèles sont silencieux sur la nature des liens que les acteurs entretiennent sur les réseaux sociaux. Les acteurs sociaux qui interagissent sur les sites Web 2.0 ont à la fois des comportements instrumentaux et non instrumentaux dictés par leur désir de partager leur expérience avec d'autres. La collaboration en ligne nécessite de solides liens sociaux entre le « donneur » et le « receveur » et un niveau élevé de confiance entre les acteurs sociaux (Bergquist and Ljungberg 2001). Bien que l'information soit partagée gratuitement, l'action collective en ligne est ainsi riche et précieuse pour les e-patients. Ce concept de don peut dès lors aider à approfondir notre compréhension de ces liens. A notre connaissance, toutefois, la recherche n'a pas examiné suffisamment en profondeur ce concept dans un environnement connecté (Bergquist and Ljungberg 2001) s'intéressant initialement aux cultures primitives qui appartiennent à des mondes réels et non connectés (Mauss 1922). Néanmoins, le

concept de don reste primordial lors de l'examen des interactions des acteurs sociaux dans les environnements virtuels, en particulier dans le domaine médical.

Quatrièmement, les recherches antérieures ont déjà souligné les limites des modèles traditionnels d'adoption. (Benbasat and Barki 2007a) et Straub et Burton-Jones (2007) par exemple, expliquent que la recherche existante sur l'adoption et l'utilisation de la technologie a étudié un ensemble trop limité de variables autour du concept de l'utilisation du système, qui a été conceptualisée d'une manière très parcimonieuse. (Benbasat and Barki 2007a) soutiennent en outre que la recherche sur l'adoption n'a pas suffisamment analysé les médiateurs ou modérateurs pourtant déterminants de l'utilisation du système tels que ceux du domaine des émotions. Afin de répondre à certaines de ces lacunes, comme mentionné précédemment, Burton-Jones et Straub (2006) font valoir qu'il est nécessaire de repenser l'utilisation du système et appellent à un développement de variables d'utilisation plus contextualisées. Malheureusement, peu voire aucune indication n'a été donnée afin de mieux comprendre la façon de prendre en compte les contextes du Web 2.0 lors de l'étude de l'utilisation des technologies de l'information.

1.2 Motivations et Objets de la Recherche

Afin de répondre à ces lacunes en matière de recherche, mais aussi dans la pratique, cette étude examine les motivations qui poussent les patients à se joindre à ces communautés en ligne et à y participer ainsi que les caractéristiques de leurs comportements dans ces espaces virtuels. En effet, le concept d'action collective en ligne, concernant les patients dans un environnement Web 2.0 a encore été trop peu étudié.

1.2.1 Etude 1 : Forces qui Mènent à l'Action Collective en Ligne des Patients

Les recherches antérieures ont déjà exploré certains aspects liés aux motivations des utilisateurs à rejoindre des communautés virtuelles. Par exemple, dans leur étude, Dholakia et al. (2004) ont adapté le modèle de comportement orienté vers un but de Perugini et Bagozzi (2001) afin d'examiner l'utilisation de sites communautaires.

Notre première recherche qualitative s'appuie sur le travail de Lewin (1947; 1939) qui étudie les comportements individuel et social de l'individu et leurs implications sur le changement. Les théories des valeurs de l'espérance - EVT (Eccles et al.1983) - et le modèle du comportement orienté vers un but - MGB (Perugini and Bagozzi 2001) - nous permettent également d'identifier de premières catégories de forces qui mènent à l'action collective en ligne. En effet, MGB (Perugini and Bagozzi 2001), est un modèle fondé sur les attitudes capables d'expliquer les comportements téléologiques, distinguant les concepts de désir et d'intention. Le désir mène à l'intention, et par conséquent, l'orientation future, dans la poursuite d'un but, en tenant compte des résultats qui seraient considérés comme bénéfiques ou néfastes. À cet égard, les émotions anticipées - positives ou négatives - sont des facteurs prédictifs du désir. Nous suggérons donc que ces déterminants du comportement téléologique soient pris en compte dans le cadre de communautés virtuelles de patients dans le but d'élaborer un modèle d'adoption des communautés virtuelles pour les patients. Les valeurs de l'espérance - EVT (Eccles et al.1983) – et celles issues du terrain viennent compléter les déterminants composant les forces qui mènent à l'action collective en ligne des patients.

Le regroupement des patients en ligne s'est tout d'abord organisé en communautés informelles avec peu de moyens regroupant des personnes touchées par les mêmes pathologies pour ensuite se professionnaliser, avec des organisations souvent nationales ou internationales capables de sensibiliser les acteurs des systèmes de santé et offrant une ressource de qualité pour les patients, en particulier pour ceux qui font face à des pathologies inhabituelles ou rares (Armstrong 2016).

Ces communautés offrent ainsi un soutien aux patients et permettent de renforcer leur estime de soi. Même si cette aide en ligne ne vise pas à remplacer les groupes de soutien « en conditions réelles », elle permet aux membres d'accéder à l'information au moment souhaité, sous couvert d'anonymat, évitant tout risque d'être jugé (Idriss et al. 2009).

Tous ces aspects ont fortement motivé la réalisation de cette étude, avec le souhait de mieux comprendre les aspirations des patients connectés. Elle a été menée en deux temps, avec une première série d'entretiens préliminaires avec des médecins, des aides-soignants, des experts de la Santé 2.0 et du Web 2.0, puis une seconde série d'entretiens menés avec des patients et des proches des patients.

Dans cette première approche qualitative, la question de recherche posée est alors la suivante :

Quelles sont les forces qui mènent à l'action collective en ligne et celles qui la freinent dans le cadre de communautés virtuelles de patients?

Suite à cette première étude, une seconde étude dont l'objet est de conceptualiser et de tester un modèle d'adoption des communautés virtuelles de patients nous a semblé pertinente. Ce modèle peut alors se décliner sous une forme générique et permettre à

d'autres chercheurs de déterminer des facettes des facteurs d'engagement propres à d'autres communautés d'intérêt en reprenant la même approche qualitative puis quantitative. Dans cette étude, le modèle concerne précisément les communautés virtuelles de patients. Cette étude est présentée dans le paragraphe suivant.

1.2.2 Etude 2 : Recherche d'un Modèle d'Adoption des Communautés Virtuelles de Patients.

Afin de mieux comprendre les interactions des patients, nous explorons donc l'action collective en ligne dans un contexte Web 2.0 et Santé 2.0. Basé sur la théorie des valeurs de l'espérance - EVT (Eccles et al.1983) - et le modèle du comportement orienté vers un but - MGB (Perugini and Bagozzi 2001) -, aidé des résultats de la précédente approche qualitative, nous développons un modèle qui prédit l'action intentionnelle et l'action collective en ligne subséquente des patients connectés en communautés virtuelles. Nous appliquons une approche mixte (Creswell 2008; Venkatesh et al. 2013), en combinant tout d'abord les ancrages théoriques de la recherche et les résultats de l'approche qualitative précédente afin d'identifier les catégories pertinentes des variables du modèle dans le contexte de la recherche. Ce processus nous a également permis d'assurer la validité du contenu des construits du modèle, c'est-à-dire, les valeurs de l'espérance, les émotions, les désirs, l'action collective intentionnelle, les comportements post-adoptifs, et l'action collective en ligne. Ensuite, au moyen d'un questionnaire de recherche, nous mesurons les impacts des valeurs de l'espérance et des émotions sur les désirs, l'action collective intentionnelle et, finalement, sur l'action collective en ligne. Le questionnaire a été envoyé via l'Internet à des patients de trois communautés virtuelles différentes, en langue française.

Dans cette recherche quantitative, les questions de recherche posées sont donc les suivantes :

- 1. Quelles sont les valeurs relatives à l'espérance dans le cadre des interactions des patients avec les communautés virtuelles?*
- 2. Ces valeurs de l'espérance permettent-elles de prédire les désirs et les intentions concernant l'usage des communautés virtuelles de patients, et par la suite leur engagement dans l'action collective en ligne?*

Suite à cette seconde étude, une troisième étude dont l'objet est la détermination des comportements des patients connectés nous a semblé intéressante. Elle se concentre sur les différentes facettes de l'action collective en ligne sur notre terrain d'étude, celui des patients touchés par des maladies chroniques ou rares. Cette étude est décrite dans le paragraphe suivant.

1.2.3 Etude 3 : Détermination des Caractéristiques de Comportements Relatifs au Don dans les Communautés Virtuelles

La littérature sur le don suggère fréquemment deux notions complémentaires et difficilement divisibles, celle de l'approche utilitaire (Mauss 1922 ; Malinowski 2010; Gregory 1982; Bataille 1967; Godbout and Caillé 1992; Alter 2010; Camerer 1988) et l'approche sociale (Hyde 2007; Bollier 2001; Skageby 2010) .

La première approche considère le don comme le signal d'échange à partir duquel la réciprocité ne peut qu'opérer et est ainsi instrumentalisée ; la seconde prend ses

distances avec cette vue principalement utilitaire mettant en avant les valeurs du lien, des relations humaines altruistes et des émotions véhiculées (Chakrabarti and Berthon 2012).

Pour les patients connectés, les liens tissés reposent principalement sur les échanges qui ont lieu dans les communautés virtuelles, même si les individus sont plus difficiles à identifier du fait des conditions particulières dans lesquelles les échanges ont lieu (anonymat, échanges partagés entre de multiples entités...). La notion d'équilibre chère à Mauss (1922) est donc plus difficile à percevoir et les fondamentaux de ces dons sont quelques peu bouleversés quand ils ont lieux dans ces espaces virtuels (Smith and Kollock 1999). Dans ces systèmes complexes, nous reprendrons les trois caractéristiques des dons le plus fréquemment cités dans la littérature et combinant ces approches utilitaires et sociales dans des espaces virtuels (Skageby 2010), ie : i) l'orientation vers autrui, ii) la valeur du lien, iii) la réciprocité généralisée.

Partant de ces concepts et des informations reçues du terrain, cette seconde approche qualitative et troisième étude menée pose les questions suivantes :

- 1. Quelles sont les caractéristiques de comportements relatifs au concept de don dans le cadre de l'action collective en ligne dans les communautés virtuelles ?*
- 2. Quels sont les comportements des patients relatifs au concept de don dans le cadre de l'action collective en ligne dans les communautés virtuelles de patients ?*

Durant toutes ces étapes de notre recherche, nous avons estimé que les cadres théoriques existants devaient être adaptés à notre champ d'enquête. Par conséquent, une approche exploratoire a été appliquée.

Avec les apports émergents du terrain et des théories telles que MGB, nous développons un modèle visant la compréhension de l'action collective en ligne des patients qui inclut spécifiquement les concepts d'émotions et de dons. De plus, nous ne sommes pas convaincus que la façon dont les concepts et les catégories sont couplés pour les utilisateurs 'standards' (Dholakia et al. 2004) soit pertinente pour les patients, compte tenu de la possible difficulté de leur situation en fonction de leur état de santé et d'un potentiel état mental fragilisé. Nous avons étudié le rôle du don, du travail initial de Mauss (2002) - également mis en évidence dans les communautés open source, afin d'expliquer les succès de ces entités de collaboration – ainsi que les travaux et résultats de (Bergquist and Ljungberg 2001). Ce travail exploratoire vise à fournir des connaissances supplémentaires sur les déterminants de l'action collective en ligne de patients. Les émotions positives, concept de base qui déclenche le désir d'agir dans MGB (Perugini and Bagozzi 2001), est également étudié dans ce contexte de participation et d'aide envers l'autre entre les patients souffrant des mêmes troubles. Cependant, tous ces concepts ont été adaptés considérant les aspects particuliers des usages et des besoins des patients.

Une approche fondée tant sur le terrain que sur la théorie a été appliquée afin d'approfondir l'action collective en ligne dans les contextes Web 2.0. En effet, bien que nous croyions que les théories existantes fournissent des indications pertinentes pour examiner cette question, nous pensons cependant qu'elles sont insuffisantes pour

permettre de rendre compte de façon suffisante de l'action collective en ligne dans des contextes en rapport avec la santé. Ce faisant, cette approche nous permet de bénéficier d'idées nouvelles provenant du terrain, tout en contribuant à la connaissance d'une manière cumulative. Les besoins et les interactions des patients sur plateformes Web 2.0 ont été examinées attentivement dès le début de la recherche. En cela, les entrevues ont été menées afin de contextualiser la recherche et d'intégrer le contexte des patients dans les analyses. Notre approche vise à aller au-delà d'une approche «purement» positiviste, parfois représentée comme un réalisme naïf "dans lequel la réalité est compréhensible et la connaissance peut être facilement capturée et généralisée sous une forme sans contexte" (Zachariadis et al. 2010, p.5), ou une approche «purement» interprétativiste qui exclut l'explication causale "au début des débats sur la philosophie des sciences sociales et concernant la compréhension par rapport à l'explication ou les raisons face aux causes" (Sayer 2000, p.96). En effet, en définissant précisément la portée du réalisme critique Zachariadis et al. écrit :

"Au lieu de chercher des lois sociales, nous devrions chercher des mécanismes de causalité et comment ils fonctionnent. Selon les réalistes critiques, les régularités cohérentes ne sont susceptibles de se produire que dans des circonstances particulières dans des systèmes fermés" (2010, p.5).

En conséquence, notre posture suit les principes du réalisme critique qui répond aux défauts ontologiques et épistémologiques du positivisme Zachariadis et al. (2010) et est conforme à la façon dont nous envisageons la construction de la connaissance. Dans la pratique, les allers-retours constants entre les témoignages des patients recueillis au cours des entretiens et les préceptes apportés par la littérature, ont façonné notre

conception de la recherche conforme à notre approche réaliste critique. Cette approche nous a permis de renforcer la pertinence de ce travail, où les concepts provenant du terrain ont été comparés à la littérature dans une quête exploratoire de réponses (Mingers 2000; Mingers 2004).

Tout d'abord, des entretiens préliminaires nous ont permis de comprendre à quel point l'étude de l'environnement était importante pour notre recherche. Deuxièmement, les premiers échanges avec les patients nous ont guidés pour la réalisation d'une étude approfondie de la littérature. Ces premiers contacts avec le terrain nous ont permis de déterminer les théories qui permettent de mieux prendre en compte la réalité de cet environnement et d'élaborer un premier projet de modèle en conséquence. Tant l'étude de la littérature que la compréhension de l'environnement en conformité avec les théories existantes ont contribué à l'élaboration de ce modèle. Les premiers facteurs du modèle ont donc été adaptés et tout en revisitant la littérature. Nous avons procédé à une approche inductive qui nous a aidés dans la construction de l'ensemble du cadre conceptuel. En prenant en compte les implications de la communication médiatisée par ordinateur (Sproull and Kiesler 1986), considéré comme moyen de sortir de l'isolement (Hugon 2010), à fortiori pour les patients, nous avons exploré le fonctionnement des groupes, influencés par les normes sociales et d'identification (Kelman 1958). Considérant, en outre, certaines des spécificités des membres des communautés de patients qui ont l'intention de participer en ligne, nous avons examiné la littérature sur la notion de don et sa pertinence pour répondre à nos questions de recherche (Larsen and Watson 2001).

Enfin, aidés par notre cadre théorique, une exploration plus en profondeur nous a permis de recouper la connaissance de la littérature ainsi que des connaissances transitives. Tous ces concepts et dimensions ont été associés à la structure du modèle. En conséquence, la connaissance transitive est un élément essentiel qui décrit l'environnement choisi et comble les lacunes de la recherche. Les concepts ont été constamment comparés à la connaissance de la littérature à laquelle ils se référaient et vers laquelle ils convergeaient. Ceci a contribué à l'ajout de nouveaux construits qui s'est traduit par la création d'un modèle original, initié par la littérature et la rationalisation du champ à travers l'ensemble du processus de recherche.

La présentation de ces trois études est résumée dans la Table 1.

Table 1. Présentation des Etudes

	1ère Etude	2nde Etude	3ème Etude
Théories	<ul style="list-style-type: none"> La Théorie des Valeurs de l'Espérance – EVT (J. S. Eccles et al. 1983), le Modèle du Comportement Orienté vers un But – MGB (Perugini and Bagozzi 2001) et le Champs des Forces de Lewin (1947). 	<ul style="list-style-type: none"> La Théorie des Valeurs de l'Espérance – EVT (J. S. Eccles et al. 1983) et le Modèle du Comportement Orienté vers un But – MGB (Perugini and Bagozzi 2001) theorizing. 	<ul style="list-style-type: none"> L'approche utilitaire du don (Mauss 1922 ; Malinowski 2010; Gregory 1982; Bataille 1967; Godbout and Caillé 1992; Alter 2010; Camerer 1988), l'approche sociale du don (Hyde 2007; Bollier 2001; Skageby 2010) et le don dans des espaces virtuels (Skageby 2010).
Approches	Qualitative	Quantitative	Qualitative
Terrains	Praticiens et soignants, experts en santé 2.0, experts web 2.0, patients et familles de patients	3 communautés de patients en ligne (i) cancer du sein, ii) maladies liées au dysfonctionnement de la thyroïde dont le cancer de la thyroïde, iii) tous types de cancers)	Praticiens et soignants, experts en santé 2.0, experts web 2.0, patients et familles de patients

Questions de Recherche	<ul style="list-style-type: none"> • Quels sont les forces qui mènent à l'action collective en ligne et celles qui les freinent dans le cadre de communautés virtuelles de patients ? 	<ul style="list-style-type: none"> • Quelles sont les valeurs relatives à l'espérance dans le cadre des interactions des patients avec les communautés virtuelles ? • Ces valeurs de l'espérance permettent-elles de prédire les désirs et les intentions concernant l'usage des communautés virtuelles de patients, et par la suite leur engagement dans l'action collective en ligne ? 	<ul style="list-style-type: none"> • Quelles sont les caractéristiques de comportements relatifs au concept de don dans le cadre de l'action collective en ligne dans les communautés virtuelles ? • Quels sont les comportements des patients relatifs au concept de don dans le cadre de l'action collective en ligne dans les communautés virtuelles de patients ?
Résultats Clés	<ul style="list-style-type: none"> • Identification des principales forces motrices et restrictives des l'action collective en ligne des patients connectés. 	<ul style="list-style-type: none"> • Création d'un modèle d'adoption des communautés virtuelles pour les patients. 	<ul style="list-style-type: none"> • Détermination des caractéristiques de comportements relatifs au don dans les communautés virtuelles de patients avec contextualisation de ces comportements.

1.3 Contributions

Cette recherche fait plusieurs contributions à la recherche et la pratique. Tout d'abord, pour répondre à nos questions de recherche, ce travail dresse un modèle d'action collective en ligne afin de mieux reconnaître le processus d'engagement chez un certain type de patients. Deuxièmement, elle illustre et contextualise, dans la cadre des patients connectés, l'action collective en ligne relative aux concepts du don. L'approche multi-méthodes (Venkatesh et al. 2013), et notre posture réaliste critique contribuent à la pertinence de l'étude (avec une approche qualitative qui enrichit le modèle de recherche avec un aperçu de l'expérience des patients et la nature de leurs actions en ligne) et à la rigueur (avec une étude quantitative subséquente pour mesurer les impacts des déterminants de l'action collective en ligne). Nous démontrons la pertinence de la combinaison de MGB et EVT pour développer ce modèle pour les patients de

communautés virtuelles afin de mieux examiner les déterminants de l'action collective en ligne. Nous avons enrichi le cadre sous-jacent de MBG – établi par Perugini et Bagozzi (2001) et adapté aux communautés virtuelles par Dholakia et al. (2004) - en présentant une compréhension holistique des déterminants du désir de participer à l'action collective en ligne avec ses valeurs EVT (Eccles et al. 1983). L'approche qualitative nous a permis de fournir une compréhension profonde du contexte de notre recherche ; l'approche quantitative nous a permis de construire un modèle qui peut, sous sa forme générique, être mobilisé dans d'autres domaines d'enquête. Les résultats du terrain mettent en exergue le désir en tant que facteur déterminant de l'action collective intentionnelle, elle-même facteur déterminant de l'action collective en ligne. Les résultats suggèrent que l'action collective en ligne est fonction de la fréquence d'utilisation, le désir fonction des valeurs sociales, valeurs utilitaires, des émotions positives anticipées, en ligne avec la dernière constatation sur les communautés virtuelles (Tsai and Bagozzi 2014). Le modèle construit peut permettre d'aider les concepteurs de communautés virtuelles à comprendre ce qui serait souhaitable en ce qui concerne la formulation des besoins des patients. Enfin, cette recherche met en lumière la notion de don et son implication dans différentes catégories de l'action collective en ligne, elle contextualise les facettes de l'action collective en ligne concernant les communautés virtuelles de patients.

Notre travail est structuré comme suit. Dans chacune des trois études présentées dans cette thèse, nous décrivons nos motivations concernant l'acquisition de nouvelles connaissances sur les déterminants de la participation des patients dans les communautés virtuelles et les composantes de l'action collective en ligne relatives au

don. Suite à cela, nous présentons les matériaux, les méthodes et conceptions pour cette recherche et toutes les procédures connexes. Faisant suite à l'étude de la littérature et aux informations provenant du terrain, un modèle a été développé selon une première approche qualitative et testé dans une seconde approche quantitative. Une seconde approche qualitative explicite l'action collective en ligne présentée à la lumière des concepts du don. Ensuite, ces résultats sont discutés et les contributions sont décrites. Nous concluons chacune des trois études avec les limites de notre recherche et les opportunités ainsi offertes pour de nouvelles explorations, ainsi que les perspectives pour les patients et l'environnement relatif à la Santé 2.0.

2 – CONCEPTUALIZING AND PREDICTING ONLINE COLLECTIVE ACTION IN PATIENTS' VIRTUAL COMMUNITIES ¹

¹ Laubie, R., Elie-Dit-Cosaque, C. (2016). Conceptualizing and Predicting Online Collective Action in Patients' Virtual Communities: the Influences of Utilitarian Values, Social Values and Anticipated Emotions" (*AIM 2016*), IESEG, Lille, France, May 15, 2016.

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Laubie, R., (2012). Expectancy-Value Model of patients' virtual communities. The determinants of desires for online collective action. (*Medicine 2.0 2012*), Harvard University, Boston, Massachusetts, USA, September 15-16, 2012.

Laubie, R., (2011). Understanding the determinants of online collective action. The Case Study of Patients Communities. (*Medicine 2.0 2011*), Stanford University, Palo Alto, California, USA, September 16-18, 2011.

Laubie, R., (2011). Extended model of Social Networks Goal-Directed Behavior. The role of anticipated emotions and habits. (*International Conference on Engaged Management Scholarship*), Case Western Reserve University, Cleveland, Ohio, USA, June 2-5, 2011.

2 CONCEPTUALIZING AND PREDICTING ONLINE COLLECTIVE ACTION IN PATIENTS' VIRTUAL COMMUNITIES

2.1 Introduction

Health 2.0 is changing the way patients inform themselves on health related matters (Eysenbach, 2008; Frost & Massagli, 2008). Health 2.0 is derived from Web 2.0, or the interactive web. It offers everyone an opportunity to communicate, share information and experiences over the Internet. That interactive aspect of Web 2.0 calls for further examination of online interactions and participation in generating web content, or *online collective action*. Accordingly, this paper explores some of the factors which contribute to the engagement of patients on online communities.

In spite of some recent developments, though, we know too little about how patients interact over the web and subsequently about online collective action in health communities. Indeed, online patients' communities offer numerous possibilities to Patients 2.0 - or ePatients - for sharing experiences, socializing, getting peer support, breaking isolation, increasing self-disclosure through anonymity (Bargh *et al.*, 2002; Joinson, 2001), as people do in other virtual communities (Mercklé, 2004) but where common interests are health-related (Orizio *et al.*, 2010). However, the determinants of patients' online commitment remain un-studied.

In "Patients 2.0" we include people who use information and communication to interact with others on health issues (Bos *et al.* 2008). A 2010 study based on a sample of adult individuals in the United States shows that about 80% of the population connect to the

Internet to learn about health related topics, 34% read comments from other Internet users, and 18% of the persons studied research carried out by persons sharing similar pathologies (Pew Internet). In France, over the same period, 64% of patients were seeking information on health (Ipsos polling Institute 2010).

In order to address those research gaps, this study investigates the individual and social factors that drive patients to participate in online collective action. This article addresses the following research question: What are the individual and social driving and restraining forces of patients' online collective action?

Based on Lewin's work (Lewin, 1947; Lewin, 1939) combined with Eccles et al. (1983) Expectancy-Value Theory (EVT), we develop a model for understanding patients' online collective action. Following this, we conducted a critical realist (Zachariadis *et al.*, 2010) work which led us to conduct 54 semi-structured interviews (Romelaer, 2005) with patients, Web 2.0 experts, physicians, and other relevant informants.

Our work is structured as follows. First, we review the relevant literature on collective action, online collective action, Lewin's field forces and the expectancy-value theorizing with some insights on Health 2.0 online community contexts. Following both preliminary insights from the field and the literature, a model is then developed. The model is confronted to emergent insights from the field; for doing so, we developed a qualitative research design. We conducted 54 semi-structured interviews (Romelaer, 2005) with patients, Web 2.0 experts, physicians, and other relevant informants. So doing, we followed a partially grounded approach. While we believe existing theories provide relevant insights to examine this issue, we also believe they are insufficient to

provide a complete account of online collective action in health contexts. That is why we have decided to ground our research on both the field and theory. This allowed us to benefit from emerging insights from the field, while contributing to knowledge in a cumulative way. The results are then discussed and the contributions are described. We conclude with the research limitations and the avenues for further research, together with the perspectives of this work for patients and Health 2.0 environments.

2.2 Theoretical Background

The literature review is organized as follows: i) the key concepts of collective action and online collective action; ii) the field force determinant of online collective action.

The work on the literature review allowed us to: i) gain a retrospective overview of key and contiguous concepts in the literature independently of the academic fields; ii) choose the relevant approaches, studies, models and constructs from different areas; iii) identify calls and venues for future research, as well as research gaps pertinent to our field of inquiry; iv) inspire the study framework during the empirical data collection; v) find safeguards in relation to findings, results, limitations, future research and conclusion.

2.2.1 Collective Action and Online Collective Action

2.2.1.1 Collective Action Concept

An understanding of collective action - and intentions that lead to joint actions - needs a command of many different disciplines and especially philosophy (Tuomela and Miller

1988; Searle 1990; Bratman 1993; Miller 2001; Gilbert 2006), psychology and sociology (Tajfel 1981; Van Zomeren et al. 2008) (see Table 2).

In the area of philosophy, researchers link collective action to joint actions (Tuomela 1995) in order to reach common goals (Miller 2001) implying collective intentions (Searle 1990) and shared values (Bratman 1993).

In the area of social psychology, Tajfel (1981) described collective actions as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common”, p. 244. Giguère et al. (2012) highlighted in this definition of collective actions the notion of collective social identity (Tajfel and Turner 1979) and shared problem perception. In the collective social identity concept, Giguère et al. (2012) explained that “stronger identification with a disadvantaged group is associated with a greater will to participate in a variety of actions aimed at protecting or enhancing the group”, p.182. In the shared problem perception concept, Giguère et al. (2012) explained that “the traditional beliefs shared by group members may bring them to collectively recognize an event as threatening and worth uniting against”, p.183. Van Zomeren et al. (2008) further demonstrated that perceived injustice, perceived efficacy and social identity affected collective action. The latter is also motivated by the perceived value of the outcome (Giguère and Lalonde 2010; Bandura 1995) “when individuals perceive a valued outcome to result from collective actions, they are more likely to have a favorable attitude toward them and be willing to participate in them” (Giguère et al. 2012; p.183). This perceived value of the outcome is also posited in the purposive behavior of the model of goal directed behavior (MGB) (Perugini and Bagozzi 2001); the feeling of injustice that bounds patients can be related

to their disease. Still, MGB is complementary to the aforementioned concepts as it includes emotion which has not been studied in the collective action literature (Tang 2008). Furthermore, Lewin (1947) outlined the concepts of change and constancy in group life stating that:

“(a) Change and constancy are relative concepts; group life is never without change, merely differences in the amount and type of change exist;

(b) Any formula which states the conditions for change implies the conditions for no-change as limit, and the conditions of constancy can be analyzed only against a background of “potential” change”, p.13.

In the area of sociology, the concept of collective action relates to the motivation of individuals to perform goals set by organizations (Olson 1965). Crozier and Friedberg also emphasized the power relationships behind collective action (Crozier and Friedberg 1977). Crozier and Friedberg for example highlighted power as a daily mechanism of the social existence, which is of particular importance for understanding the life of organizations in particular. However, we will leave aside the concept of power behind collective action as it may be less relevant in the context of patients' online interactions. Therefore, to understand the dynamics of group life, one needs to get information about “desire for and resistance to specific change” - namely, in this study, collective action and the associated social forces.

Table 2. Collective Action and Related Concepts

Area	Concept	Definition	Author
Philosophy	We-Intentions	“A commitment of an individual to participate in joint action and involves an implicit or explicit agreement between the participants to engage in that joint action.” (Tuomela 1995, p.2), (Tuomela and Miller 1988)	(Tuomela 1995)
	Collective Intentionality	“Collective intentionality presupposes a Background sense of the other as a candidate for cooperative agency; that is, it presupposes a sense of others as more than mere conscious agents, indeed as actual or potential members of a cooperative activity.” (Searle 1990, p.414)	(Searle 1990)
	Shared Intention	“We should, instead, understand shared intention, in the basic case, as a state of affairs consisting primarily of appropriate attitudes of each individual participant and their interrelations” (Bratman 1993, p.99)	(Bratman 1993)
	CET (Collective End Theory) of joint action	“Joint actions are a species of interdependent action in which there is little or no conflict; joint actions involve a number of agents performing interdependent actions in order to realise a common goal” (Miller 2001, p.36)	(Miller 2001)
	Joint Commitment	“Collective action is interpreted as a matter of people doing something together, and it is assumed that this involves their having a collective intention to do that thing together... the parties are jointly committed to intend as a body that such-and-such.” (Gilbert 2006, p.3)	(Gilbert 2006)
Social Psychology	Collective Actions	Collective actions are described as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common” (Tajfel 1981, p. 244)	(H. Tajfel 1981))
	SIMCA (Social Identity Model of Collective Action)	Van Zomeren et al. (2008) demonstrate that “the key subjective predictors of collective action as well as their interrelationships” are “subjective injustice, identity, and efficacy”, p.504.	(Van Zomeren et al. 2008)
Sociology	Social Action	Social action implies that individuals will adapt their behaviors depending on social contexts and actions' results on other people, embedding, therefore, that social action will be correlated with the present, past or future behavior of others. (Weber, Runciman, et	(Weber et al.1978)

	Matthews 1978)	
Social Action	Action is directed by individuals' motives. Therefore, actions need to offer tangible significance and outcomes to each actor in the actor-situation system, even they act collectively. (T. Parsons 1949)	(T. Parsons 1949)
Collective Action	Collective action put the organizations' interests before individuals' ones which can foster free-riding of individuals on the effort of others. In order to avoid this phenomenon, organizations have to motivate participants in collective action efforts and coordinate their efforts.	(Olson 1965)
Collective Action	Collective action is studied within organizations where individuals are players and not passive agents who perform instructions. Individuals develop strategies based on personal goals that sometimes disregard the organization's interests.	(Crozier and Friedberg 1977)
Collective Action	Collective action suggests that dynamics implying a "startling homogeneity of organizational forms and practices" (DiMaggio and Powell 1983) and therefore rules and requirements in compliance with institutional and impersonal customs of interaction that don't leave room for out-of-the-box thinking skills.	(DiMaggio and Powell 1983)
Collective Action	"The digital-media environment prompts new and unforeseen opportunities for collective action as people are increasingly immersed in an atmosphere in which it is their routine practice to share ideas, connections, and interests." (Bimber et al.2012) Therefore, "all sorts of organizational structures and processes are implicated in the new technological landscape for collective action" (Bimber et al. 2012, p.6) that can be called organizational fecundity.	(Bimber et al.2012)

2.2.1.2 Online Collective Action Concept

Collective action has also been somewhat examined in the information systems' literature. Prior research for example draw from social theories (Coleman 1994; Fishbein and Ajzen 1975), social scientists and psychologists' reasoning (Hardin 1968; Olson

1965; Sweeney 1973; Schelling, 2006; Oliver et al. 1985) for example to: i) understand the necessary conditions of collective action (Garud et Kumaraswamy 2005), ii) help explain why individuals engaged in a collective action choose not to free-ride (McLure et al. 2005), or to iii) highlight the importance of public goods arising from collective and alliance-based collaborative work (Monge et al. 1998). In spite of those contributions, the concept of online collective action is still largely unexplored in Information Systems. Among the major contributions in social psychology, Bagozzi and Dholakia (2006) relate we-intentions to collective action. Referring to Tuomela (1995) and Tajfel (1978)'s researches, they defined open source software user communities' we-intentions as follows:

“Such group intentions are oriented toward shared activity, which requires (1) mutual responsiveness among participants to the intentions and actions of others, (2) collective commitment to the joint activity, and (3) commitment to support others involved in the activity” (p.1101).

Interactions in online communities are sometimes considered to be based on foundations other than traditional cost-benefit rationality. Researchers argue that online collective action dimensions depend strongly on the virtual community itself, its social identity (Allen and Meyer 1996; Bergami and Bagozzi, 2000; Luhtanen and Crocker 1992) and its groups norms (Dholakia et al. 2004) . In recent years, open source software development and open source revolution (Bergquist and Ljungberg 2001; Bezroukov 1999; Feller and Fitzgerald 2000; Kollock 1999; Mockus et al. 2000), have contributed significantly to the interest of online collective action in the literature. Researchers for example realized that the functioning of virtual communities introduces

gift relationships and must therefore consider the gift economy (Rheingold 1995), which have the potential to frame many online collective actions (Skageby, 2010).

Overall, though, there is no consensus in the literature concerning the role of the technology as a medium of collective action. Walther (1995, 1992) argues that computer mediated communication has positive outcomes on social relationships as compared to Face-to-Face meetings. However, the results and conclusions of those aforementioned studies appeared to be strongly linked with the context in which they has been conducted (Walther et al. 2010; Yates and Orlikowski 1992). Therefore, for online communities addressing the sensitive matters of disease, these factors ought to be examined cautiously.

2.2.1.1 Online Collective Action Concept in Health 2.0 Contexts

With the adoption of the Internet, online communication on health issues has contributed to transforming medical practice. Traditional medical practice is usually performed through top-down approaches, where health professionals and third parties involved communicate information to patients. Only a limited amount of information is delivered in a unidirectional way. Together with online 2.0 tools, the health communication paradigm is transforming towards *many-to-many* approaches, opening wide, connected spaces characterized by collaboration and a willingness to help other patients. As a result, patients switch from a passive to an active way of functioning, where individuals connect with others with similar disease. They share information about symptoms and treatments, along with their thoughts about the way they make their health-related decisions.

Yet, revealing health-related information raises some issues. For example, the related information is often very sensitive, with respect with employment decisions (Heeney et al. 2011) and privacy protection (California Healthcare Foundation 2010). Nevertheless, patients are quite inclined to talk about these issues. The 2012 survey from PwC titled “Social Media “Likes” Healthcare: From marketing to social business” reports consumer-specific behaviors, highlighting that 42% of consumers have used social media to access health-related consumer reviews (e.g. of treatments or physicians). Nearly 30% have supported a health cause, 25% have posted about their health experience, and 20% have joined a health forum or community. It also reports that one-third of the 1,060 U.S. adults questioned use social web for health discussions, at any hour of the day with someone in the house next door or halfway across the globe. The progression is rising at a rapid pace, from 5% of all adults in 2005 using social networking sites, to half of all adults (50%) in 2011. Following this, according to Orizio et al. (2010):

“Health social networks are likely to become an important entity of influence in the medicine of the future, as they are generated bottom-up rather than top-down, by those who make medicine exist, namely, patients” (Orizio et al. 2010, p.6).

In fact, in the context of Health 2.0, there are a number of benefits and risks, related with of the use of Computer Mediated Communication (CMC) to support patients' need to interact (White and Dorman 2001). There is no consensus in the literature concerning the influences of the technology as a medium of collective action. Walther (1995, 1992) argues the positive outcomes of CMC compared to Face-to-Face meetings. However, the

context of such studies appeared to be determinants to raise conclusions (Walther et al. 2010; Yates and Orlikowski 1992). For online communities addressing the sensitive matters of disease, these background factors ought to be examined cautiously. As described in Table 3 below, benefits are manifold and represent useful resources for patients' everyday hardship (Orizio et al. 2010; Bos et al. 2008; Bottles 2009; Diaz et al. 2002). Those benefits mainly relate with overcoming isolation, acting anonymously, the wisdom of crowds, and the possibility to use the online community as a political tool.

Table 3. The Benefits of Health 2.0	
Benefits	Description
Overcoming Isolation	Overcoming isolation allowed by asynchronous communication accessible 24/7/365 on demand respecting a patient's time required to respond, as well as erasing geographical barriers
Anonymity	Anonymity, allowing patients to discuss sensitive issues as well as sidestepping the disclosure of socio demographic factors such as age, gender, racial or ethnic identity, income, social status or disabilities. Nonverbal cues are eliminated for the sake of enhanced privacy
Wisdom of Crowds	Wisdom of crowds, due to the "unlimited" number of participants, allows group members to draw from a wide variety of perspectives, experiences, disabilities and points of view
Political Power	Increased influence in advocacy capacity and a means of organizing and networking politically for a particular cause or disease

Despite those benefits, there are also many risks in the use of those communities, such as a digital divide effect, the time consuming use, misinterpretation of information, and the risks of lack of anonymity, as described in Table 4 below. Among the risks of online collective action, for example, the danger of getting wrong medical information/ misinterpreting information then propagated among the Internet users. For this, while mostly absent, a scrupulous control of potential erroneous information should be mandatory to avoid these pitfalls (Culver et al. 1997).

Table 4. The Risks of Health 2.0

Risks	Description
Digital Divide Effect	Digital divide effect, that eliminates from participation poor populations or those without a rudimentary knowledge of how to use a keyboard and computer
Time Consuming	Time-consuming effect, while browsing through the extensive amount of information
Misinterpretation	Misinterpretation, an inconvenience of the absence of nonverbal cues
Lack of Anonymity	Anonymity can be a concern, due to the relative impersonal nature of the medium as well as deceiving behavior that can occur under the cloak of anonymity
Inaccurate Medical Information	Inaccurate medical information, that can happen when medical advice is given by people without medical training or expertise
Addiction	Addiction, with online relationships replacing gradually real-life social interactions

Some researches suggest that Health 2.0 discussions offer mostly accurate information, especially because corrections may be reported rapidly; some researchers found as rapidly as within five hours (Esquivel et al. 2006). Thus, patients 2.0 may get reliable information by connecting on virtual communities. This virtual communication allows them for example, to maintain a continuous link with the community members (24/7). They may feel that they do not have to wait for new appointments with their practitioners to be informed on minor issues surrounding their disease and their daily life.

Together, those insights offer contrasting perspectives on the advantages and risks of engaging in online patients' communities. For these reasons, there is a challenge of better understanding the characteristics of online collective action. Further, arguably, the use of online patients' communities is growing over time. In fact, it should probably be encouraged as the sociological, economic and scientific outcomes could help to tackle some of the ageing and dependent population's health challenges. It may help to

improve some diagnostics and provide support to patients (Wicks et al. 2010; Lieberman 2007).

2.2.2 The Field Force Determinants of Online Collective

Action: Expectancy Values and Social Factors

2.2.2.1 Field Forces Theory and Human Behavior

Lewin's work on group focused on various aspects such as *group structure, group dynamics, social change, constancy* and *resistance to change* and *field forces*. Lewin (1947) argues that: "certain aspects of behavior can be directly related to the resultant force" and "we are able at present to determine psychological component forces only under special conditions", (p.15).

Johnson and Johnson (2008) defined a group by people embracing one or more of the following characteristics: "A small group may be defined as two or more individuals who (a) interact with each other, (b) are interdependent, (c) define themselves and are defined by others as belonging to the group, (d) share norms concerning matters of common interest and participate in a system of interlocking roles, (e) influence each other, (f) find the group rewarding, and (g) pursue common goals." Therefore, the community is either defined by external or internal criteria (Tajfel 1982). External criteria are the outside designations and internal criteria are the group identification. External criteria, as laws that human-beings have to comply with or adapt and which will influence their behavior and perceptions, have been studied by Lewin (1947) in the Field Theory.

The terminology “group dynamics” has been used to relate to dynamic interdependence as a label covering dynamic group properties, where properties are defined as *types of reactions* or *types of influences* representing certain types of interdependence.

The concepts examined by Lewin in social psychology experiments, aim at explaining social behavior (Lewin, 1939). Lewin (1939) indeed explains that human behavior is influenced, from childhood, by social facts and social relations. This allows him to distinguish warm from unfriendly conduct and to divide social attitudes accordingly. Therefore, any goal setting will scrutinize social facts and the characteristics of a given situation to anticipate the level of success of a particular action. This level will influence and justify ones' aspiration. Indeed:

“The level of aspiration is greatly influenced by such social facts as the presence or absence of other persons or by the competitive or noncompetitive character of the situation. It has been shown, too, that the goal-setting depends upon certain ideal goals” (Lewin, 1939, p.869).

The Field Forces theory represents a significant contribution to social psychology. It provides a holistic conceptual framework for indentifying driving forces and restraining forces, which picture “the direction and strength of the tendency to change” (Lewin, 1946).

Elie-Dit-Cosaque et al. (2011) also drew on social change theory and the above-mentioned Lewin concepts, in the context of IT usage, highlighting the distinction between “the driving that leads to locomotion” and “the restraining forces referring to

the physical or social obstacles that may hinder locomotion”, p.206. However, this study does not address the purposes of collective action.

In summary, this purposive behavior, which reminds us of MGB principles (Perugini and Bagozzi 2001), allows us to adopt a practical approach spurred by the Lewin's field-theoretical account. In this respect, the following sections will concentrate on the identification of “the driving forces” and “the restraining forces” of online collective action, once the contextual background has been clearly outlined.

2.2.2.2 Field Forces Theory in Online Contexts

Social networks and virtual communities often mean the same in the literature. However, Dholakia et al. (2004) differentiated the two concepts, defining virtual communities as “consumer groups of varying sizes that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism to achieve personal as well as shared goals of their members”, p.241-242. On the other hand, Ellison and Boyd (2007) argued that social network sites “are primarily organized around people, not interests... structured as personal (or egocentric) networks, with the individual at the center of their own community”, p.219.

The size of the network is a major factor of these two ways of functioning. Indeed, online social networks gather a broad audience enabling users to articulate and make visible their social networks, but the opportunity to come into contact with strangers usually is of minor importance (Ellison and Boyd 2007; Grabner-Kräuter 2009). Putnam (2001) argued that weak ties - referring to social networks - imply a bridging behavior between individuals leaving aside emotional support whereas strong ties – referring to virtual

communities - imply a bonding behavior involving strong emotional support between individuals.

Furthermore, Meglino and Korsgaard (2004) argue that “sociality maintains that group members suspend their personal interests in order to ensure their group’s continued existence”, p.947. Nevertheless, although online social networks and virtual communities are often confused in the literature, this concept will not always apply to both online networks. Virtual communities indeed differ from social networks, in particular because common interest is an important prerequisite for gift-giving culture through the Internet medium (Bergquist and Ljungberg 2001). Therefore, in the context of patients’ networks, the first approach described by Dholakia et al. (2004) applies, leading us to focus on patients’ virtual communities, instead of that of social networks.

Within these virtual communities, one should consider the differences in the user profiles and their willingness to participate in the group’s mission. Janzik and Raasch (2011) distinguish between: “ (1) Innovators and activists, (2) crowd-followers and tourists and (3) lurkers. The group of innovators and activists leads discussions and forms opinions, and is a fundamental driver of the Online Communities for its survival and advancement. Tourists have a passing interest in the main topic of the Online Communities. Crowd-followers have individual interests differing from the main topic of the Online Communities and participate in discussions for other reasons e.g., closer social ties. Lurkers participate passively without contributing within the Online Communities”, p.801-802.

Although not referring to Lewin's Field Theory specifically, some driving and restraining forces that would make online communities successful or not have already been discussed by researchers (Toral et al. 2009).

Further, online action of communities' members, which characteristics have been outlined above, also imply system usage issues. In those contexts, for example, a well structured, easy to use website, compliant with the right principles for appropriate visual appeal or navigation will not always be sufficient to ensure active and successful communities (De Souza and Preece 2004). Referring to virtual communities as opposed to social networks, the pervasiveness of social facts remains a crucial characteristic:

“This is because online communities should be understood as a social phenomenon that establishes social networks of people with common interests. Consequently, success of online communities should be determined by social factors” (Toral et al. 2009, p.379).

Based on the Field Forces theory and Expectancy-Value Theory (EVT), the following sections will concentrate on the identification of the driving and restraining forces of online collective action in an online community context.

2.2.2.3 Expectancy-Value Theory (EVT) Adapted to Online Contexts

Expectancy-Value Theory (EVT) (Eccles *et al.*, 1983), outlined four components of task-value, which have been defined as follows. The first component, social value, draws upon attainment value also related to self-schema and identity theories (Markus & Wurf, 1987), which reflects on oneself and one self's relevance of engaging in a task (Eccles &

Wigfield, 2002). It also includes “the personal importance of doing well on a task” (Eccles & Wigfield, 2002, p.119). In virtual environments, (Dholakia *et al.*, 2004) defined it as a means to “understand and deepen salient aspects of one’s self through social interactions” (p.144).

The second component, utilitarian value, refers to the determination of the task itself and its relation to future goals’ achievement. “A task can have positive value to a person because it facilitates important future goals” (Eccles & Wigfield, 2002), p.120.

The third component, hedonic value, draws upon intrinsic value or “the enjoyment the individual gets from performing the activity or the subjective interest the individual has in the subject” (Eccles & Wigfield, 2002, p.120). It is also a determinant for participation in virtual communities (Dholakia *et al.*, 2004).

The fourth component, cost value, reflects the negative aspects of engaging in the task” (Eccles & Wigfield, 2002, p.120). In social exchange theory, trust is a core component of a cost-benefit analysis with respect to social interaction (Rolloff, 1981). For interactions that take place in online communities, many researchers associate trust concerns with privacy concerns (e.g., Dong-Hee, 2010; Fogel & Nehmad, 2009; Dwyer *et al.*, 2007) or quality of information (Kwon & Wen, 2010).

Following those insights, the present research draws on the functioning of groups through social influence and social identity, exploring the role of positive emotions in behavioral action. We will focus on the driving forces of the value of online collective action – namely social, utilitarian and anticipated positive emotions of EVT (Eccles *et al.*

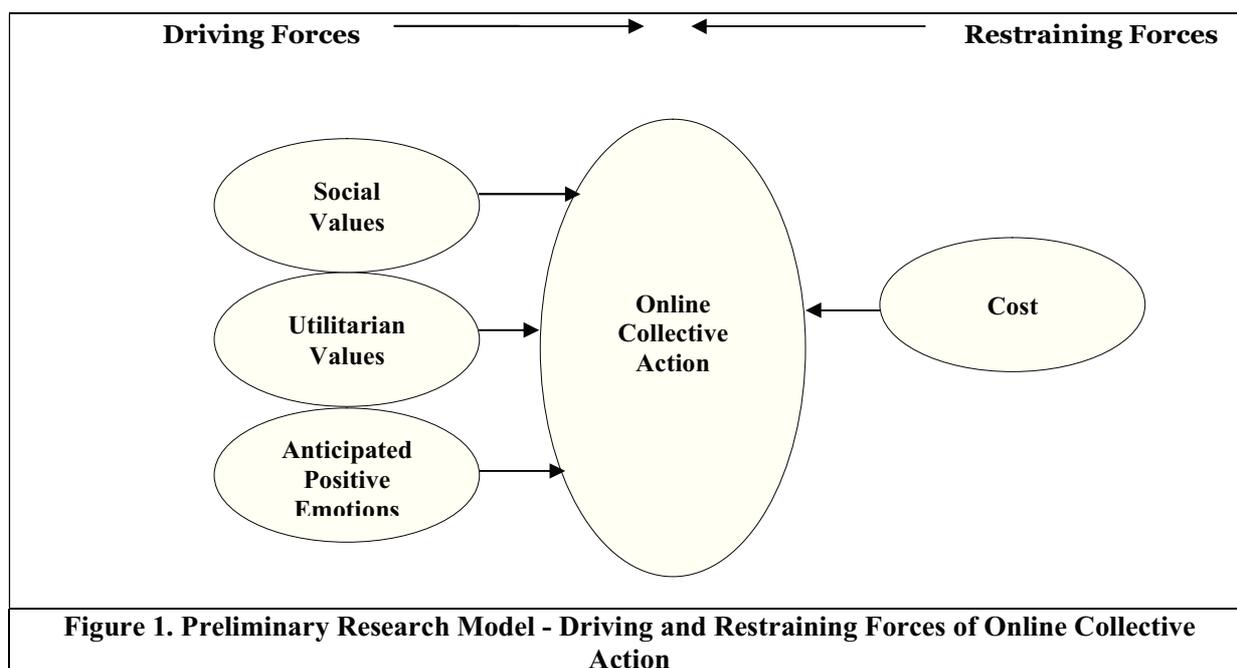
1983) – and the restraining forces of online collective action – namely cost value of EVT - to establish the design of our critical realism research (Zachariadis et al. 2010).

All these concepts were brought by the literature but influenced, from the very start of this research, by our field experience as well as during the interview process.

2.2.3 Driving and Restraining Forces of Online Collective

Action: First Draft Model of Online Collective Action

Following Lewin's framework, EVT theorizing, and prior insights from the field qualitative interviews, a generic, synthetic conceptual model (Figure 1 below) has been developed. Specifically, drawing on the functioning of groups through social influence and social identity, the model depicts the expectancy values' "driving" and "restraining" forces (Lewin 1947) and its role in the dynamics of online collective action in online community contexts. Also based on EVT (Eccles et al. 1983), the model aims to help better acknowledging in particular the role of social, utilitarian and anticipated positive emotions in the development of collective action on the one hand; that of cost value on the other hand. The qualitative inquiry presented hereafter helps in particular to identify which facets of the expectancy values specifically emerge in the dynamics of online collective action on online communities and appear to be the most relevant ones.



2.3 Design and Methods

In order to respond to our research question, we applied a qualitative approach following the tradition of qualitative methods in information systems (IS) (Trauth 2001). We chose direct contact, close listening, dialogue and conversation with patients and stakeholders for our exploratory approach in order to better understand the recent phenomenon of engaging in virtual communities (Branthwaite and Patterson 2011).

2.3.1 Research Field

It was important to make a cautious identification of the relevant patient populations. Indeed, the condition of the patient is likely to contribute to his/her need for information sharing and exchange between people affected by the same disease. Further, the desires of interaction between patients on sporadic concerns are fundamentally different from the concerns of patients with acute or chronic disease (PwC 2012). We

therefore first conducted interviews with healthcare professionals, which enabled us to identify the most relevant patients 2.0 populations. It resulted that not only patients but also patient's relatives were relevant people to interview. Indeed, patients' families are also facing problems in their daily lives and are interested to hear the feedback from others involved in similar difficulties. Our sample was therefore restricted to patients affected by chronic and serious diseases and patients with rare diseases and their families.

Following this, we identified two groups of patients 2.0 for the study, one comprising members of a breast cancer community, the other comprising parents of people suffering from rare diseases.

The breast cancer community studied is one of the very first French virtual communities that came out of an isolated initiative and has no real economic model, except fundraising. The social network, founded in 2002, is a nonprofit association and thus operates through donations and is maintained in this manner. The virtual community displays, as a first feature, the forum where women exchange comments about their daily fight against breast cancer. The site has now over 10,000 registered patients. The platform is open and its messages can be read without registration. This leaves the choice to any member either to show complete transparency about her personal information or to keep anonymity.

The rare disease community for patients' relatives studied is a closed Facebook group created in 2010. It results from an independent platform that decided to use Facebook's services to reduce its operational costs. Only patients' relatives, who are parents of

autistic children and have been co-opted by a group member, are allowed to join this closed virtual space that comprises around 100 persons. A moderator is present. He is active and acts in a positive manner in order to inspire an uplifting mood within the group, despite the difficult testimonies from parents talking about their children's sickness.

Out of the 29 patients, 25 females and 4 males were interviewed. The interviews had an average duration of one hour. They have all been recorded and fully retranscribed. The interviewees were chosen as summarized in Table 5 below.

Table 5. Interviews		
Interviewees	#	Purpose
Doctors and caregivers	5	To increase our understanding of the feelings and concerns of the patient population from a medical standpoint.
Health 2.0 experts	13	To increase our understanding of the patient population's driving and restraining forces for joining Health 2.0 IT from a medical and technological standpoint.
Web 2.0 experts	7	To increase our understanding of an individual's driving and restraining forces for joining online communities. To establish contrasts between health communities and more traditional communities.
Patients	21	To contextualize the individual and social determinants for joining virtual communities from a patient standpoint.
Patients' relatives	8	To find the individual and social determinants for joining virtual communities from the standpoint of patients' relatives.
Total	54	

2.3.1 Procedures

In order to mitigate the way data collection and interpretation activities could affect both the researcher and the interviewee (Klein et Myers 1999) we chose to conduct semi-structured interviews (Romelaer 2005). These added rigor and consistency across interviews to the data collection (Myers 2013), “where the researcher urges the

respondent to communicate many, detailed and quality information on topics related to the research, with limited influences that guarantee the absence of bias and serve a good scientificity” (Romelaer 2005, p.102). Therefore, interview guides (see Table 6, 7) were elaborated for conducting the interviews (McCracken 1988). They were constructed in compliance with DeMarrais (2004)’s guidelines suggesting to alternate short and clear questions, questions that would allow participants to recall specific event, and few open-ended questions. These questions were developed based on the literature review and the information gathered from the field.

The interviews have been conducted taking into account the potential difficulties of qualitative interviews, namely: elite bias, Hawthorne effects (H. M. Parsons 1974) and construction of knowledge for our main concerns (M.D. Myers et Newman 2007).

Our motivations to use such interviews were multiple. Firstly, we felt the existing theories were insufficient in some respects to examine engagement in online communities and consequently had to be adapted to the selected field of inquiry. Secondly, we were further expecting that some constructs regarding determinants of online collective action could potentially emerge from the patients’ experiences. Thirdly, we were convinced that our specific field of inquiry required this partly inductive approach. Hence, this method was expected to contribute to i) the content validity for the constructs in the subsequent quantitative part and to ii) enrich the conceptual framework, which is grounded in both theory and actual human thoughts.

Table 8 below, summarizes the objectives of the interviews that have been conducted with a number of different actors in the domain of Health 2.0 and of patients.

Table 8. The Research Approach		
Approach	Objectives	Procedures
Qualitative Approach	<ul style="list-style-type: none"> - Identify the specificities of patients that join virtual communities. - Contextualizing the variables chosen for the research model and survey instrument; ensuring content validity. - Identifying in practice the emerging individual and social determinants of patients joining web-based patients' virtual communities. - Examining the role played by the IT artifacts versus information and emotional needs in patient's commitment. 	<ul style="list-style-type: none"> - Ethnographic research approach in order to gain preliminary insights on patients' sociological typology as well as driving and restraining forces for online collective action. - 25 preliminary semi-structured interviews with Doctors and caregivers, Health 2.0 experts and Web 2.0 experts, users of patients' social networks. - 29 subsequent interviews conducted with participants who had to deal with their own health issues or that of relatives.

We proceeded in two steps. First in order to obtain insights into patients' social characteristics as well as on the factors that can potentially foster or hinder their interactions on online communities we conducted a preliminary series of interviews. Interviews were conducted with Doctors and caregivers (5 persons), Health 2.0 experts (13 persons) and Web 2.0 experts (7 persons). Of the 25 persons interviewed for these preliminary interviews, 11 were female and 14 were male. The preliminary interview guide is provided in Table 6 below.

Table 6. Interview Guide in Preliminary SDCI	
Questions	Objectives
Is there an existing patient typology for a focus group whether they gather online or offline?	To identify a patient panel to address for the study
Are there patients' networks that are more suitable for some patients than other	To identify a patient's panel that would not be relevant for the study
What would be the patients' motives for online engagement?	To compare the feedback of experts about determinants for patients' online engagement against the literature
What would be some hindrances to engagement?	To compare the feedback of experts about hindrances to patients' online engagement against the literature
What about privacy and data protection?	To compare the feedback of experts about hindrances for patients' online engagement against the literature
Do you think these portals help patients during the healing process?	To compare the feedback of experts about positive psychology and patients' online engagement against the literature

The preliminary investigations provided us insights into the most relevant patient profiles to interview for the main study. Some testimonies reassured us of the need to address specific categories of virtual communities:

“Virtual communities are probably not for all patients, but they are particularly suitable for two categories of patients: chronic patients and patients suffering from rare diseases. They also cater to families. The greatest proof of the usefulness of virtual communities for health matters lies in the categorization.”

“The sites are especially suitable for chronic diseases. And patients need to be informed ... I do think that one is informed when a chronic patient, when one has a rare disease he may know it better than his doctor.”

In particular, the information obtained revealed that, in accordance with the main topic of the targeted communities, patients with chronic diseases, severe diseases and patients' relatives were the most relevant persons to participate in the research.

As mentioned above, patients' families are also involved in the problems of everyday life experienced by their loved ones and are conscious of the crucial importance of the feedback coming from others with similar problems (PwC 2012).

We then proceeded by interviewing selected patients (21 persons) and patients relatives (8 persons) irrespective of whether they were willing or reluctant to join these virtual spaces. We included in our sample patients who were reluctant to join online

communities, women engaged in a breast cancer community, and relatives of autistic children engaged in a rare disease community.

In completing the interviews, we have been cautious in taking into account some potential bias, such as elite bias, Hawthorne effects (Parsons, 1974) and construction of knowledge (Myers & Newman, 2007). The anonymity of the respondents was also guaranteed.

The interviews have been conducted while the literature was still being analyzed. This allowed developing an online collective action (OCA) model through a constant a back and forth process between the literature and the field. In this, the model is in part grounded on the field: while the broad EVT categories came from the literature, the expectancy value facets, which make sense in an online community context, have emerged from the analysis of the interviews. So doing, this approach allowed us to let some concepts coming from the field and be compared with the literature in an exploratory approach (Mingers, 2000; Mingers, 2004). The interview guide for patients and patient's relatives is given in Table 7 below.

Table 7. Interview Guide in Patients and Patients' Relatives SDCI	
Questions	Value's Dimension Addressed
Do you feel the need to be informed on your disease?	Information Needs
Where do you go to find medical information?	Inaccurate Medical Information
Do you think online medical information is relevant?	
What (other than information) would you seek on an online medical portal?	Instrumental Needs, Positive Emotions, Belongingness Needs, Exclusive Value, Overcoming Isolation
Would you say special relations are developed with other patients participating?	Belongingness Needs, Group Norms

Do you trust online medical portal participants?	
Do you feel the need to be connected to other online patients?	
Do you mind your testimonies being exposed online?	Privacy Protection
How do you feel when you're connected to people living the same pathologies?	Positive Emotions, Negative Emotions
Do you feel pleasure while connected to these participants?	
Do you think you're helping people while connected?	Giving-Help
Do you feel your participation in the debate useful?	
What would be the ideal patients' community?	Other emergent dimensions
Is it easy to find what you are looking for on the patients' virtual community web site?	
Is the patients' virtual community web site attractive?	

Once we had collected enough material and semantic saturation was reached – i.e. when the last of our 54 interviews' coding didn't make any further category emerge (Glaser et Strauss 1967), we conducted the data analysis in two steps.

2.3.2 Coding and Analysis Sequencing Perspective: Critical Realism Paradigm

Before coding interview data, we defined an initial set of themes drawn from the literature. The aim of interview coding was to identify the value dimensions of online collective action from the literature and interviewees' day-to-day experiences of virtual communities. Hence, we also expected unknown or new categories to emerge from interviewees' accounts.

During the course of the interviews, and throughout the transcripts' analysis and coding, new codes and concepts emerged and the list of themes grew accordingly (Mason, 2002). The coding has been completed through the use of NVivo 9 and 10. Thematic coding and data mapping have been completed (Bazeley & Jackson, 2013). We proceeded in two steps.

First and before coding the data obtained in interviews, we set broad categories as explained above. The initial dictionary of categories was drawn from the literature study resulting in 10 a priori themes (See § 2.5.2).

Second and as an ongoing process we created categories from the data itself and established coherent links between all these categories. The approach considered both prior theoretical insights and interview data. It was an incremental approach to data gathering, as, throughout the transcripts' analysis and coding process, new categories were added when related to our study issues. "A key to this process is to consider a broad range of literature" (Eisenhardt 1989, p.544).

This first coding process ended up in a dictionary of themes comprising 28 themes. This was done in light of our goal to follow the critical realist paradigm (Zachariadis et al. 2010; Mingers 2000), implying that since, in this Web 2.0's research, "IS is conducted within social organizations, social science is also of relevance" (Mingers 2004, p.91). Mingers (2004) further argues on this philosophical position stating that:

"critical realism asserts that the conditions for knowledge do not arise in our minds but in the structure of reality, and that such knowledge will not be universal and ahistorical", p.92.

Therefore, aware of intransitive objects of knowledge – namely non-human-invented-, our work on the field was intended to discover the transitive dimension of knowledge helped by social sciences theories and their potential human-invented alterations (Bhaskar 2010). In this regard, Mingers states that:

"This distinction allows us to admit the epistemic relativity of science, the fact that knowledge is always historically and socially located, without losing the ontological dimension" (2004, p.299).

Indeed, the list of categories and its principal theme were developed according to prior literature, but we changed this list during the course of the interviews following this critical realist perspective. Thus, in this research, we sought theoretical emergence through an exploratory process and analysis of the production of concepts by social actors in real settings and specific fields of inquiry- i.e., transitive dimension of knowledge. We examined how well data either fits or shapes conceptual categories we identified from the literature, in an iterative back and forth work between the research field and literature.

After the entire coding process and through interview analysis, some categories were restructured – and some were dropped when considered as non relevant - as follows (Bhaskar, 1979).

The Table 9 below give details about the different driving and restraining forces of online collective action, which have been identified and coded, whether they have been identified from the literature or emerged from the interviews.

Table 9 The Driving Forces of Online Collective Action

Broad Nodes	Sub-Nodes	References
Driving Forces for Online Collective Action	UV Information Needs	(Flanagin & Metzger, 2001)
	SV Belongingness Needs (Social Identity)	(Baumeister & Leary, 1995)
	SV Exclusive Value	(Baumeister & Leary, 1995)
	HV Positive Emotions	(Perugini & Bagozzi, 2001; Dholakia <i>et al.</i> , 2004)
	UV Overcoming Isolation	(White & Dorman, 2001)
	SV Group Norms	. (Tajfel, 1982)
	UV Instrumental Needs	(Grabner-Kräuter, 2010)
Restraining Forces for Online Collective Action	Negative Emotions	(Perugini & Bagozzi, 2001)
	Privacy Protection	(Green, 2007; Goldberg <i>et al.</i> , 1997; Graber <i>et al.</i> , 2002)
	Inaccurate Medical Information	(Green, 2007; Williams <i>et al.</i> , 2003)

UV = Utilitarian Value, SV = Social Value, HV = Anticipated Positive Emotions

2.4 Model Formulation and Propositions

Following Lewin (1947) and Eccles *et al.* (1983) theories, we have built on a first draft model of driving and restraining forces of online collective action (See Figure 1), influenced by the Dholakia *et al.* (2004) work in an online context, itself inspired by MGB (Perugini *et al.* 2001). Although this model does not respond to the complete understanding of online collective action phenomenon in Health 2.0 environments, it values a synthetic framework of this construct and its field forces. Indeed, none of these models thoroughly covered all aspects of what would drive patients to join online virtual communities and participate in communal work. In order to ensure a more comprehensive perspective of the patients' online collective action phenomenon, this research seeks clarification and further information from both literature and field.

Therefore, constantly attentive to both sources, we revisited the literature accordingly and enriched the model subsequently.

Following the chronology of our findings, this section is organized as outlined below.

Firstly, we address each construct of driving forces enumerated by Eccles et al. (1983) EVT – namely: social, utilitarian and anticipated positive emotions – applied to online contexts, in search of existing and new concepts.

So, we listened to patients' testimonies concerning IT artifacts and the notions of habits and consulted the relevant literature.

Thereafter, we address EVT construct of restraining forces – namely cost value – applied to online contexts, in search of existing and new concepts.

Finally, we completed our model with every sub-dimension gathered by this constant to-and-from between the literature and patients' testimonies.

2.4.1 Driving Forces of Online Collective Action

2.4.1.1 Social Values

Pursuant to the already mentioned three components of task-value of Eccles et al. (1983) that may spur online collective action, we will seek, helped by both field and literature review in our critical realism research design, what concepts and dimensions they may refer to for online users and especially patients connected on virtual communities. These components are comprised of social value, utilitarian value and anticipated positive emotions.

2.4.1.1.1 Functioning of Groups through Social Influence: Introducing Social Identity and Group Norms

In the context of patients' communities, we find it relevant to explore social influence literature about the driving forces for online collective action.

Dholakia et al. (2004), drawing on Kelman's (1958) perceptions of interpersonal influences, categorize social influence's variables for online participants. The latter are comprised of social identity and group norms' constructs, observing that face-to-face social context cues differ with media communication (Sproull et Kiesler 1986). Compliance, the Kelman's third variable of social influence, has been left behind by Dholakia et al. being considered of minor importance in the case of online communities. Indeed, participants do not feel the need to conform to the online group, expecting rewards or fearing punishment, as the possibility to leave the virtual engagement can easily be done, as the feeling of freedom is high.

2.4.1.1.2 Identification or Social Identity

Social identity comprises the psychological and sociological aspects of individuals' conducts in a group entity embracing three components that explain social cognition and behavior. Group identification or social identity requires: i) cognitive component (awareness of membership), ii) evaluative component (value connotations), iii) emotional component (as an investment).

For patients 2.0 as for members of non-patient groups, social identity refers to a strong sentiment of group belongingness comprised of an affective commitment (Bergami and

Bagozzi 2000), a self-awareness of community membership (Ashforth and Mael 1989) and a self-worth evaluation as group member (Dholakia et al. 2004). As chosen by Dholakia et al., in terms of terminology development, we will adopt the term belongingness needs. Therefore:

Proposition 1: Belongingness Needs is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

2.4.1.1.3 Group Norms or Internalization

In collective or shared intention, participants' attitudes need consistency in order to face reasoning and coherence towards collective planning and future shared activity (Bratman 1999). Collective intention - aka we-intentions - implies commitment and agreement to joint-activity from each protagonist (Tuomela 1995). Dholakia et al. (2004) include these aspects in their model of group norms related to Kelman's concept of internalization, when an individual accepts influence from others towards a behavior because it is congruent with his/her value system (Kelman 1958).

Drawing on Tajfel (1982) theories, - illustrating common interest, interlocking roles, influencing each other, and shared goals- Postmes et al. (2000) investigated the formation of group norms in CMC, positing that group norms have to be understood as emergent properties of the group that organize behavior and that "social and normative context has a substantial impact on CMC use", p.366.

We will further study this CMC use in the following section in the “IT artifacts” paragraph, but first, the aforementioned points allow us to state that in the context of patients' communities:

Proposition 2: Group Norms is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

2.4.1.1.4 Exclusive Value from Patients' Perspective

To our knowledge, absent from the literature addressing determinants of online action, we however identified the notion of exclusive value. Exclusive value would be referring to Baumeister and Leary's approach on interactions stating that:

“Interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s), and relatedness without frequent contact will also be unsatisfactory” (1995, p.497).

Indeed, many patients were arguing about their need to interact with exclusive partners, meaning with those that share the same disease, in the case of patients' communities, because:

“When the site is dedicated to a specific category of patients, if I may say so, they have a stronger relationship; there is a very important community effect tenfold ...” (Breast cancer community patient)

Therefore:

Proposition 3: Exclusive Value is positively related to online action regarding virtual patients' communities.

(Social Value of Online Collective Action's Driving Forces)

2.4.1.2 Utilitarian Values

2.4.1.2.1 Purposive Value: Information Needs and Instrumental Needs

The notion of information, nurturing and occasionally flooding virtual spaces has often been covered in the above sections.

Besides, information needs and instrumental needs have raised significant interest in Dholakia et al.'s (2004) research as well as in previous studies (Bagozzi et Dholakia 1999). Gathering these two concepts under a single denomination purposive value, Dholakia et al. defined it as follows:

“the value derived from accomplishing some pre-determined instrumental purpose (including giving or receiving information)” through virtual community participation”, (2004, p.244).

Unquestionably of relevance in the context of patients' communities, according to patients' testimonies, we however suggest to keep the two concepts separate for a better understanding of patients' functioning. Therefore:

Proposition 4: Information Needs is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

Proposition 5: Instrumental Needs is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

2.4.1.2.2 Overcoming Isolation from Patients' Perspective

While online, a real break in patients' isolation occurs, erasing all geographical as well as sociological barriers that could have been created by the stigma of a disease itself (White et Dorman 2001). Obviously, those benefits are different – although complementary – from those they would get from traditional social groups operating in real life and of relevance in the present study:

“I understand the need, the need to exchange. When illness isolates, there is a need to regain a semblance of social life.” (Breast cancer community patient)

Testimonies suggested that virtual communities fill these social needs while decreasing patients' isolation and helping them overcoming the burden of loneliness.

Therefore:

Proposition 6: Overcoming Isolation is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

2.4.1.3 Positive Anticipated Emotions

2.4.1.3.1 The Role of Positive Emotions in Behavioral Action

Another dimension that seems to be important in communities of patients relates to the emotions conveyed. As it seemed to be a predominant dimension of online collective action from the patients' standpoint, we conducted an in-depth literature review of the emotions construct and its various aspects.

We will come back to the fundamental of action to explore it. Engaging in collective action supposes first being determined to engage in personal action. Previously, philosophers and researchers emphasized the dynamics of reason and passion for understanding action. Pascal, in 1670, exposed the contradiction between passion and reason (Genet 1983, Pascal 2007, Cottingham 1998). Differently, Descartes, in 1649, postulated on the supremacy of reason over passion (Descartes 1989, Cottingham 1998) while Hume, in 1739, advocated a theory in which reason is governed by passion (Hume 2004) (Beauchamp 2009).

In his model, Hume (2004) asserted that reason does not by itself constitute grounds for an action of volition, and that reason only intervenes to explain passion's impulses to action's proceedings and thus connecting between the two elements. However, Hume also stated that reason cannot oppose passion for directing the will for action:

“Reason is, and ought only to be the slave of the passion, and can never pretend to any other office than to serve and obey them” (2004, p. 375) .

By passion, Hume categorizes the following feelings: i) direct passions (desire, aversion, joy, hope and fear), ii) indirect passions (pride, humility, love, hatred, vanity, envy, pity, malice, esteem, benevolence, respect and compassion).

While exploring other research areas, we found that positive psychology literature highlighted that “positive emotions broaden the scope of attention, cognition and action” (Fredrickson 2004, p. 1369), and “improve psychological well-being, and perhaps also their psychological health” (Fredrickson 2004, p. 1371; 2000). Clinicians, using the benefits of positive psychology with depressed people by questioning their recalling of events responsible for positive emotions, saw improvements in their condition. Indeed, faster healing but also greater autonomy from the disease is experienced (Rudd, Joiner, et Rajab 2004).

Therefore, positive emotions contribute to their welfare and its optimal function in the present moment (Diener, Sandvik, et Pavot 1991). Positive emotions also encourage stepping back in the face of upcoming events, avoidance of negative thoughts, emotional resilience and the development of resources in times of trial (B. L Fredrickson 2004). A responsible environment provides further positive emotions to the patients, his/her relatives and other patients 2.0; not only for the immediate satisfaction it provides but also because it endows them with a force that will be of help in future battles and will allow them to find the right resources in a flexible adaptation and virtuous cycle (B. L Fredrickson et Joiner 2002).

Neuropsychological theories further show that cognitive performance is improved by the presence of positive emotions, indicating that positive affect is associated with an

increased level of dopamine in the brain, developing the capacity of flexible and creative thought patterns in respect and response to the problems encountered (Ashby et al. 1999, Isen 1987). Positive emotions are also presented in marketing literature, as Dholakia et al. (2004) relate to entertainment value, “derived from fun and relaxation through playing or otherwise interacting with others”, p.244.

Referring to gift concept, Chakrabarti and Berthon (2012) also argued that “in order to understand the total gift-giving experience, researchers should emphasize more on the intangible thoughts and emotions over the tangible object of the gifts per se”, p.155, referring to the positive anticipated emotions of our levels of value of online collective action (see Figure 1) .

2.4.1.3.2 The Role of Emotions in IS Research

All these studies, from researchers in fields other than IT, urge us to pay thorough attention to emotions in order to better understand patients 2.0 behavior.

In online context, researchers demonstrated that, besides decreased isolation, patients' virtual communities fostered emotional support while interactions and shared experiences (White et Dorman 2001). The CMC offers convenience for collective action and “50% of postings concerned socio- emotional exchanges” (White and Dorman 2001, p.700).

Coming back to IT use, the literature demonstrated the relationship between emotions and IT through intermediate adaptation behaviors (Beaudry et Pinsonneault 2010). However, to our knowledge, prior research didn't address the context of patients' usage

of online communities. Therefore, we will further explore the patients' behaviors in the context of virtual communities, drawing on Beaudry and Pinsonneault's statement: "emotions are a mental state of readiness for action that promote behavioral activation" (2010, p. 690), therefore:

Proposition 7: Positive Emotions is positively related to online action regarding virtual patients' communities.

(Anticipated Positive Emotions of Online Collective Action's Driving Forces)

2.4.1.4 IT Artifacts: Utilitarian Values and Anticipated Positive Emotions

2.4.1.4.1 IT Artifacts

User satisfaction, likelihood and frequency of use are valuable online commodities, as Internet users are exposed to so many different choices and are becoming reluctant to noise and time wasting. Indeed, meeting system usage concepts of TAM (Davis 1989), Shackel and Richardson (1991) explained that usability "is not only conceived of as ease of use but also equally involves efficacy i.e., effectiveness in terms of measures of (human) performance", p.24. However, the question opens a wide field of research with an extensive set of usability and performance measures (Benbunan-Fich 2001, Van Waes 2000, Benbunan-Fich 1999, Fang and Holsapple 2007) considering the variety of online websites categories themselves dedicated to different audiences and purposes.

Phillips and Chapparro (2009) noticed that when users appreciated the visual appearance of a website at first glance, they may continue the browsing experience regardless the website's usability, and as a result, perceived usability can be more

influential on the intention to use than ease of use and efficacy (Kurosu et Kashimura 1995), (Brady et Phillips 2003). Other researchers demonstrated that visual appeal influences users rating of perceived usability, sometimes in contradiction with actual usability (Tractinsky, Katz, et Ikar 2000).

Therefore, we drew on (Nelson, Todd, et Wixom 2005) to select navigational structure as a system quality parameter that affects trust in the IT artifact (e.g.,(Vance, Elie-Dit-Cosaque, et Straub 2008) Wang et al. 2008; Loiacono et al. 2007; Montoya-Weiss et al. 2003; Wolfinbarger and Gilly 2003). Visual appeal has also been widely studied as a website quality dimension (Vance et al. 2008; Loiacono et al. 2007; Tseng and Fogg 1999; Wagner 2005), and together with navigational structure, both these attributes may be leading to attitudes, intentions and ultimately behaviors (M. Fishbein et Ajzen 1975) (see Table 10).

Table 10. IT Artifacts as Utilitarian Value and Anticipated Positive Emotions

Dimension	Relevant Facet	Definition	Author	Implication for Online Collective Action
Utilitarian Value	Navigational Structure	“Navigational structure is defined as the organization and hierarchical layout of the content and pages in a Website and involves the relative effort required for a user to traverse an IT artifact user interface” (Vance et al. 2008, p.79)	(Vance et al. 2008)	The model including system quality constructs of navigational structure and visual appeal influences positively the intention to use an online platform and possibly to contribute to online collective action
Anticipated Positive Emotions	Visual Appeal	“Visual appeal is defined as the tangible aspect of the online environment that reflects the ‘look and feel’ or perceived attractiveness of a Website. Visual appeal connotes the attractiveness of the Web site, including graphics, colors, and fonts.” (Vance et al. 2008, p.79)	(Vance et al. 2008)	

2.4.1.4.2 IT Artifacts from Patients' Perspective

For the specific population of patients, the usability of e-health web sites as information providers has been studied, examining authority of source, layout and appearance, advertising presence and aspect, readability, etc. (Eysenbach 2002, Curtis 2010, Sillence and Briggs 2007, Sillence et al. 2007). Researchers have been exploring some of these aspects and developed dedicated scales such as the Perceived Health Web Site Usability Questionnaire (PHWSUQ), which includes 25 principles in 4 categories: (1) readability, (2) presentation of information, (3) incorporation of other media, (4) ease of navigation (Nahm et al. 2004). However, research lacks information about health-related virtual communities and the role of emotions in their rating of perceived usability, with regard to visual appeal that may influence the usability perception of users.

Therefore, we will add to our study the two aforementioned categories – namely navigational structure as a utilitarian value as it refers to “how well a task relates to current and future goals” (Eccles and Wigfield 2002, p.120) and visual appeal as a anticipated positive emotions as it refers to “the enjoyment the individual gets from performing the activity” (Eccles and Wigfield 2002, p.120) – in order to help us understand the functioning of Health 2.0 communities.

Proposition 8: Navigational Structure is positively related to online action regarding virtual patients' communities.

(Utilitarian Value of Online Collective Action's Driving Forces)

Proposition 9: Visual Appeal is positively related to online action regarding virtual patients' communities.

(Anticipated Positive Emotions of Online Collective Action's Driving Forces)

2.4.1.5 Habits

2.4.1.5.1 On Habits

In TPB, Ajzen (1991) did not subscribe to the view of past behaviors as being meaningful for predicting present ones. For researchers such as Bamberg et al. who stated that: “if social behavior is reasoned, then—it is argued—frequency of prior behavior should have only an indirect link to later behavior; its effect should be mediated by intention and perceived behavioral control” (2003, p.176), or others such as Sommer (2011): habits would not be a relevant predictor of action according to TPB.

However, many researchers have examined this factor in greater depth (Ouellette and Wood 1998; Aarts et al. 1998; Perugini and Bagozzi 2001). Some specifically expanded the subject to IT use focusing on habits, and found a significant effect of the latter “triggered by environmental cues” (Ortiz de Guinea and Markus 2009, p.440).

Past Behavior can be conceptualized in many different ways, such as frequency of behavior, recent behavior (Perugini et Bagozzi 2001) or habits. Habits have been defined as “the tendency to repeat past behavior in a stable context” (Ajzen 2002, p. 108; Ouellette and Wood 1998). Thus, even when it deals with IT use, habits refer to habitual behaviors, rather than to behaviors guided by intentions (Limayem and Hirt 2003; Kim and Malhotra 2005). In this regard, goal-directed behaviors differ from intentions in terms of appreciation and consciousness of decision (Ahuja et Thatcher 2005). Indeed, as primary reasons induce action in the concept of intention, goal-directed-behavior theory suggests that goals can be reached without individuals being fully conscious of his

or her thoughts. This occurs especially when the goal-directed-behaviors encounter frequent repetitions and thus action is performed in a familiar environment as habits.

Aarts and Dijksterhuis further assert that habits can be considered as links between goals and actions, activated by the environment, and which contributes to reaching these goals through automatic behavior. Therefore, the more often the activation of a goal conducts to the same behavior, the stronger the unconscious processes (Aaarts and Dijksterhuis 2000; Heckhausen and Beckmann 1990; Reason 1990).

2.4.1.5.2 Habits from Patients' Perspective

Concerning patients, the phenomenon of addiction that relates to the development of habits, outlined above, was demonstrated to be of relevance by White and Dorman (2001) in CMC patients' support groups.

We acknowledge that the repeated connection of the patient may lead to the Internet addiction, implying an extensive level of virtual community interactions (Beard and Wolf 2001; Young 2004), and thereby of online collective action (Laubie et Elie-Dit-Cosaque 2012).

However and despite the above mentioned inputs taken from the literature, the automatic nature of this concept questions the relevance of its introduction in our model.

Drawing on Ajzen's (2005) statement about background factors – that will be further explained in a following section – we will include habits in the background factors category, as past experiences that may be related to or influence users' beliefs. Therefore, we will study and code it but put it apart from our research model, namely driving forces of online collective action.

2.4.2 Restraining Forces of Online Collective Action

In the same perspective and taking into account the above mentioned last component of task-value of Eccles et al. (1983) that may hinder online collective action, we will seek, through the literature review as well as helped by patients' inputs, what concepts and dimensions ought to be included in our model concerning the cost value.

2.4.2.1 Cost Value

2.4.2.1.1 The Role of Trust in Behavioral Action

As already described, cost value relates to “negative aspects of engaging in the task” (J. S. W. Eccles et Wigfield 2002).

In online community interactions, many researchers associated the cost value with trust, referring to privacy concerns (Metzger 2004; Dwyer et al. 2007; Dong-Hee 2010; Fogel and Nehmad 2009). On this subject, the press related several users' unfortunate experiences with personal data disclosure (Read 2006). As Peter Steiner put in the caption to a cartoon: “on the Internet, nobody knows you're a dog” and from the very beginning of online chat services, the “Joan and Alex” story featured the case of a psychiatrist who pretended to be a young disabled woman (Van Gelder 1991). Some years later “a rape in cyberspace” was depicted (Dibbell 1998) as well as the social networking website Bebo's privacy issues (Eriksen 2008), Facebook being used by students to mislead campus police (Hass 2006) or Friendster-at-that-time's new feature: "Who's Viewed Me" highlighting “Friendster's own insecurity” (Mintz 2005).

2.4.2.1.2 Trust from Patients' Perspective

In the specific context of online patients' communities (Laubie and Elie-Dit-Cosaque 2012), trust is also an essential dimension of cost.

Indeed, on the Internet, patients will be the very first population concerned about the respect of privacy (Goldberg et al. 1997):

“Yes, I think one must still be wary of Internet. You quickly forget that everything can be seen there that it seems to be a sphere of confidence.” (Breast cancer community patient)

Secondly, the accuracy of information (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000) will be of significant importance, especially when they interact online with groups of people concerning very personal issues, such as health (Coulson 2005; White and Dorman 2001):

“The misinformation fear still remains.” (Breast cancer community patient)

Lastly, any negative emotion that can be triggered by online comment could have dreadful impacts, so much so that some patients would prefer leaving these virtual spaces for a period of time or even indefinitely:

“Sometimes we read very difficult stories. It is not clear how to receive it when it's written by people who really write with deep sincerity in distress. When you are not prepared, it's hard to take.” (Breast cancer community patient)

Therefore:

Proposition 10: Negative Emotions are negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

Proposition 11: Privacy Protection is negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

Proposition 12: Inaccurate Medical Information is negatively related to online action regarding virtual patients' communities.

(Cost Value of Online Collective Action's Driving Forces)

2.4.3 Emerging Model of Online Collective Action

All the variables and propositions discussed in the above sections have to be taken into account and considered for further analysis in the emerging model of patient's online collective action (See Figure 2).

After the complete analysis of the interviews and the closing of the coding, some slight changes in the model occurred, that would then be further identified in figure 2.

Indeed, the underlying framework and our research design allowed us to let any new concept emerge during the data collection and analysis process and to identify regularities and demi-regularities pursuant to the design of critical realism research (Zachariadis, Scott, et Barrett 2010). Lawson defined demi-regularity as follows:

“A demi-regularity ... is precisely a partial event regularity which prima facie indicates occasional, but less than universal, actualization of a mechanism or tendency, over de definite region of space-time” (1998, p.149).

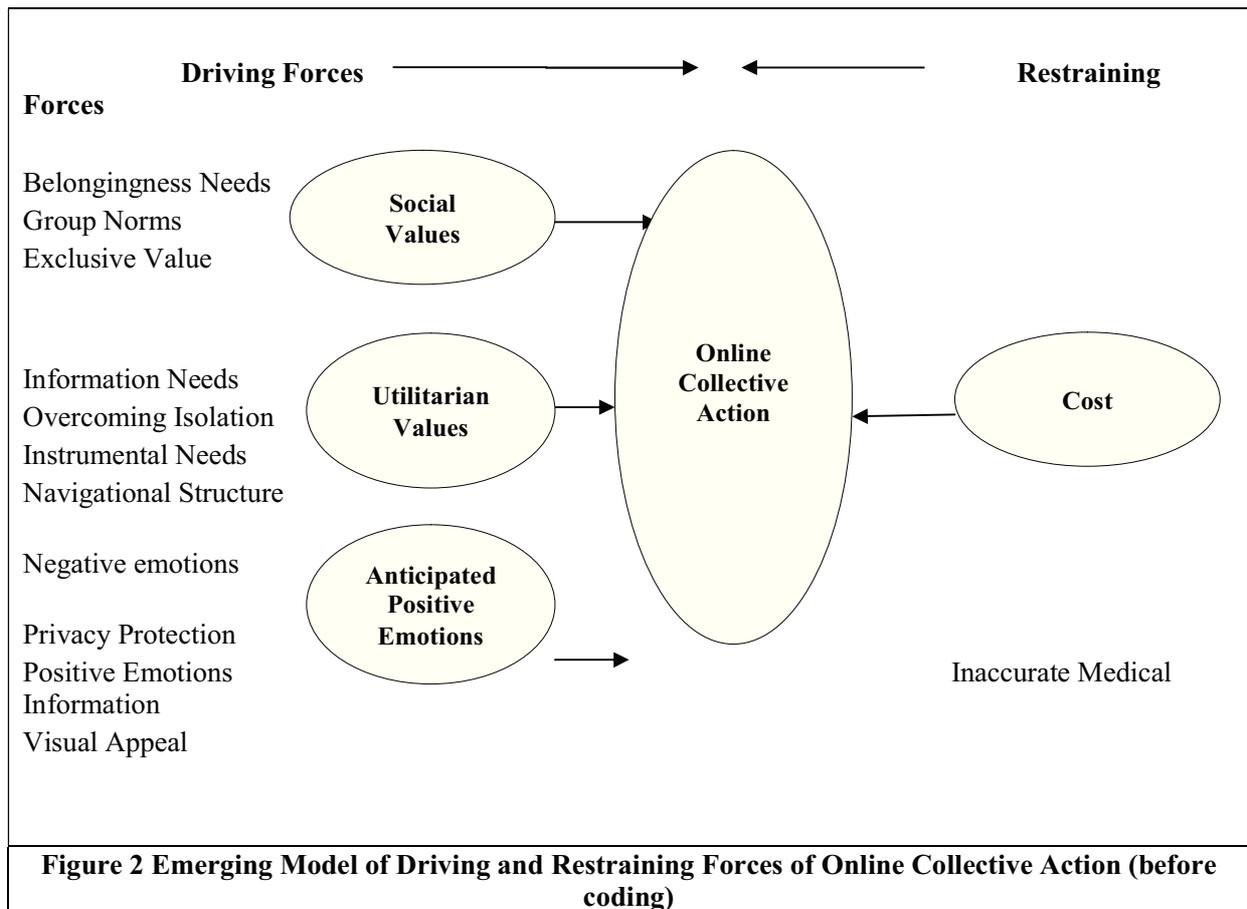
We will follow this thought, even if “Lawson's examples of demi-regularities include cases that are much more conducive to statistical modeling” (Pratschke 2003, p.25). All

the more so as Bhaskar (1979) argued that statistical research designs are irrelevant to social sciences as closure of systems can't possibly be achieved in society, but he moderated his adamant statement positing that open systems demi-regularities can encode social mechanisms' patterns.

On demi-regularities and Lawson research process guidance, Bache also states that:

“Lawson admits a role for demi-regularities at two stages in a realist research project. First, demi-regularities have a role in the context of discovery. Demi-regularities help direct the research process and contribute to the generation of hypotheses about causal mechanisms. Second, demi-regularities could have a role in the assessment of causal explanations” (2003, p.14).

Therefore, critical realism allows us, given the specification of our ontological domain, to explain the widest possible range or phenomena and thus enlightens black boxes and reveals emergent dimension (Pratschke 2003).



2.5 Model Analysis

In this section we argue our research's coding methodology that led to the final dictionary of theme building and the final drawing up of the model.

Through all that work, we kept in mind that researchers agree on what is needed to produce a good qualitative research design: "a skilled activity requiring critical and creative thinking" (Mason 2002, p.46); "a dynamic, intuitive and creative process of inductive reasoning, thinking and theorising" (Basit 2003, p.143).

2.5.1 Coding Protocol

We used the computer assisted qualitative data analysis software (CAQDAS) NVivo9 and then NVivo10 during the data analysis process throughout this qualitative research, leaving aside manual techniques as:

“proponents of CAQDAS argue that it serves to facilitate an accurate and transparent data analysis process whilst also providing a quick and simple way of counting who said what and when, which in turn, provides a reliable, general picture of the data” (Welsh 2002, p.5; Morison and Moir 1998; Richards and Richards 1994).

Our coding protocol was sketched in four dictionaries of themes knitted together by our emerging model of driving and restraining forces of online collective Action (See Figure 2), namely: i) open codes for driving forces of online collective action (See Table 11.1), ii) open codes for restraining forces of online collective action (See Table 11.2), iii) open codes for background factors of online collective action (See Table 12.1), iv) open codes for benefits of online collective action (See Table 12.2).

As a result, driving and restraining forces of online collective action were first classified according to the EVT (Eccles et al. 1983) underlying framework, but also inferred by Dholakia et al. (2004) determinants for participation in virtual communities. The remaining categories were coded to bring contextual information about background factors and benefits of online collective action as a willingness to add rigorousness to the research and to provide possible managerial contributions.

At the beginning of the interviews, we developed an initial list of themes drawn from the literature that allowed us to create the interview guide (See Table 6). During the course

of the interviews, new codes and concepts emerged and the list of themes grew accordingly. We explain the choice and in-depth process of his methodology in the paragraphs below.

Mason (2002, p.74), on qualitative research strategy's discussion, outlined three ways of deriving data from interviews: literal, interpretive or reflexive.

Literal reading of interviews derives data "in a literal manner", where attention is focused on literal dialogue and substance, its form and sequence. Interpretive reading of interviews allows the researcher to "read the interviews for what they mean", i.e. draw inference from the content itself.

Reflexive reading of interviews goes beyond the two preceding ways and allows the researcher to read something about his role and his contribution to the data creation and analysis process.

From our critical realism perspective, we chose the interpretive reading manner of our data, not to be confused with purely interpretive approaches where the researcher "not only sees people as primary data source, but seeks their perceptions...the 'inside view' rather than imposing an 'outsider view" (Mason 2002, p.56). Therefore, as critical realism imposes itself "between empiricism and positivism on the one hand and antinaturalism or interpretivism on the other, thus, reinventing a new and more sophisticated version or realist ontology" (Zachariadis et al. 2010, p.4), interpretive reading appeared to offer the right posture for this research. It allowed us to unearth hidden characteristics and to highlight the actual meaning of data. Therefore, we accepted to be involved in constructing a version of what we "think the data mean or

represent” and accepted to be engaged in a “reading through or beyond the data in some way, be they texts, artefacts, visual images or whatever” (Mason 2002, p.149).

Besides, our coding was multidimensional, allowing us to apply “multiple codes to the same passage of text” (Saldaña 2012, p.83).

Most of the interviewees were female, and all were adults. The anonymity of the respondent was guaranteed, and the interviews conducted were recorded and fully retranscribed.

The responses provided us with primary information about individual motives for online collective action. It also helped us to identify the most relevant expectancy values to be included in the research model. To do so, the NVivo9 software was used to proceed to the thematic coding and data mapping of the interview material. We coded the interviews after having set broad a priori categories, according to the draft research model and theoretical background.

As we were also looking for potentially new concepts by examining how well data fit with the conceptual categories identified in the literature, we also allowed for the possible emergence of other categories. In this ongoing coding we hence created new categories drawn from the interviews themselves. This process was repeated three times in order to ensure the nodes' relevance. Recurrent interactions with the research supervisor also ensured the accuracy of the coding process.

2.5.2 Model Illustration: Categorization Results

Before launching the interviews, the dictionary of a priori themes was comprised of:

- 7 categories for the driving forces of online collective action (See Table 11.1);

Table 11.1 Open Codes for Driving Forces of Online Collective Action		
Broad Nodes	Sub-Nodes	
Driving Forces for Online Collective Action	UV*	Information Needs
	SV**	Belongingness Needs (Social Identity)
	HV***	Positive Emotions
	SV**	Group Norms
	UV*	Instrumental Needs
	UV*	Navigational Structure
	HV***	Visual Appeal

*Utilitarian Value **Social Value ***Hedonic Value

- 2 categories for the restraining forces of online collective action (See Table 11.2);

Table 11.2 Open Codes for Restraining Forces of Online Collective Action		
Broad Nodes	Sub-Nodes	
Restraining Forces for Online Collective Action	Negative Emotions	
	Privacy Protection	

- 1 category for the background factors of online collective action (See Table 12.1);

Table 12.1 Open Codes for Background Factors of Online Collective Action		
Broad Nodes	Sub-Nodes	
Background Factors	Habits	

- No category for benefits of online collective action (See Table 12.2).

Table 12.2 Open Codes for Benefits of Online Collective Action		
Broad Nodes	Sub-Nodes	
Benefits of Online Collective Action		

As shown in the second version of the dictionaries of themes , 5 categories for the driving forces of online collective action (See Table 13.1) and 2 categories for the restraining forces of online collective action (See Table 13.2) emerged from the field through the interview interpretive approach (Mason 2002). Besides, we added 3 categories for the

benefits (See Table 14) and 4 categories for the background factors of online collective action (See Table 15).

Table 13.1 Open Codes for Driving Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number references
Driving Forces for Online Collective Action	UV*	Information Needs “I had a question”, “asked a question”, “I got the answer”, “girls explain”, “share information”, “looking for information in order to know”	101
	SV**	Belongingness Needs (Social Identity) “bound by the same diseases”, “share the same experience as us”, “I feel like this is my family”, “ this relational we share”, “ I needed to talk to women sharing the same disease”	94
	SV**	Exclusive Value “sharp people in the field, in the pathology and it is very reassuring”, “we know that this person is concerned”	61
	HV***	Positive Emotions “positive emotions”, “successful experience”, “an operation that succeeded”, “when you feel that parents are pleased”, “people's emotions”	61
	UV*	Overcoming Isolation “the disease is a social handicap”, “I am a bit lonely”, “come out of my isolation”,	44
	SV**	Group Norms “we share the same vision”, “same thoughts”, “people who share my problems, my opinions, my values”	31
	UV*	Instrumental Needs “when girls explain”, “I can find no answer” “they give you the information you need’,” “give tips”	30
	UV*	Navigational Structure “website is fluid”, “it meets my needs”, “user-friendly interface”	26
	HV***	Visual Appeal “the appearance of the website”, “website page is catchy”	12
	UV*	Preference over Medical Process “more easily than taking an appointment with a doctor”, “administrative medical system”	5
	HV***	Doctors Positive Perception “my doctor recommended me the website”, “my doctor indicated me the community”	4
	HV***	Boredom Avoidance “need to do something”, “I have more time”	3

*Utilitarian Value **Social Value ***Hedonic Value Codes Added from the Field

Table 13.2 Open Codes for Restraining Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of references
Restraining Forces for Online Collective Action	Negative Emotions	“negative diagnosis”, “punch in your stomach”, “your fear is coming back and spreading”, “negative emotions”, “anxiety”, “more afraid”, “announce their bad news”, “diagnosis of metastases”	46
	Privacy Protection	“it exposes you”, “confidential information”, “control”, “confidentiality of data”, “the Internet is risky”, “sense of security”	33
	Inaccurate Medical Information	“they aren’t necessarily enlightened patients”, “not been validated”, “invalidated information”, “can be dangerous”	30
	Complexity of Information	“difficult to understand”	2

Codes Added from the Field

Table 14. Open Codes for Background Factors of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Background Factors	Habits	“risk of addiction”, “I do not spend a day without connecting”, “automatic”, “automatic behavior”, “I don’t realize I got connected”, “every day”	29
	Females Disinhibition	“There are women really them talking about their womb”, “women express their emotions more easily”, “women may reveal more of themselves”	26
	Information Control	“This self-moderates”, “moderation is required”, “safeguards.”	18
	Online Clinical Advices Requirement	“there should scientific profiles”, “from medical sector to speak on the subject”, “to provide expertise”	12
	Open Virtual Space	“it to be open”, “open is normal”	7

Codes Added from the Field

Table 15. Open Codes for Benefits of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Benefits of Online Collective Action	Belongingness Speed and Strength	“Immediately”, “taken under the wing of the other patients”, “I immediately felt the supported”	18
	Enlightened Patients	“sometimes, patients are true experts”, “they are more experts than doctors”	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal”, “we feel better, more quickly”	12

Codes Added from the Field

Finally and after the entire coding process and through interview analysis, categories were restructured as follows (Bhaskar 1979):

- 5 categories were dropped for the driving forces of online collective action, leaving 7 categories (See Table 16.1);

Broad Nodes	Sub-Nodes	Key Terms and Phrases	References
Driving Forces for Online Collective Action	UV*	Information Needs “I had a question”, “asked a question”, “I got the answer”, “girls explain”, “share information”, “looking for information in order to know”	101
	SV**	Belongingness Needs (Social Identity) “bound by the same diseases”, “share the same experience as us”, “I feel like this is my family”, “this relational we share”	94
	SV**	Exclusive Value “sharp people in the field, in the pathology and it is very reassuring”, “we know that this person is concerned”	61
	HV***	Positive Emotions “positive emotions”, “successful experience”, “an operation that succeeded”, “when you feel that parents are pleased”, “people's emotions”	61
	UV*	Overcoming Isolation “the disease is a social handicap”, “I am a bit lonely”, “come out of my isolation”	44
	SV**	Group Norms “we share the same vision”, “same thoughts”, “people who share my problems, my opinions”	31
	UV*	Instrumental Needs “when girls explain”, “I can find no answer” “they give you the information you need”, “solve practical problem”, “give tips”	30
	UV*	Navigational Structure “website is fluid”, “it meets my needs”, “user-friendly interface”	26
	HV***	Visual Appeal “the appearance of the website”, “website page is catchy”	12
	UV*	Preference over Medical Process “more easily than taking an appointment with a doctor”, “administrative medical system”	5
HV***	Doctors Positive Perception “my doctor recommended me the website”, “my doctor indicated me the community”	4	
HV***	Boredom Avoidance “need to do something”, “I have more time”	3	

*Utilitarian Value **Social Value ***Hedonic Value

Codes Added from the Field Codes Dropped by the Researcher Interpretive approach

- 1 category was dropped for the restraining forces of online collective action, leaving 3 categories (See Table 16.2);

Table 16.2 Open Codes for Restraining Forces of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of references
Restraining Forces for Online Collective Action	Negative Emotions	“negative diagnosis”, “punch in your stomach”, “your fear is coming back and spreading”, “negative emotions”, “anxiety”, “more afraid”, “announce their bad news”, “diagnosis of metastases”	46
	Privacy Protection	“it exposes you”, “confidential information”, “control”, “confidentiality of data”, “the Internet is risky”, “sense of security”	33
	Inaccurate Medical Information	“they aren’t necessarily enlightened patients”, “not been validated”, “invalidated information”, “can be dangerous”	30
	Complexity of Information	“difficult to understand”	2

Codes Added from the Field

Codes Dropped by the Researcher Interpretive approach

- 1 category was dropped for the background factors of online collective action (See Table 17);

Table 17. Open Codes for Background Factors of Online Collective Action

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Background Factors	Habits	“risk of addiction”, “I do not spend a day without connecting”, “automatic”, “automatic behavior”, “I don’t realize I got connected”, “every day”	29
	Females Disinhibition	“There are women really them talking about their womb”, “women express their emotions more easily”, “women may reveal more of themselves”	26
	Information Control	“This self-moderates”, “moderation is required”, “safeguards.”	18
	Online Clinical Advices Requirement	“there should scientific profiles”, “from medical sector to speak on the subject”, “to provide expertise”	12
	Open Virtual Space	“it to be open”, “open is normal”	7

Codes Added from the Field

Codes Dropped by the Researcher Interpretive approach

- The 3 categories for benefits of online collective action were left unchanged (See Table 18).

Broad Nodes	Sub-Nodes	Key Terms and Phrases	Number of References
Benefits of Online Collective Action	Belongingness	“Immediately”, ”taken under the wing of the other patients”, “I immediately felt the supported”	18
	Speed and Strength		
	Enlightened Patients	“sometimes, patients are true experts”, “they are more experts than doctors”	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal”, “we feel better, more quickly”	12

Codes Added from the Field

Codes Dropped by the Researcher Interpretive approach

The following sections explain, for each category, the reasons for the changes introduced.

2.5.3 Dropped Themes

This section refers to the codes and themes that were dropped. The reason why these concepts were left aside is twofold. Firstly, it was not possible to reconcile these codes with other existing codes. Secondly, the occurrences of associated codes were too few to be taken into account.

2.5.3.1 Dropped Variables for Driving Forces for Online Collective Action

2.5.3.1.1 Role of IT Artifacts on Online Collective Action (Navigational Structure and Visual Appeal)

During the interviews with patients’ testimonies were more focused on highly-emotionally-loaded feedback than comments on sites’ usability. Indeed, patients’ empathy, other-orientation volition or bounding values were at the center of concerns.

Without these strong expressions of feelings on forums, design or navigational structure won't appeal much to them, as feedback on the positive or neutral role of these two variables were somewhat mitigated (see Table 19). So, although navigation shouldn't be an obstacle to browse fluently on the site, patients reported they paid more attention to what makes the sites warm and welcoming.

Table 19. Categorization of IT Artifacts and Role on Online Collective Action			
Broad Nodes	Role on Online Collective Action	Illustration	Number of References
Navigational Structure	Positive Role	“Yes, the website is fluid and it meets my needs.”*	26
	Neutral Role	“It is not that the site is particularly well thought out, but just I easily get what I'm searching for. Besides I have my habits. Through conversations I easily find what I need.”*	23
Visual Appeal	Positive Role	“The appearance of the website brings to it seriousness and the trust that I will give it. Yes it is important.”*	12
	Neutral Role	“The appearance of the website has little importance compared to the heat or human comfort that I can find through conversations.”*	27

* Quotes from interviews with breast cancer community patients

Indeed, during the course of the interviews, we were particularly interested in comments of patients with a long experience of attending patients' virtual communities – who happened to frequent them for more than 5 years – highlighting the minor relevance of sites' visual appeal:

“It is of little importance to me. You know the struggle of the disease will not be relieved by beautiful colors, there is something else in these spaces.” (Breast cancer community patient)

The design is of little importance in the end we are left with the warmth, the emotion conveyed.” (Breast cancer community patient)

However, navigational structure attracted more interest by the same category of patients:

“Yes, in the end the site is simple, easy to navigate and it is important. We should not be embarrassed by the navigation, this is a prerequisite. Some are already anxious about their own request, and what’s more by the technology usage.”

(Breast cancer community patient)

Given the low rate of occurrences reached in the interviews, we won’t keep the navigational structure and visual appeal concepts as driving forces of online collective action, considering them secondary. However, and following this qualitative approach, we recommend and will conduct in a future research study the consolidation of this study by testing these observations and therefore the two aforementioned dimensions in a quantitative analysis.

2.5.3.1.2 Preference over Medical Process, Doctors Positive Perception and Boredom Avoidance

Preference over Medical Process could be illustrated by:

“This could easily become an automatic behavior compared to making an appointment with a doctor who is not necessarily available before 2-3 months. When you see him, well, you took one hour to go to the hospital. In consultation, you’ve waited 1 more hour and on the top of all that... he does not necessarily have the answer. So there, it is true that the immediate side, effective, with persons you trust, it can be tempting.” (Rare Disease Community patient’s family member)

Doctors Positive Perception could be illustrated by:

“It was during an interview with the surgeon, he recommended the site, thinking it might bring me something.” (Breast cancer community patient)

Boredom Avoidance could be illustrated by:

“At the same time, you're sick and you do not go out, you must do something to avoid boredom.” (Breast cancer community patient)

However, instigated by patients' testimonies, none of these factors appeared to be significant enough to keep them as sub-nodes of driving forces for online collective action. Some patients mentioned these aspects and that's why we highlighted them as emergent categories from the field, but out of the 54 codings, few interviews were neither relating nor confirming these statements. Therefore we decided to drop these values.

2.5.3.2 Dropped Variables for Restraining Forces for Online Collective Action

2.5.3.2.1 Complexity of Information

Complexity of Information could be illustrated by:

“But I thought it was complex, patients sometimes become too expert, one can't understand them anymore.” (Breast cancer community patient)

Here again, although it was an interesting testimony, the occurrences were far too few, only rising to 2, to keep this value in our model. We, thus, left this factor aside.

2.5.3.3 Dropped Variables for Background Factors of Online Collective Action

2.5.3.3.1 Open Virtual Space

Out of the two communities studied, stances against the opening or the closing of platforms were opposed.

On one hand, it is certainly understandable that parents of autistic children are reluctant to let strangers read the comments posted every day about the evolution of their children's disease. That is the reason why the Facebook group remained closed to public access

On the other hand, it may seem surprising that women facing the hardship of breast cancer are willing to open their platform to strangers – whether they express themselves anonymously or not. Furthermore, when they are asked about such behavior, this question resonates as something that never came to their minds:

"I think it's normal. It is a question I have never thought of. No, for me it is something entirely normal." (Breast cancer community patient)

Due to the few mentions about this factor, the lack and sometimes absence of reflection about it when questioned, and the ethical matters this issue can raise, we decided to drop this category from the results of this research.

2.5.4 Resulting Model Variables

The below tables 20.1, 20.2 and 21 detail the different facets of the constructs that were identified and kept according to both the whole aforementioned coding process and the inputs of literature.

Table 20.1 Categorization and Leading Concepts - Driving Forces

Broad Nodes	Sub-Nodes	Definition
Driving Forces for Online Collective Action	UV*	Information Needs "The Internet was broken down into various communication and information functions: information retrieval, information giving and conversation." Therefore, information needs to comprise the following items: "to get information, to learn how to do things, to provide other with information, and to contribute to a pool of information" (Flanagin and Metzger 2001, p.162).
	SV**	Belongingness Needs (Social Identity) "The belongingness hypothesis is that human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships." (Baumeister and Leary 1995, p.497).
	SV**	Exclusive Value "Interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s), and relatedness without frequent contact will also be unsatisfactory" (Baumeister and Leary 1995, p.497).
	HV***	Positive Emotions "Positive (anticipated) emotions refer to success in achieving a goal" (Perugini and Bagozzi 2001, p.83). In online communities' contexts, it refers to "fun and relaxation through playing or otherwise interacting with others" (Dholakia et al. 2004, p.244).
	UV*	Overcoming Isolation "With asynchronous communication, participants in online groups have access 24 h a day, 7 days a week, at times most convenient to them" (White and Dorman 2001, p.694).The concept of overcoming isolation refers to the possibility for patients to get an in-demand response for interpersonal relationships.
	SV**	Group Norms Group norms is the concept of people sharing norms concerning matters of common interest and participate in a system of interlocking roles, influencing each other, and pursuing common goals. (Tajfel 1982)
	UV*	Instrumental Needs "When social interactions in online communities help participants to accomplish specific tasks, such as solving problems, validating a decision already reached or buying a product" (Grabner-Kräuter 2010, p.509).

*Utilitarian Value **Social Value ***Anticipated Positive Emotions

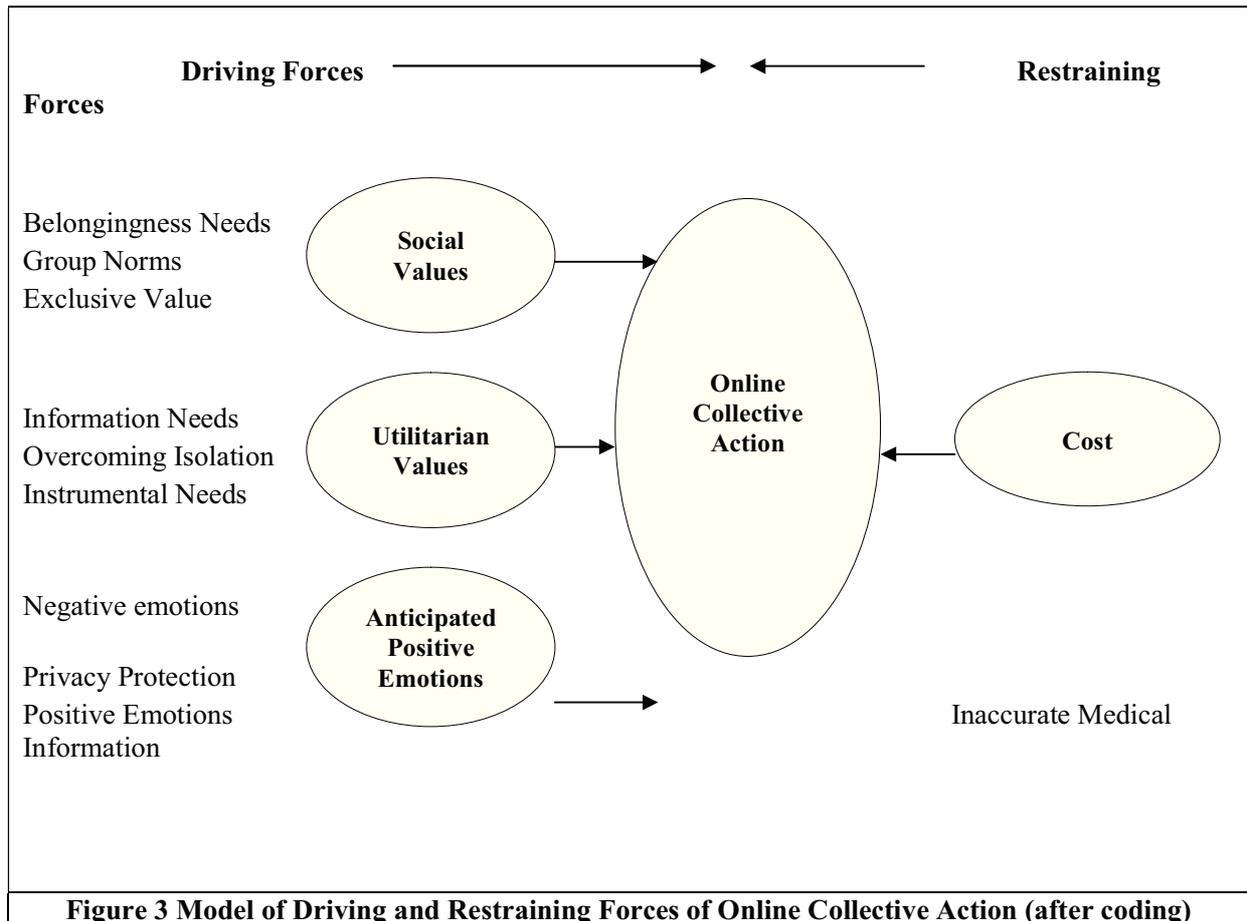
Table 20.2 Categorization and Leading Concepts - Restraining Forces		
Broad Nodes	Sub-Nodes	Definition
Restraining Forces for Online Collective Action	Negative Emotions	“Negative (anticipated) emotions refer to failures in achieving a goal” (Perugini and Bagozzi 2001, p.83). In online communities’ contextual background, it can refer to stress and anxiety through interacting with other patients.
	Privacy Protection	“On the Internet, individuals may trust others to keep private information confidential” (Green 2007, p.44). For health purposes, privacy protection may be of relevance due to patients’ conditions (Goldberg et al. 1997) as well as the privacy policies of health Web sites (Graber et al. 2002).
	Inaccurate Medical Information	“On the Internet, individuals may trust others to provide honest and accurate information” (Green 2007, p.44). In the context of health purposes, there is a risk of dangerous and inaccurate medical information appearing online (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000)

Table 21. Categorization and Secondary Concepts		
Broad Nodes	Sub-Nodes	Definition
Benefits of Online Collective Action	Belongingness	Patients, upon entering this virtual world, will feel immediately surrounded and supported
	Speed and Strength	
	Enlightened Patients	Virtual communities offer patients valuable knowledge, so much so that they become experts
	Role in Healing	Patients claim a positive role on their healing
Background Factors	Habits	Virtual communities are addictive and affect a population who is imprisoned in idleness and pain.
	Females Disinhibition	More than men, females have the tendency to confide in virtual communities
	Information Control	Patients wish the information gathered online to be moderated
	Online Clinical Help Requirement	Patients wish the information gathered online to be moderated by healthcare professionals

Based on the insights brought by the critical realism approach, the draft and then emerging research models have been enriched and contextualized as exhibited in the figure 3 below.

Furthermore, the content validity of the model-variables has been improved, as we have identified multiple sub-facets of expectancy values with 4 dimensions for social value (group norms, belongingness needs, exclusive value, and giving-help), 3 dimensions for utilitarian value (information needs, instrumental needs, overcoming isolation), and 1

dimension for anticipated positive emotions (positive emotions). We have also identified 3 dimensions for cost (inaccuracy of medical information, privacy protection, and negative emotions) and were able to contextualize online collective action.



2.6 Model Results

Together with the field forces of online collective action, the interviews led to important insights, such as the benefits of online collective action and the categorizations of background factors being as expected and outlined in tables 17 and 18.

Data outlined evidence that Perugini and Bagozzi's model needs adaptation when it comes to patients' communities, as well as Bagozzi and Dholakia's succeeding studies

(see Figure 3). The results revealed emerging concepts that are frequently cited by interviewees, such as exclusive value, i.e. not mixing purposes or common interests of the communities, and thus offering a specific disease forum in the case of patients. Some categories need to be integrated into a dedicated model for patients' engagement in virtual communities to complete existing ones, such as the matter of privacy, or being confronted with inaccurate medical information or negative emotions and, as a result, the cost of engaging in online collective action.

The following section will present the answers to our research question.

2.6.1 Research Question: Determinants of Online Collective Action

2.6.1.1 Driving forces for Online Collective Action

2.6.1.1.1 Utilitarian Value: Information Needs, Overcoming Isolation, Instrumental Needs

Information needs was the most salient driving force of patients engagement in virtual communities. For both communities investigated, the quality and relevance of the advice, as well as its easiness to understand, satisfy this need to be informed (see Table 16.1).

Indeed, interviews confirmed the importance of informational needs as a leading factor for patients to engage in virtual communities. For both communities, quality and relevance of advice or flows of information, as well as its ease of understanding, satisfy this need to be informed:

“Yes. In fact, every time I had a question, every time I asked a question, I got the answer.” (Breast cancer community patient)

However, depending of which community was questioned, the incentives for the exchanges were not the same.

For breast cancer patients, motives reside in the information value, but also its immediate access made feasible through the IT tools:

“Between Doctor’s appointments, we have time to get anxious. On the network, we can speak freely whenever we need it.” (Breast cancer community patient)

For the relatives of patients with rare diseases, healthcare professionals may understandably lack answers for the families, due to the lack of scientific and medical knowledge itself. Therefore, virtual communities can represent a unique and important source of information for families:

“When I'm looking for information myself, I reach the Rett syndrome’s group. In here, technical information is really at a top level ... when I have a question, I ask my question and I still have girls or guys who will answer me and much better than a practitioner. There is no doubt. What's more, they will respond on all levels to questions practitioners would be unable to answer to.” (Rare Disease Community patient family member)

Second, virtual communities also offer patients valuable psychological support available on demand, which contributes to overcoming their isolation, as well as the restoration of a social life, which has often been put on hold because of the disease:

“Very few friends stay nearby when you are sick. And you do not want to bother them with your problems ... So, yes, it's much easier to speak with someone who will understand and hear what you say because she experiences the same thing.”

(Breast cancer community patient)

Finally, instrumental needs reflect the fact that, together, with the help of other patients' testimonies, a patient can get support for solving some issues s/he faces and make better decisions. Table 22 below illustrates the utilitarian values:

“When girls explain what happened to them even in the reconstruction process, they really know what they're talking about, almost as well as doctors and other medical professionals.” (Breast cancer community's patient)

Table 22 Categorization and Leading Concepts – Utilitarian Value

Broad Nodes	Sub-Nodes	Illustration	Number of References
Utilitarian Value	Information Needs	“I was looking like so many other people who seek information to know whether what we had was serious or not serious, to know what was my 5-year survival, whether I was going to die within 5 years or not.”*	101
	Overcoming Isolation	“The disease is a social handicap, I am a bit lonely...I really think social networks are perfect. I express there this "me-digital" which is different from "physical self". So you can keep the image you want on the net, either by being someone different or by being yourself.”*	44
	Instrumental Needs	“And then we could ask them a question, no problem. If I have a problem where I can find no answer, I go to them and they often give me the answer.”**	30

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

To conclude, utilitarian value is an important driver for online collective action with information needs taking the lead over any other social or anticipated positive emotions. However, social value appeared to bring high incentives for collaborative action according to patients.

2.6.1.1.2 Social Value: Belongingness Needs, Group Norms and Exclusive Value

Social values are also salient driving forces for online collective action among the research participants (see Table 16.1). This can be explained by the social environment surrounding collective action, even when performed online. Besides, this contributes to the very differentiation of virtual communities compared to social networks, proven not to be that socializing (Ellison and Boyd 2007; Grabner-Kräuter 2009).

Belongingness needs conveys a very important motive for online collective action with the second highest number of references. This concept includes the search for similar

experience and feedback among the community members due to the sharing of the same pathology's concerns:

“We feel that people support each other. People are willing to help each other, even if we don't know each other well. All of this because we are bound by the same diseases.” (Rare Disease Community patient' family member)

It also discloses important benefits of these communities, which we will describe below, such as the rapid sense of belonging and its strength.

“Because they are human beings and intelligent ones and share the same experience as us. And I feel like this is my family. I feel like these girls are in my living room, and we are talking. And it is really because of this relational we share.” (Breast cancer community patient)

Besides, it reveals patients' need to gather online and to feel that they belong to the group of peers, while they often experience exclusion, sometimes within their own families, due to the effects of the disease and its physiological consequences. , This, only other patients can empathize with.

“Well, during my disease, although I was well surrounded by my family, I needed something else. I needed to talk to people, women sharing the same disease.”
(Breast cancer community patient)

Besides, strong ties between online patients highlight the patients' needs to be connected to their networks, in order to share experiences about the course of their illness - which refers to the concept of giving-help, an actual component of online collective action, but

not necessary a driving force of patients' engagement. We label this phenomenon exclusive value:

“So why did I make a blog on that issue after so long time? This is what I am often asked. Because, ultimately, it shouldn't be forgotten. Furthermore, it's because we never forget and because I really wanted to tell myself that I can testify.” (Breast cancer community patient)

Access to multiple feedback and support groups provide patients with shared anecdotes about their disease. Moreover, interviews showed that, while living difficult times, they do not have the mental availability to listen to stories that are too different from theirs. Indeed, they fear getting lower quality information and they don't want to share their disorders and day-to-day stories with 'strangers', preferring to exclude patients with other diseases from their platform:

“When it's opened to everyone, as a result, it loses in terms of information. While in our site, we know that we will inevitably connect with sharp people sharing our concerns... and it is very reassuring.” (Breast cancer community patient)

Finally, group norms, the concept of people sharing norms concerning matters of common interest (Tajfel 1982), binds patients and fosters their participation in the online action as well as their long term dedication to the group:

“We realize that we share the same vision with these other women, the same thoughts, perhaps because we share the same problems. This is why we got there; it's mostly why we stayed there.” (Breast cancer community patient)

All these concepts are recalled in table 23 and demonstrate the importance of social values and their identified sub-facets as motives for online action.

Table 23 Categorization and Leading Concepts – Social Value			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Social Value	Belongingness Needs (Social Identity)	“Because it is reassuring. Because we can meet with other moms going through the same thing. Because you can ask questions that you would not ask to your companion or to your doctor or even to your family, or even to your best friend.”**	94
	Exclusive Value	“When it is more general, you can really get on very distant people concerning the disease. It is a little open to everyone. As a result, the information loses quality. While there, we know that we will inevitably fall on sharp people in the field, in the pathology, and it is very reassuring. So, we spend less time and we know that someone will answer us. We know that this person is concerned, is mostly concerned herself.”**	61
	Group Norms	“I needed people who share my problems, my opinions, my values.”**	31

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

2.6.1.1.3 Anticipated Positive Emotions: Positive Emotions

Patients also join these platforms to find emotional assistance to help them overcome the hardship of everyday life. Furthermore, some believe that these emotions help them to live better during their illness, as others think that it may even help them to heal:

“Emotions are present, regularly. In fact, when I'm in low spirits, I go on the network and it goes away.” (Breast cancer community patient)

While less salient in the interviews, anticipated positive emotions is, nevertheless, an essential value that needs to be taken into account when virtual patients' communities launch and further studied in the academic area (See Table 24).

Table 24 Categorization and Leading Concepts – Anticipated Positive Emotions			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Anticipated Positive Emotions	Positive Emotions	“Positive emotions! When you see a successful experience, an operation that succeeded, where everything went well, when you feel that parents are pleased that the child did well. Either they post videos, photos or short phrases. Immediately you can feel it. It is palpable. It breathes. This communicates very quickly ... It's fabulous! This is extraordinary. It is magical to live, thousands of kilometers apart, people's emotions and power, at a given instant to be able to feel what they feel and how they share these emotions. I find it very powerful, really, very powerful.”*	61

* Quotes from interviews with breast cancer community patients

2.6.1.2 Restraining forces for Online Collective Action

The auspicious picture of patients' virtual communities may end with the many negative aspects unearthed by further testimonies highlighting restraining forces for online collective action.

2.6.1.2.1 Cost Value: Negative Emotions, Inaccurate Medical Information, Privacy Protection

Sometimes, any negative emotion that can be triggered by online comment could have dreadful impacts, so much so that some patients could prefer leaving these virtual spaces for a period of time or even indefinitely:

“When a person does his check-up and returns with a negative diagnosis, then you get a punch in your stomach because your fear is coming back and spreading...”

(Breast cancer community patient)

In online community interactions, many researchers associated the cost value with trust, referring to privacy concerns (Metzger, 2004; Dwyer et al., 2007; Dong-Hee, 2010; Fogel and Nehmad, 2009). In the specific context of online patients' communities, trust is also an essential dimension of cost. Indeed, on the Internet, patients will be the very first population concerned about the respect of privacy (Goldberg et al., 1997). However, even if for some patients the struggle to preserve confidentiality is a minor battle compared to the one they face with their illness, privacy protection remains an important issue when interacting online on the daily experiences of their illness:

"In fact, at one point, the shock of news exposes you. Because what you live is very scary, so scary that you're not afraid any longer to give up confidential information." (Breast cancer community patient)

“Control is important, as is the confidentiality of data. It was a prerequisite for me, if I was asked my name, I would be gone, because the Internet is risky”

(Breast cancer community patient)

Finally, the accuracy of information (Williams et al., 2003; Diaz et al., 2002; Dickerson et al., 2000) will be of significant importance, especially when they interact online with groups of people concerning very personal issues, such as health (Coulson, 2005; White & Dorman, 2001):

“The big problem on the forum is that only patients participate with their own feelings, with their own knowledge... And they aren’t necessarily enlightened patients...” (Breast cancer community patient)

Occurrences of the dimension of cost value prove its high relevancy and a vast room for improvement that would benefit patients’ well-being during their online experience (see Table 25).

Table 25 Categorization and Leading Concepts – Cost Value			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Cost Value	Negative Emotions	“Ah, negative emotions... It’s about anxiety when you compare yourself to people who are in a worse position than you, who are even more afraid than you and who announce their bad news. I mean the person who will have a check-up and comes with a diagnosis of metastases. You take it in the chin because it is your fear that comes back too ... So yes, I’ve already had those damn negative emotions, yes.”*	46
	Privacy Protection	"I think the problem with these social networks is... this sense of security among quotes, but that is not real. And so, people drop out, confide very easily without really measuring the risks. Yes, they reveal a little too much I'd say. Especially, that information can be kept, operated, tested, sorted and segmented. So..."**	33
	Inaccurate Medical Information	“And so it is extremely dangerous, I see when girls exchange information. They found, for example, a new reconstruction technique etc., And when I got interested in information I realized that the reconstruction technique has not been validated, or works in the U.S. but not in France ... but the other girls will say that there is a super reconstruction technique and that it is imperative for them to find the doctor for that, etc.. You see? So I think this kind of invalidated information can be dangerous, yes of course...”**	30

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

2.6.2 Surrounding constructs of Online Collective Action

Besides the leading concepts questioned and discussed during the course of the interviews, the close listening and open conversations offered us insights about constructs that are worth being disclosed and commented for managerial purposes and contributions.

2.6.2.1 Benefits of Online Collective Action

While discussing the determinants of online collective action, patients pointed out what formed the DNA of these online communities they gather on and what were their founding characteristics and assets.

Recurrent values emerged from testimonies, such as the strong feeling of belonging, as well as its speed, the patients' expertise about their disease and related issues, the positive impact of online exchanges on patients' well-being.

2.6.2.1.1 Belongingness Speed and Strength

The peculiarity of these communities' approach, with regard to patients, is probably the speed and strength of bonds it creates. The users, upon entering this virtual world, feel immediately surrounded and supported by peers:

“Like I say to my friends, overnight, I got 10 friends, and then one month later, I got 50 friends. Now we are 9000 patients connected...and I immediately found a community...” (Breast cancer community patient)

“I realized that I had my first breast cancer in 1992 and now, in 2001, I'm still connected to this site... You see how strong it is...” (Breast cancer community patient)

2.6.2.1.2 Enlightened Patients

Virtual communities offer patients the positive response to their need for information, so much so that with this wealth of knowledge they may become experts. Besides, one of the striking features of these enlightened patients is that they often know how to use understandable language for the newcomers:

“Sometimes, patients are real experts and I can hardly follow the discussion.”
(Doctor)

“Yes, because I find tips and ideas from other parents who have children with the same syndrome, especially when it is very rare... and parents are more expert than doctors.” (Rare Disease Community patient family member)

2.6.2.1.3 Role in Healing

What is the healing power of this general phenomenon? When patients are asked whether online exchanges have increased their chances of recovery, their responses are often enthusiastic and affirmative:

“These forums can help you heal. I'm sure of that ... And I'm someone quite realistic ... I am sure that when you have positive thoughts and laughter despite all the things that happen to you, it helps you.” (Breast cancer community patient)

These benefits (See Table 26) have to be differentiated from drivers for online collective action as they are caused by patient collaboration. Besides, although well documented and discussed in the above literature review (Fredrickson 2004; Fredrickson 2000), one should remain - not to argue the obvious - cautious about the impact of online collaboration on healing.

Table 26 Categorization and Secondary Concepts - Benefits of Online Collective Action			
Broad Nodes	Sub-Nodes	Illustration	Number of References
Benefits of Online Collective Action	Belongingness Speed and Strength	“Immediately, when you approach it, you are taken under the wing of the other patients. And me, I was especially pleased ... I'm not very good, I'm not someone who goes on Facebook and all that. So I like things easy, I'm a little disinterested in the technology...So my first reaction has been to say: oops, it works and it works very quickly... And the fact that they replied very quickly, it was also very nice and I immediately felt the support.”*	18
	Enlightened Patients	“Yes because like us, she has a disability, she has a rare disease. Practitioners frequently tell me that, sincerely, they do not know enough about this disease. And they also say that they do not have all the knowledge parents show themselves...”**	13
	Role in Healing	“I am convinced that sharing positive emotions helps heal ... Here, there is not a direct exchange ...I think it really helps with the healing.”*	12

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

2.6.2.2 Background Factors

Following the benefits found in patients' collaborative work, they expressed background factors that should be taken into account while using virtual spaces. Among them, addiction or automatic behavior driving to patients' online connection - see the aforementioned concept of habits – was the most cited of online collective action

surrounding constructs. Female ability to freely speak about almost any health-related matter also appeared spontaneously in testimonies (See Table 26).

2.6.2.2.1 Habits

Indeed, virtual communities have a highly addictive effect and affect a population that is imprisoned in idleness and pain. Therefore, they are a little more at risk of breaking contact with the real world from which they are already estranged:

"In difficult times, I think I was in auto mode connection. The first thing I did in the morning, on waking, was to log on to the forum, and after I took my breakfast and I accompanied my children to school ... In the evening, I spent another 2 or 3 hours ... Yes, it was an automatic reflex." (Breast cancer community patient)

2.6.2.2.2 Females Disinhibition

Due to our field of inquiry, we were mainly faced with females' on line behavior and from a consensual perspective, they are much more likely to reveal their feelings and tell their own stories when online:

"Women have much less difficulty in expressing their emotions, especially when online." (Health 2.0 expert)

2.6.2.2.3 Information Control

When considering background factors, patients called for the development of a better environment for these patients' online communities. As a result, the needs to be

addressed would be: i) information to be better controlled, ii) online clinical advice to be provided.

Even if self-moderation does occur thanks to the wisdom of crowds, control of the released information about patients' everyday life is often considered inadequate.

Patients often fear the presence of inaccurate information, which frequently caused anxiety, particularly among the silent crowd of the community.

"After, it's always the same problem, depending on who manages the sites. We really need to be very strict and sites have to be moderated." (Breast cancer community patient)

2.6.2.2.4 Online Clinical Advices Requirement

In the wake of the fear of being misinformed by wrong statements, patients are demanding a professional presence that would certify the information's veracity on these platforms.

"I was also looking for people who had authority, people who seemed to be certified, licensed, relevant and legitimate with all the scientific and medical background." (Breast cancer community patient)

All these background factors, open virtual space excluded as explained above, are summarized in table 27.

Table 27 Categorization and Secondary Concepts – Background Factors

Broad Nodes	Sub-Nodes	Illustration	Number of References
Background Factors	Habits	“There is a risk of addiction, yes indeed. There is a risk of addiction to the extent that it is true that I do not spend a day without connecting there.”*	29
	Females Disinhibition	“There are women really there talking about their womb, their breasts. There are plenty of breasts, there are many wombs. And also printed somewhere was that she found her femininity, you know? These are beautiful exchanges. This is because they are women, mainly.”**	26
	Information Control	“This self-moderates, although moderation is required on these sites, it is unthinkable to leave women without safeguards.”**	18
	Online Clinical Advice Requirement	“This is where there should be scientific profiles, from the medical sector to speak on the subject, to provide expertise, to take time to answer questions online.”**	12

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

2.6.3 Summary of Results

Among the participants, information needs and belongingness needs remain the main reasons to reach and collaborate in virtual communities. However, testimonies also showed the emergence of new factors, such as the need to give-help, the desire for positive emotions, and the wish for platform exclusivity.

Conversely, fear of negative emotions, privacy protection and inaccurate medical information are major hindrances for patients who would otherwise be willing to join virtual spaces.

Characteristics related to social behavior have also emerged from interviews, including psychosocial impacts resulting from membership of these communities. Benefits from this commitment are noticeable, namely enhancement of decision-making processes and choices and the role in healing.

The needs and the perceived breaches of these platforms have also been underlined, highlighting the need for moderation of irrelevant comments coupled with a professional medical presence.

Many outcomes are drawn by the interviews and among the most important is the one that allows us to design a model of online collective action (See Figure 3). But we also stressed managerial contributions that can practically inform industry stakeholders about the reality from the inside.

2.7 Discussion and Conclusion

This study's main objective was to examine the determinants of online collective action on patients' communities, given the specificities of a patients' community typology that was chosen for this purpose.

Based on the Field Theory of Lewin (1947), the Expectancy-Value Theory (EVT) (Eccles et al. 1983), the model of goal directed behavior (MGB) (Perugini and Bagozzi 2001) and Dholakia et al. (2004) online resulting study; together with insights and knowledge accumulated from the field (Bhaskar 2010); we conceptualized a model to predict online collective action on patients' virtual communities (See Figure 3).

When engaging in a patients 2.0-related research topic, we knew that the study would require specific attention on the diseases to be addressed. The preliminary interviews

with experts suggested which way we should focus. The feedback was consensual and chronic or rare diseases were indicated to be suitable for such investigation.

Although we decided to focus on French participants, research performed in the US confirmed this choice, with Internet users living with chronic disease being more likely than other Internet users to access health information online:

“Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine” (Pew Internet Research 2010).

Understandably, the condition of rare disease patient also amplifies this need to spread their network far and wide and online connection will provide some answers:

“In rare disease communities, each person is an expert in observing the effects of a disease or a treatment on their own or a loved one's body or mind. In this way, rare-disease patients and caregivers who gather together online are an example of a “smart” group...They are diverse and decentralized, yet able to pool knowledge and summarize their observations” (Pew Internet Research 2010).

Although this research was conducted in both communities, one should recall that, out of the 37 interviews, 8 were performed on a rare disease community patient family member, 21 on a breast cancer community patient.

Overall, the results show that information needs and belongingness needs are important reasons for collaborating in virtual communities. However, testimonies have also shown the emergence of new factors, such as the desire for positive emotions, and the willingness for platform exclusivity. Conversely, the fear of negative emotions, privacy protection and inaccurate medical information are major hindrances for patients who would otherwise be willing to join virtual spaces. The needs and the perceived breaches of these platforms have also been underlined, highlighting the need for moderation of irrelevant comments coupled with a professional medical presence.

2.7.1 Coming back to the research question

2.7.1.1 Discussion on Research Question

2.7.1.1.1 Driving Forces of Patients' Online Activity and Emergent Categories

Once the research field was defined, our concern was to determine the individual and social determinants of patients joining web-based patients' virtual communities, i.e. what would be the driving or restraining forces for patients to collaborate online.

As the literature guided us through what was learned from studies performed on online communities and what were patients' online behaviors, we were however questioning the emergence of new categories to deliver ad hoc knowledge.

The driving forces for online collective action were distinguished into three dimensions: utilitarian value, social value and anticipated positive emotions in accordance with EVT. Among the ones that were the most salient and frequently quoted, the need to give and to get information (information needs) and the need to belong to the community of peers (belongingness needs) were the main driving forces among the participants.

Another category, related to the social dimension of the motivation to participate in the community, actually emerged from the analysis of the interview transcripts namely exclusive value. As a matter of fact, it was quite unexpected that, on the one hand, patients would be inclined to give online support to others and, on the other hand, that “the others” would be carefully restricted to strictly the same categories of patients for providing this help.

Finally and among the driving forces that were expected to be found based on the literature, the positive emotions' category was relatively less salient, contrary to our expectations, as were group norms. These somewhat mitigated results do not remove the relevant aspect of these latter variables. Though, further analyses may provide further on these concepts.

2.7.1.1.2 Restraining Forces of Patients' Online Activity and Emergent Categories

The interviews have shown that, cost value of online collective action is related with the concept of trust.

Trust relates to a specific field of inquiry and would involve different facets depending on the actors and their environment.

The insights found on trust support the emphasis of the importance of privacy concerns and fear of inaccurate medical information found in the literature.

It is therefore important to account for the role of trust in patients' communities in particular (Dwyer et al., 2007; Fogel and Nehmad, 2009; Luhmann, 1979). Indeed, trust

is relevant in particular regarding the investment in personal relationships in a virtual context, including a reciprocal approach (Grabner-Kräuter, 2010).

Therefore, this variable needs to be implemented in the patient engagement model with respect to the dimensions revealed by the interviews, namely, inaccurate medical information and privacy issues.

Another major restraining force of patients' online collective action is negative emotions, triggered by what can be stated on collaborative platforms. Those emotions constitute probably one of the main obstacles for joining these virtual spaces. This fear was very salient among the study participants and often elaborated with concrete examples of what can generate sorrow or anxiety among other negative emotions.

Therefore, we cannot really argue the emergence of new categories when aggregating literature's constructs. But considering that these literature insights came from different fields and that our underlying frameworks (Field Theory, EVT) were non health-related, many aspects appeared to bring new values, inspired from the field and in compliance with the general and stringent scope of models.

As a result, models and conclusions taken singly failed to draw the complete picture we depicted in the above sections, but this study remedies such breach.

2.7.2 Contribution

This study makes three major contributions to research and practice.

First, this research emphasizes the main expectancy-value factors, which determine online collective action on patients' virtual communities. It further enriches the

literature through the use of Lewin's force field theory and EVT, applied to online environments.

A broad literature review and interview evidence help examine new concepts that add to social value dimensions – exclusive value –, to utilitarian value dimensions – overcoming isolation – and to cost value dimensions – inaccurate medical information. In this regard, from theories taken from the social psychology arena, as well as considering insights provided by the field, we developed a model of online collective action for patients who meet on virtual communities (See Figure 3).

From guidance provided by interviews' feedback, we chose to focus on patient's virtual communities rather than patient's social networks. Indeed, as virtual communities imply strong ties between individuals, bonding value and emotional support, and as the sense of belongingness is a key determinant of online collective action, these community virtual spaces for patients were indicated to be relevant for our study.

Second, we examined OCA beyond the use of the community platform, considering users as social actors (Lamb and Kling, 2003) and in order to frame interdependencies-in-use. We contextualized IT use in the e-health domain, and contributed to the analysis of online collective action of patients. The research design helped us get insights from both the field and the literature to build knowledge. This helped understanding why patients are motivated to act online and interact with other patients through technology, and the role of non-IT determinants in this process.

As a result, system usage and IT artifacts have to be learned but do not contribute a response to the research questions. For that purpose, knowledge of social psychology is

also needed in order to draw the right field forces of online collective action, especially with a population of patients.

Furthermore, on one hand, one can notice the correspondence between the hedonic driving force for online collective action – positive emotions – and the emotional support activity that does actually result from patients' activity. On the other hand, there is also a correspondence between the utilitarian driving force for online collective action – information needs – and the sharing of information, whether health-related or from a general perspective, that can be found on patient's virtual spaces.

Finally, the research highlights the cost-value or trust aspects that are relevant in patients' virtual worlds. The study shows that the need for patients to contribute to the others' well-being is rooted in their behavior. It also shows that inaccurate medical information and privacy concerns decrease interaction with peers through the online communities. In the particular case of patients often experiencing the burden of loneliness when faced with illness, the possible lack of medical accuracy of information or privacy protection can demotivate patients and dampen their strength or capability to recover in the best possible conditions. Managers should address those issues

The study applies a rigorous exploratory approach, which makes the results relevant because they specifically take into account the context of patients' use of health-related virtual communities. This approach also helps emphasize contributions of the research for managers. In particular, the results should help Health 2.0 practitioners to better address the issues of individual engagement on online communities and interpret the factors they can leverage in order to encourage experience sharing among patients.

In this regard, insightful comments were received, such as the need for information control, the need for online clinical advice that would be performed by health professionals and the wish to leave virtual spaces open. The first two would imply a more involved medical presence in patients' platforms, which is already the case in many examples, but not always systematic. The last point would need confirmation and has been dropped by our interpretive research approach, due to the very few references to this matter as well as to weak or unfounded claims from patients' perspectives, and understandable ethical issues. Furthermore, it goes against the common practice. Indeed, patients' platforms often require users to log in to be allowed to read forum contents.

To conclude, a major concern should be highlighted behind these trust issues, with a growing and ageing worldwide population, and growing Internet use. In the particular case of patients often experiencing the burden of loneliness when faced with illness, these issues, designed in this research by the possible lack of medical accuracy of information or privacy protection can demotivate them and dampen their strength or capability to recover in the best possible conditions.

2.7.3 Limitations and Future Research

We conducted a high number of interviews, due to our volition to operate preliminary ones in order to get to know what patients would be more concerned with by our research, and in order to reach semantic saturation. Despite this fact, we consider this qualitative research as an intermediate exploratory phase that would require a

quantitative phrase in order to be able to draw further conclusions as well as a complete model of patients' online collective action (Laubie and Elie-Dit-Cosaque 2012).

From its inception, this research has been designed to be the first part of an ongoing research process, whose aim is to further validate the insights brought by both the literature exploration and the interviews.

Indeed, this research presents limitations and therefore opportunities for further investigations.

Firstly, we targeted French patients in order to avoid introducing biases from multicultural settings. Therefore, future research may explore differentiations and/or similarities of behavior of patient's online collective action.

Secondly, preliminary interviews suggested focusing on specific patients' virtual communities. It may also be relevant to investigate populations other than the breast cancer community and a community of parents of autistic children, whether mixed or exclusive types of patients gathered on the same platform. It may also be advisable to explore the attributes of social networks in order to compare the results to those of virtual communities when it comes to patients as users.

Thirdly, our patients interviewed were mostly female. Extending this study to both genders or exclusively to male patients may drive interest for comparing results.

Finally, all concepts that were considered secondary would have to be carefully taken into account in order to make conclusions on their relevance, i.e.: the influence of IT artifacts and background factors.

Indeed, we account for the role of a number of background factors in the model that would require investigation in a possible follow-up quantitative study. Ajzen has posited that:

“a multitude of variables may be related to or influence the beliefs people hold, such as: age, gender, ethnicity, socio-economic status, education, nationality, religious affiliation, personality, mood, emotion, general attitudes and values, intelligence, group membership, past experiences, exposure to information, social support, coping skills, and so forth” (Ajzen 2005, p.134).

Ajzen has thus distinguished between the categories of personal, social and informational factors.

Prior research has identified a number of virtual communities' (Lin 2008) and patients' (Rahmqvist 2001) characteristics that are relevant to the quantitative phase of the research.

These factors have to be included as control variables in the model. Demographics comprise age, gender, education, socio-economic status, and marital status. General individual factors comprise general attitudes about interacting with online communities, computer anxiety, perceived behavioral control about the online community, Internet experience, media exposure and habits. Health-related individual factors comprise disease handicap and disease stage. IT Factors comprise the perceived ease of use and the perceived usefulness of the online community.

Future research may hence try to identify variations across these background factors regarding the determinants of online collective action on patient's online communities.

2.7.4 Conclusion

EVT, following Lewin's underlying framework, applied to virtual communities, offer important information concerning the leading determinants of online collective actions for patients. However some adjustments have to be made to fit our field of enquiry in patients' virtual communities. Indeed, our community-based background of patient members includes a large number of users, most often weakened by their disease, seeking interaction on these platforms.

Although the emotional dimension remained meaningful in patients' motives for joining online communities, the findings suggest that the MGB failed to offer a relevant model for predicting intentional action to engage online. The social values complete the lack of an explanation, highlighting the notion of bonding values that are comprised of determinants such as belongingness needs or exclusive value. Furthermore, the interviews demonstrate that the model was still lacking variables concerning the cost that explains patients' reluctance to join these communities. Indeed, the concept of trust embodied by the relevant medical information has to be considered as a predictive variable together with the concept of security of use embodied by a privacy protection concept. Other utilitarian values, such as information, needs to be integrated in the model, as they are in the adaption of MGB in Dholakia et al. (2004) past study.

These above mentioned aspects contribute to expand this trend of developing virtual spaces for people seeking information and support online. The Internet and patients' initiatives are changing the face of medical practice, previously limited to a top-down

approach where health professionals and third parties involved communicated a restricted amount of information to patients.

Hopefully connecting to virtual communities, patients may improve their quality of life, for the benefits provided by online collective action, which are often different from those they would get from traditional collective action in social groups acting face to face. This research hopefully helps to better take into account important issues for the ageing population's health challenges and emphasizes how patient's virtual communities can help support patient's concerns.

3 – THE DETERMINANTS OF ONLINE COLLECTIVE ACTION IN PATIENTS' VIRTUAL COMMUNITIES: THE CONTRIBUTION OF SOCIAL, UTILITARIAN AND EMOTIONAL INFLUENCES IN AN EXTENDED MODEL OF GOAL-DIRECTED BEHAVIOR ²

² Laubie, R., Elie-Dit-Cosaque, C. (2012). Exploring and Predicting Online Collective Action on Patients' Virtual Communities: a Multi-method Investigation in France. Research (*ICIS 2012*), Orlando, Florida, USA, December 16-19, 2012.

3 THE DETERMINANTS OF ONLINE COLLECTIVE ACTION IN PATIENTS' VIRTUAL COMMUNITIES: THE CONTRIBUTION OF SOCIAL, UTILITARIAN AND EMOTIONAL INFLUENCES IN AN EXTENDED MODEL OF GOAL-DIRECTED BEHAVIOR

3.1 Introduction

In 2014, out of the total world population, 3.73 billion of people were Internet users, which points to an increase of 934% since 2000 (Nielsen Online, 2017). This development of the Internet has been accompanied those recent years by a tremendous development of virtual communities. Online interactions mediated by those communities are further becoming significant endeavors for patients who want to communicate about health (Pew Internet Research, 2011). For health-related issues in particular, people browse the Internet in order to find information (68%), self-diagnose (46%) or look for other patients' testimonials (39%) (Bupa Health Pulse 2010). In this, patients are empowered by health-related, web 2.0 information technologies (IT) (Eysenbach 2008). In addition to those individual benefits, these IT are expected to contribute to public health by helping reducing the number of consultations with healthcare professionals, especially those regarding minor health nuisances. They can also help making health professionals becoming more available to patients suffering from more severe diseases (Bhatia and Sharma 2008). Eventually, those capabilities may contribute to substantial cost savings on the behalf of patients (Baker et al. 2005). Overall, the information delivered on some famous health virtual communities (e.g., MedHelp or PatientsLikeMe in USA, Les Impatientes or Vivre Sans Thyroïde in France)

has, in many instances, been demonstrated to be accurate (Esquivel 2006). Arguably, such communities may hence be regarded as ready and useful sources of information for patients. Yet, a number of risks of using the Internet for health purposes have already been noticed. For example, being misinformed, being exposed to outdated information or evaluating online medical information is still in question (Diaz et al. 2002).

In this context, as those websites bring their value from patients' interactions, health professionals wish to better know what determines or impede interactions, or online collective action (OCA) within health-related virtual communities. Accordingly, this research explores the determinants of online collective action in the course of patients' interactions on virtual communities.

Better acknowledging the development of Online collective action is important for both researchers and practitioners in IS. This, this research helps respond to two main knowledge gaps.

First, a significant amount of prior research dealing with technology adoption and success has focused on system usage (Benbasat and Barki 2007b) Burton-Jones and Straub 2006; Usluel and Mazman 2009), creating, thus, a progressive coherence (Locke and Golden-Biddle 1997) among researchers focusing on the explanation of use by the technology features, the user himself/herself, the system or the task. The evolutions of the web in particular, makes it necessary to make evolve the approaches to the success of IS to better acknowledge online collective action phenomenon. The first generation of the World Wide Web or Web 1.0, allowed people to get varied and rich contents over the Internet on a top-down manner. In contrast, the second generation of the web, often labeled as Web 2.0 or social web (Governor et al. 2009; Lai and Turban 2008; O'Reilly

2007), further allows individuals to interact one another. A large part of its benefits stems from its collaboratively generated content, which helps enriching the information made available to web users. In those contexts, formal organizations are often no longer critical for fostering collective action among individuals with an interest in shared goals (Bimber et al. 2012). On another and, many researchers display synthesized coherence (Locke and Golden-Biddle 1997), coming from different fields of expertise, considering that the Web 2.0 has significantly changed the way people seek, discover, and redistribute information (Ganley and Lampe 2009; Borland 2007, Eysenbach 2008). It has also profoundly changed the way people build relationships and interact with one another (Boyd 2006). The social web reflects in fact a radical paradigm shift, which consequences depend on users and usage contexts. In this context, examining online collective action in the context of Web 2.0 may help better reflecting the success of such IT implementations.

Second, in the specific context of virtual communities, such as patients' virtual communities, the utilitarian perspectives of most of the extent adoption models (e.g., Davis 1989; Venkatesh et al. 2003) are probably not the most relevant for better understanding online collective action. In such communities, being meaningful for other community actors is often more important than obtaining any economic reward. The determinants of altruistic action may also reflect a quest for the sense of self, belonging and ownership (Abma and Baur 2012). For those reasons, we may, expect that individuals interacting on hedonic virtual communities differ from other users in more traditional settings of technological interaction, such as in organizations. For example, patients may be significantly influenced by emotional factors due to some concerns

about their illness, or by their trust on the platform when very private information is shared. Prior research has for example attempted to explain how collective action may contribute to knowledge creation, at the network level, in online contexts such as with communities of practices dedicated to legal professionals (Wasko and Faraj 2005; Wasko et al. 2004). Relatedly, research has also examined how social actors decide about to what issues they will be willing to contribute in knowledge sharing and why, among engineering consultants through on online discussion tools (Haas et al. 2014); or why social actors will engage in knowledge sharing, showing that the greater centrality in the network, the ability to share knowledge, and the motivation of the actor, the greater his/her propensity to share knowledge (Reinholt et al. 2011). While together those research offer important insights that may be useful for the study of collective action in organizational contexts, to our knowledge, research does not provide a comprehensive model that may help better explain the individual and social determinants of collective action in more altruistic contexts. Overall, due to the paucity of research in this domain, we therefore still know very little about why patients engage in online collective action through these communities, and what their motivations are. Meanwhile, the interactions among collectives of patients on virtual communities has grown tremendously in recent years (Eysenbach 2008; Smith and Christakis 2008; Orizio et al. 2010), which makes practitioners ask for more guidance in the way to manage and ensure the success of their online communities, while collective action is seen as a way to encourage knowledge sharing and reduce “free riding” behaviors.

In order to respond to those knowledge gaps, based on Expectancy Values theorizing (Eccles and Wigfield 2002) and the Model of Goal Oriented Behavior (Perugini and

Bagozzi 2001), this research examines the determinants of patients' engagement in OCA. Accordingly, OCA is conceptualized as being influenced by task values beliefs, expectancy values beliefs (Eccles and Wigfield 2002), emotions and past behavior.

The research questions tackled in this paper are the following:

- 1) What are the relevant expectancy values in the course of patients' interactions with virtual communities?
- 2) Do these expectancy values predict patients' desires and intentions regarding virtual communities' usage, and subsequently their engagement with online collective action?

The expectancy-value Theory – EVT (Eccles et al. 1983) and the model of goal directed behaviors - MGB (Perugini and Bagozzi 2001) theorizing, allow us to conceptualize a model that predicts intentional action and subsequent online collective action during individual interactions on patients' virtual communities. In order to test the model, we then apply a rich, sequential, mixed-method approach (Venkatesh et al. 2013; Creswell 2008). First, in combination with the theoretical anchors of the research, we have conducted a qualitative inquiry in order to check the relevance and the completeness of the identified facets of the model variables. This process has also enabled us to ensure the content validity of the model constructs, namely expectancy values, emotions, desires, intentional collective action, post-adoptive behaviors, and online collective action. Second, we have completed a survey in order to measure the impacts of expectancy values and emotions on desires, intentional collective action, and ultimately on online collective action.

This research contributes to both the literature and practice within the domain of Health Information Systems and IT adoption. By conceptualizing and validating an enriched model of virtual communities' adoption, it allows better acknowledging Web 2.0 success. It uncovers the determinants of patients' engagement in interactions with and through virtual communities. So doing, it helps practitioners identifying the factors on which they may act to leverage the benefits of Web 2.0. A particular strength of this research is its grounded, multi-method approach, which helps going beyond some method issues, and allows to subsequently gain a better and more practical understanding of patients' engagement in online collective action.

The paper is organized as follows. In the first section, we discuss our main theoretical anchor – the EVT and MGB – as applied to patients' online virtual communities. In order to answer our research questions, we then conceptualize a model and accordingly develop hypotheses. Following this, we explain the design and methods for the research. The different determinants of online collective action are then described and discussed. Following this, the contributions and implications of the results for e-health and IT-adoption research and practice are emphasized. We then conclude the paper.

3.1.1 Online Social Networks and Virtual Communities

Online social networks and virtual communities have often been defined the same way in the literature. Ellison and Boyd (2007) defined social network websites as web-based services that allow individuals to: (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share some connections, and (3) view and traverse their list of connections and those made by others

within the system. A major feature of web-based social networks compared with real-life ones, is the opportunity for anyone to meet new contacts from other's current visible contacts. These connections may differ in nature and strengths, depending on websites' objectives and on the nature of the ties developed between users, whether they are strong or weak (Granovetter 1983). They also allow content's streams generated by users, which may differ in terms of types, frequency, intimacy or duration (Haythornthwaite 2005). These latent relations are important resources for the development of crowds' wisdom and use generated content (Nov 2007). Furthermore, they result in the creation of individuals' social capital. This social capital is considered to be the goodwill, which is engendered by the creation of social relations, and, which can facilitate action (Adler and Kwon 2002).

While most of those features seem common between social networks and online communities, some differences, however, can be noticed. For example, Dholakia et al. (2004) have defined virtual communities as "consumer groups of varying sizes that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism to achieve personal as well as shared goals of their members" (p.241-242). In contrast, Ellison and Boyd (2007) consider that social network sites are primarily organized around people rather than around interests, structured as egocentric networks, with the individual at the center of their own community. The size of the network is also a major determinant of these two ways of functioning. Online social networks are dedicated to a broader audience than virtual communities and enable users to emphasize their social networks, whereas contacts with strangers are of minor importance (Ellison and Boyd 2007; Grabner-Kräuter 2010).

In spite of the benefits of those Web 2.0 technologies, early predictions regarding computer-mediated interactions were warning against potentially unethical behaviors and low-level of communication (Short et al. 1976; Sproull and Kiesler 1986). Nowadays, however, online communication seems to be installed as a common endeavor in both the corporate and the private worlds, overcoming geographical barriers (Haythornthwaite and Wellman 2002; Salaff 2002). Specifically, observers argue that Web 2.0 technologies enable social network websites and social capital expansion through social interaction tools and are easily accessible. Indeed, Web 2.0 is “both an outcome gained by individuals in an online community and a tool for facilitating the governance of such spaces” (Ganley and Lampe 2009).

3.1.2 Patient's Engagement in Virtual Communities

The interest in social networks has grown over years, with sometimes the expectation that online communication would result in transforming virtual connections into real-life contacts (Rheingold 1993; Rheingold 2003; Kendall 2002). In virtual life, specifically, social networks change the way people represent themselves, communicate and interact with the real world. Activities may also change, based on users' objectives. Those objectives range from broadening their network or social capital to serving a specific goal, depending on users' willingness to go beyond geographic barriers, to discuss sensitive issues, to address similar problems or to decrease isolation (White and Dorman 2001). They are sometimes reached at the cost of privacy (Donath and Boyd 2004).

For health-related issues, in particular, the information generated and transmitted online does represent a valuable resource for patients (White and Dorman 2001; Smith and Christakis 2008). Virtual communities allow patients to share common interests, and for many of them their daily disease and/or non-disease-related concerns. In the United States (US), where Web 2.0 and Health 2.0's usages are largely developed, patients are looking for medical information, mainly for self-diagnosis (40%), discovering the experiences of other patients (35%), and getting information about hospitals or clinics (34%) (Bupa Health Pulse, 2012). Health information retrieval over the Internet in France appears to be lower than in many other industrialized countries such as the US, the United Kingdom (70%), Spain (77%), and emerging economies such as China (94%) (Bupa Health Pulse, 2011). However, 64% of French people use the Internet to seek health information (Bupa Health Pulse, 2010). A greater focus reveals that 65% online patients go online for informational needs, and 37% for getting the testimony of other patients (HAS, 2010). This search for testimonials from other patients is mainly done on virtual communities, which may be standalone or hosted on platforms like Facebook or even Twitter (HAS, 2010).

In spite of this knowledge about individual usage of web-based communities for health-related purposes, we still lack knowledge about the precise process through which patients engage in patient's community websites.

Prior research suggests that some factors such as IT beliefs factors (Davis 1989), emotional factors (Perugini and Bagozzi 2001) and trust may determine patients' – seen as technology users – willingness to engage and testify on patients' virtual communities (Loiacono et al. 2007) Grabner-Kräuter 2010). Multiple disciplines such as information

systems (IS), social psychology, marketing, but also medical research indeed provide interesting, yet piecemeal insights about those issues. Interestingly, patients looking for information or online interaction may not behave like users in more traditional IT use settings (White and Dorman 2001). This is due, for example, to the patients /user conditions, their battle against the illness, their level of isolation, even when they are well-surrounded by their relatives. A more complete view of the factors that influence patients' adoption and forms of interactions with medical interactive websites would therefore call for a more integrative, multidisciplinary approach.

3.1.3 Online Collective Action on Virtual Communities

Collective action has been the focus of many different disciplines, such as philosophy (Tuomela and Miller 1988; Searle 1990; Bratman 1993; Miller 2001; Gilbert 2006), social psychology (Tajfel 1981; Giguère et al. 2012; Tajfel and Turner 1979; Van Zomeren et al. 2008) and sociology (Olson 1965; DiMaggio and Powell 1983; Bimber et al. 2012) (See Table 28).

Area	Concept	Definition	Author
Philosophy	We-Intentions	“A commitment of an individual to participate in joint action and involves an implicit or explicit agreement between the participants to engage in that joint action.” (Tuomela 1995, p.2), (Tuomela and Miller 1988)	(Tuomela 1995)
	Collective Intentionality	“Collective intentionality presupposes a Background sense of the other as a candidate for cooperative agency; that is, it presupposes a sense of others as more than mere conscious agents, indeed as actual or potential members of a cooperative activity.” (Searle 1990, p.414)	(Searle 1990)
	Shared Intention	“We should, instead, understand shared intention, in the basic case, as a state of	(Bratman 1993)

		affairs consisting primarily of appropriate attitudes of each individual participant and their interrelations” (Bratman 1993, p.99)	
	CET (Collective End Theory) of joint action	“Joint actions are a species of interdependent action in which there is little or no conflict; joint actions involve a number of agents performing interdependent actions in order to realise a common goal” (Miller 2001, p.36)	(Miller 2001)
	Joint Commitment	“Collective action is interpreted as a matter of people doing something together, and it is assumed that this involves their having a collective intention to do that thing together... the parties are jointly committed to intend as a body that such-and-such.” (Gilbert 2006, p.3)	(Gilbert 2006)
Social Psychology	Collective Actions	Collective actions are described as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common” (Tajfel 1981, p. 244)	(Tajfel 1981)
	SIMCA (Social Identity Model of Collective Action)	Van Zomeren et al. (2008) demonstrate that “the key subjective predictors of collective action as well as their interrelationships” are “subjective injustice, identity, and efficacy”, p.504.	(Van Zomeren et al. 2008)
Sociology	Collective Action	Collective action put the organizations’ interests before individuals’ ones which can foster free-riding of individuals on the effort of others. In order to avoid this phenomenon, organizations have to motivate participants in collective action efforts and coordinate their efforts.	(Olson 1965)
	Collective Action	Collective action is studied within organizations where individuals are players and not passive agents who perform instructions. Individuals develop strategies based on personal goals that sometimes disregard the organization’s interests.	(Crozier and Friedberg 1977)
	Collective Action	Collective action suggests that dynamics implying a “startling homogeneity of organizational forms and practices” (DiMaggio and Powell 1983, p.148) and therefore rules and requirements in compliance with institutional and impersonal customs of interaction that don’t leave room for out-of-the-box thinking skills.	(DiMaggio and Powell 1983)
	Collective Action	“The digital-media environment prompts new and unforeseen opportunities for collective action as people are increasingly	(Bimber et al. 2012)

immersed in an atmosphere in which it is their routine practice to share ideas, connections, and interests.” (Bimber et al. 2012, p.5) Therefore, “all sorts of organizational structures and processes are implicated in the new technological landscape for collective action” (Bimber et al. 2012, p.6) that can be called organizational fecundity.

In the IS domain specifically, prior IS acceptance and adoption models have been applied to examine how individuals use IT in different contexts with Web 1.0 and Web 2.0 technologies around the concept of system usage (Hofmann 2002; Bokhari 2005; Straub and Burton-Jones 2007; Burton-Jones and Gallivan 2007; Usluel and Mazman 2009). Collective action has also been discussed, referring principally to social theories (Coleman 1994; Fishbein and Ajzen 1976) and social scientists and psychologists' reasoning (Hardin 1968; Olson 1965; Sweeney 1973; Schelling 2006; Oliver et al. 1985). Social teams and dynamics of knowledge development and transfer in both “more and less” virtual teams have also been studied, highlighting the assets of virtual work resulting from information technology use (Griffith et al. 2003).

For conceptualizing online collective action, we first draw on the We Intentions concept, leveraged in Tuomela (1995) and Tajfel's (1978; 1981) (Table 28) underlying frameworks to conceptualize online collective action (Dholakia et al. 2004). We-intention, have been defined as “a collective intention rooted in a person's self-conception as a member of a particular group (e.g., an organization) or social category (e.g., one's gender, one's ethnicity), and action is conceived as either the group acting or the person acting as an agent of, or with, the group.” (Bagozzi 2005, p.18).

Notwithstanding those contributions, the paucity of the developments in IS research on the OCA concept calls for further analyzing emerging collective action phenomena from the field. Accordingly, in addition to those aforementioned theoretical insights, we also confront the theoretical accounts to emerging field accounts. According to Zachariadis: al:

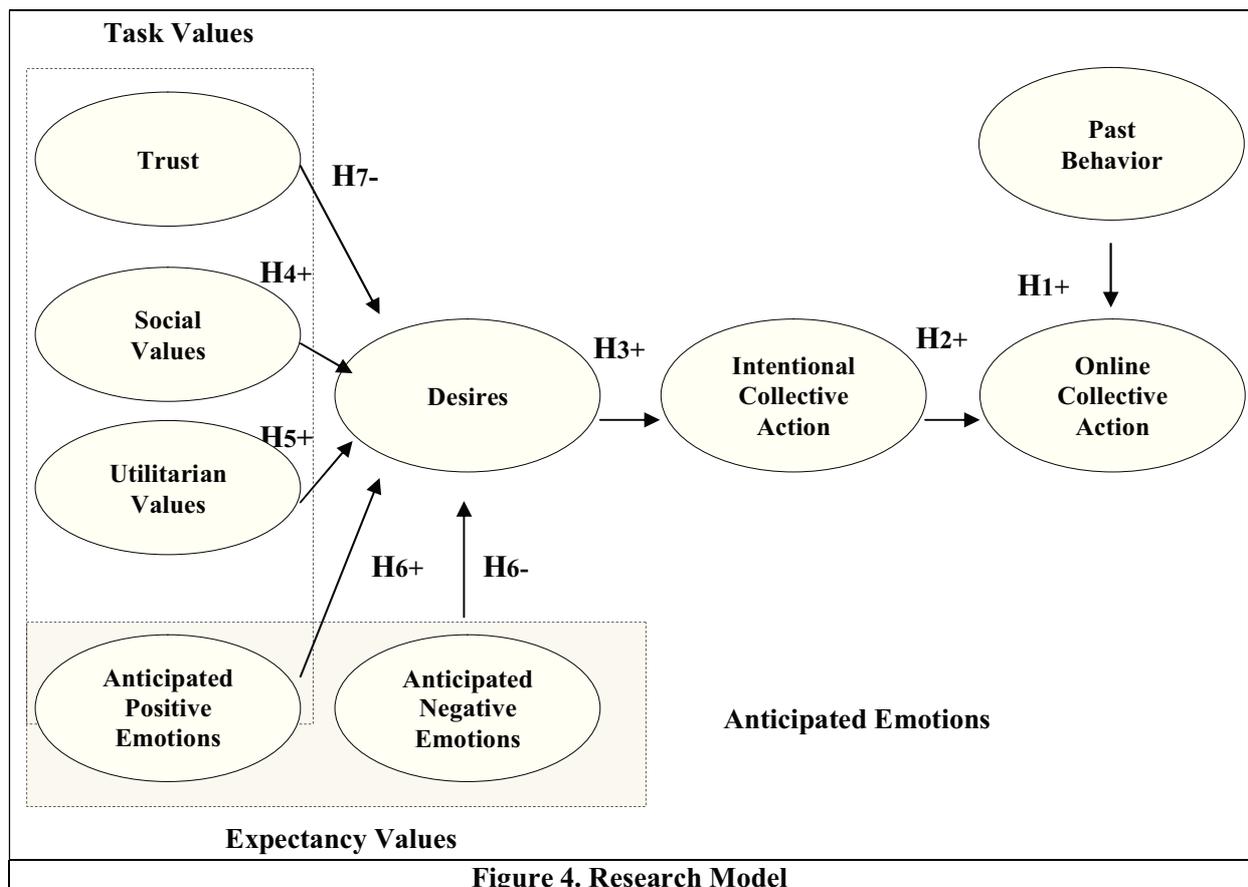
“There are two sides of knowledge... the transitive and intransitive objects of knowledge. Intransitive objects of knowledge are the ones that don't depend on human activity. In other words, it is the knowledge of things which are not invented by humans e.g. gravity, death etc. On the other hand, transitive phenomenon are “artificial objects fashioned into items of knowledge by the science of the day” (2010, p.7; Bhaskar 1998).

Indeed, this “science of the day” is expected to complete the theoretical inputs from research, benefitting from relevant contextual information about patients.

Overall, we lack a precise description of the concept of online collective action in the context of virtual communities as it would depend on the specificities of the community: i) its social identity (Allen and Meyer 1996; Bergami and Bagozzi 2000; Luhtanen and Crocker 1992) and ii) its group norms (Dholakia et al. 2004). In the context of virtual communities, our approach to online collective is closed to the concept of contribution behavior, such as “contribution activities in virtual communities often require multiple members to act in concert in a particular way to be meaningful”, (Tsai and Bagozzi 2014, p.145).

3.2 Model Development and Hypotheses

In conceptualize a model to predict patients' engagement in online communities, we articulate the Model of Goal-directed Behavior (MGB) (Perugini and Bagozzi 2001) and the Expectancy-Value Theory (EVT) (Eccles et al. 1983). The literature offers some insights on individual's motives to engage in collective action, and some studies have focused on virtual communities. Though, we believe that the combination of these models offers greater insights than each model taken separately. The MGB and EVT offer complementary perspectives for providing a richer view on patient's interactions with virtual communities. The resulting research model, which we describe in the following section, is shown in Figure 4 below.



Both those theories aim at explaining individual, volitional behavior.

The MGB draws on the Theory of Planned Behavior – TPB (Ajzen 1991), itself inspired by the Theory of Reasoned Action – TRA (Fishbein and Ajzen 1976). Essentially, the TRA explains a behavioral intention via the influence of subjective factors, such as one's attitude towards an action to be performed (Behavioral Beliefs) or beliefs about others' attitudes regarding an action or subjective norms (Ajzen and Fishbein 1980). The TPB partially adopts the TRA's conceptual framework. In fact, Ajzen (1991) introduced an additional predictor of intention and behavior, i.e. perceived behavioral control (PBC), or “the perceived ease or difficulty of performing the behavior, [which is] assumed to reflect past experience as well as anticipated impediments and obstacles” (Ajzen 1991, p.188). PBC is inspired by Bandura's self-efficacy theory (SET) (1977). Then, the intention and ability to perform the behavior will depend on one's expectations and self-efficacy judgment (Bandura 1977).

MGB comes from multiple research domains such as “attitude theory, motivational research and social identity research” (Bagozzi and Dholakia 2002, p.4). This theory has facilitated the expansion of the TPB (Ajzen 1991) by introducing behavioral desire as a mediator of the influence of anticipated emotions on behavioral intentions (Perugini and Bagozzi 2001). In this, the MGB introduces emotions as a “new decision criteria with respect to a person's goal” (p.80). Anticipated emotions are indeed posited to predict one's behavioral desire to perform an action, which determines his/her behavioral intention and finally the behavior itself. To be applied to predict the Internet and other social media usage behaviors and other forms of interactions, however, MGB must be

adapted. Indeed, as explained by Hartwick and Barki (1994), the use of IT can be inferred only by considering the contextual background of the target users.

As it explicitly includes emotions, we believe that the MGB is arguably more appropriate than the TPB or than other adoption models such as TAM (Davis 1989) or UTAUT (Venkatesh et al. 2003) for examining individual interactions with patients' virtual communities. Further, Bagozzi and Dholakia have demonstrated the relevance of this model and its ability to “explicate the individual and social variables that shape the member's we-intention to participate in virtual community interaction” (2002, p.4).

In spite of the predicting power of MGB in many contexts, Bagozzi and Dholakia (2002) identify only three antecedents of intentions to engage in virtual communities: positive emotions, social identity and desires. Later on, Tsai and Bagozzi (2014) identify cognitive, emotional and social drivers to contribute to virtual communities. In the specific context of patients' virtual web-based communities, arguably, MGB should be enriched using, at least, this triple perspective.

In order to provide this more complete view, we combine MGB with the expectancy value model by including task values - namely: attainment value, intrinsic value, utility value and cost, where expectancies are defined as “individuals' beliefs about how well they will do on upcoming tasks” (Eccles et al. 1983, p.119). EVT helps distinguishing between the different values that will predict intentions, while in the same time accounting for the influence of the factors identified by Bagozzi and Dholakia (2002). Drawing on Bandura's (1977) theorizing about personal efficacy expectation (which focuses on outcome expectations), Eccles et al. (1983) have defined “beliefs about ability” as the “individuals' evaluations of their competence in different areas” (Eccles and

Wigfield 2002, p.119). They have subsequently identified four components related to these beliefs: attainment value, intrinsic value, utility value and cost, namely task values. Those four components appear to be particularly relevant in the assessment of patients' online collective action in virtual communities, considering the latest research in the domain (White and Dorman 2001; Tsai and Bagozzi 2014).

3.2.1 Model Formulation and Hypotheses

Following MGB and EVT, this study examines users' motives for joining online patients' communities. In accordance with our theoretical background, the research model articulates virtual communities' expectancy values as determining online collective action through the patients' intentional action and desires. Patients fulfill their motivations such as feeling emotions described in MGB but also social values, utilitarian value and trust, that is to say in a goal-directed way. Past behavior is posited to directly impact online collective action. We explain the rationale for these relationships below.

3.2.1.1 Online Collective Action in Health 2.0 environments

In the area of social psychology, Tajfel (1981) described collective actions as “efforts by large numbers of people, who define themselves and are also often defined by others as a group, to solve collectively a problem they feel they have in common”, p. 244. Giguère et al. (2012) highlighted in this definition of collective actions the notion of collective social identity (Tajfel and Turner 1979) and shared problem perception. In the collective social identity concept, Giguère et al. (2012) explained that “stronger identification with a disadvantaged group is associated with a greater will to participate in a variety of actions

aimed at protecting or enhancing the group”, p.182. In the shared problem perception concept, Giguère et al. (2012) explained that “the traditional beliefs shared by group members may bring them to collectively recognize an event as threatening and worth uniting against”, p.183. Van Zomeren et al. (2008) further demonstrated that perceived injustice, perceived efficacy and social identity affected collective action. The latter is also motivated by the perceived value of the outcome (Giguère and Lalonde 2010; Bandura 1995) “when individuals perceive a valued outcome to result from collective actions, they are more likely to have a favorable attitude toward them and be willing to participate in them” (Giguère et al. 2012; p.183). This perceived value of the outcome is also posited in the purposive behavior of MGB (Perugini and Bagozzi 2001); the feeling of injustice that bounds patients can be related to their disease.

In Health 2.0 arena, it has been proven that discussions barely suffer from misinformation, especially since corrections may be reported as rapidly as within five hours (Esquivel et al. 2006). Thus, patients 2.0 may get an improved quality of life by connecting on virtual communities for the many benefits provided. This virtual communication allows them, for example, to maintain a continuous link with the community members (24/7). They are therefore no longer forced to wait between appointments with their practitioners to be informed about aspects of their daily life, to be reassured about their symptoms or to wait for actions to be taken. It also allows them to find their own rhythm in the Internet asynchronous mode. This allows them to accommodate conversations to their needs and to relieve their anguish at any time of the day or night.

The overall approach and the proliferation of testimonies allow patients to expand significantly their perspectives and feedback. This is also the case for information about rare diseases, whereby those platforms offer important advantages on very specific issues.

However, patients' online collective action also carries its risks. Among them, for example, the danger of wrong medical information being propagated among the Internet users. Furthermore, while mostly absent, a scrupulous control of potential erroneous information should be mandatory to avoid these pitfalls (Culver et al. 1997).

3.2.1.2 Past Behavior: Habits and Use Frequency

Past behaviors pertain to the domain of post-adoptive behaviors, which refers to a stage of routinization (Hsieh and Robert 2006), implying the frequency use of technology as well as the habits (Jasperson et al. 2005), moving through the stage “where alterations to the system ensure that IT is no longer perceived as new or out of the ordinary” (Ahuja and Thatcher 2005, p.430). Therefore, past adoptive behaviors imply that the individual's cognition that leads to usage dissipates over time along with intention to use, when an ultimate state reached (Kim et al. 2005), leading to an automatic behavior. Past behavior can be conceptualized in many different ways, such as frequency of behavior, or habits (Perugini and Bagozzi 2001; Jasperson et al. 2005). Both concepts “predict the occurrence of future behavior over and above established antecedents of behavior such as attitudes and intentions” (Verplanken and Orbell 2003, p.1313; Ouellette and Wood 1998). However, use frequency differs from habits as it does not respond to specific cues and doesn't imply a mental representation of an association

pairing a goal and an action (Verplanken and Orbell 2003). Habits have been defined as “the tendency to repeat past behavior in a stable context” (Ajzen 2002, p. 108; Ouellette and Wood 1998). Thus, even when dealing with IT use, habits refer to habitual behaviors rather than to behaviors guided by intentions (Limayem and Hirt 2003; Kim and Malhotra 2005). Some researchers found that habits have a significant effect on IT use that is “triggered by environmental cues” (Ortiz de Guinea and Markus 2009, p.440). Aarts and Dijksterhuis (2000) have further asserted that habits can be considered as links between goals and actions, activated by the environment; it contributes to the reaching of these goals through automatic behavior. Therefore, the more often the activation of a goal leads to the same behavior, the stronger the unconscious processes (Aarts and Dijksterhuis 2000; Heckhausen and Beckmann 1990; Reason 1990).

Hypothesis 1a: Habits are positively related to online collective action regarding virtual patients' communities.

In this research, we are interested in IT-directed behavior (Ahuja and Thatcher 2005) as automatic goal-directed responses to specific cues. These responses result from a mental representation of the instrumental goal-action link in reaching the goal (Verplanken and Orbell 2003). Concerning virtual communities, in addition to habits, we expect that the repeated connection of the patient – namely, use frequency - will lead to a certain level of Internet addiction with the Internet usage performed in a social way by active users (Emmanouilides and Hammond 2000), implying an extensive level of virtual communities' interaction (Beard and Wolf 2001; Young 2004), and thereby of online collective action because of one's customary way of behaving. Therefore:

Hypothesis 1b: Use Frequency is positively related to online collective action regarding virtual patients' communities.

3.2.1.3 Intentional Collective Action

According to Bagozzi and Dholakia (2002), individual participation in online community websites reflects intentional (social) action, or intentional collective action in the context of this study. These researchers assert that “the community member acts intentionally and that these actions have a collective basis in that both what is done and why it is done in the virtual community are determined by the community’s social characteristics” (p. 7). In the context of virtual communities, intentional actions predict online collective action (Dholakia et al. 2004). It implies a commitment and an agreement from each protagonist to participate in joint-activity (Tuomela 1995; Tuomela 2005). As a result, intentional collective action will predict behavior or online collective action (Bagozzi and Dholakia 2002) in the context of patients' communities since “it has already been stressed that intention is the central factor in personal causality, that is the intention of a person that brings order into the wide variety of possible action sequences by coordinating them to a final outcome (Heider 2013, p.112). Therefore:

Hypothesis 2: Intentional collective action is positively related to online collective action regarding virtual patients' communities.

3.2.1.4 Desires

While intentions drive the action, desires are only conducive to the course towards it (Bratman 1987). Davidson has emphasized that acting intentionally is synonymous with having a reason in mind, namely a desire, which is accompanied by beliefs about

how to achieve this desire. For example, a person's primary reason for getting medical information will necessarily imply two elements, 1) the desire to get medical information and 2) the belief that connecting to a medical information-related website is a means of obtaining medical information. Davidson (2001) further stresses that intentions can be influenced, depending on the conditioned evaluative judgments that may alter the appreciation of the situation. For example, a patient's evaluative judgment on medical information will be achieved by connecting on patient's virtual communities. Therefore:

Hypothesis 3: Desires are positively related to intentional collective action.

We conceive desires as a mediating variable that transform motivational antecedents of online collective action into reasons for action (Dholakia et al. 2004). Task values, anticipated emotions, and trust – namely expectancy values - are among such antecedents. We review these next.

3.2.1.5 Expectancy Values

Expectancy values are likely to determine the desires regarding the interactions with patients' virtual communities. The subcategories of the four expectancy values will be grouped under the same hypothesis, because those hypotheses share a similar conceptual rationale.

3.2.1.5.1 Social Value

Social values relate to ideas that are shared in communal and non-competitive ways, which results in the social experience as an aggregation of the social participation (Kim and Lee 2015). A number of such values have been identified; for example, social values

such as the attainment value are described by Eccles and Wigfield as “the personal importance of doing well on a task” (Eccles and Wigfield 2002; Eccles et al. 1983). This concept, linked by Markus and Wurf (1987) to one’s self-schema, is defined by Dholakia et al. (2004) as a means to “understand and deepen salient aspects of one’s through social interactions” (p.144).

The social influence literature (Kelman 1958) brings insights about categorization to be drawn to better acknowledge social value formation, namely: i) compliance or normative influence of others’ expectations which is proven irrelevant in the case of virtual communities (Dholakia et al. 2004), ii) internalization/group norms or congruence of one’s goals with those of group members, iii) identification/social identity or conception of one’s self in terms of the group’s defining features (Bagozzi and Dholakia 2002).

Compliance, the Kelman’s first variable of social influence, has been considered to be of minor importance in the case of online communities by Dholakia et al. (2004). Indeed, participants do not feel the need to conform to the online group, expecting rewards or fearing punishment. Rather, they have the possibility to leave the virtual engagement easily and the feeling of freedom is high.

Group norms features the influence performed by the group towards an individual because of shared values among the community (Kelman 1958).

Social identity, which concept relates to the belonging of a group, involves i) an affective sub-facet characterized by the affective commitment to the group (Massimo Bergami and Bagozzi 2000), ii) an cognitive sub-facet characterized by the self-awareness of community membership (Ashforth and Mael 1989) and iii) an evaluative sub-facet

characterized by the evaluation of self-worth as a member of the group (Dholakia et al. 2004).

Hypothesis 4a: Affective social identity is positively related to desires regarding the participation in virtual patients' communities.

Hypothesis 4b: Cognitive social identity is positively related to desires regarding the participation in virtual patients' communities.

Hypothesis 4c: Evaluative social identity is positively related to desires regarding the participation in virtual patients' communities.

3.2.1.5.2 Utilitarian Values

Deci and Ryan (1985), highlighted the extrinsic motivation concept, which refers to doing something because it leads to a separable outcome and where extrinsic motivation is similar to the utilitarian benefit that leads to utilitarian value (Chiu et al. 2014).

Indeed, utilitarian values are “determined by how well a task relates to current and future goal” (Eccles and Wigfield 2002, p.120). In the context of virtual communities, utilitarian values are likely to foster desires regarding online patients' communities use. Indeed, the individual sees such websites as a means through which he/she can reach his/her social goal. These values have been referred to as thinking dimensions (Sweeney and Soutar 2001) or confirmed as utilitarian values (Grabner-Kräuter 2010). These utilitarian values - purposive, namely instrumental and informational needs values were also studied by Dholakia et al. (2004), have been adapted from the MGB, and help to create the link between the MGB and EVT. Following this, utilitarian values are likely to foster desires. Indeed, patients will use websites because they view them as providing

useful health-related information and tools that will allow them to considerably reduce their level of isolation (White and Dorman 2001). We therefore, posit:

Hypothesis 5a: Isolation rupture is positively related to desires regarding the participation in virtual patients' communities.

Hypothesis 5b: Information needs are positively related to desires regarding the participation in virtual patients' communities.

Hypothesis 5c: Instrumental needs are positively related to desires regarding the participation in virtual patients' communities.

3.2.1.5.3 Anticipated Emotions

Deci and Ryan (1985) highlighted the intrinsic motivation concept, which refers to doing something because it is inherently interesting or enjoyable. Positive anticipated emotions also relate to Eccles and Wigfield (2002) intrinsic value – or “the enjoyment the individual gets from performing the activity or the subjective interest the individual has in the subject”, (p.120). These values have also been shown to determine participation in virtual communities (Dholakia et al. 2004), have been referred to as feeling dimensions (Sweeney and Soutar 2001), or anticipated emotions (Grabner-Kräuter 2010, Bagozzi et al. 1998; Tsai and Bagozzi 2014), where negative anticipated emotions are added. These anticipated emotions values – anticipated positive that capture the action's pleasure and satisfaction (Chiu et al. 2014) but also negative emotions - were also studied by Dholakia et al. (2004) and have been adapted from the MGB, and help to create the link between the MGB and EVT.

Following this, anticipated emotions are likely to foster desires in participating in virtual communities. Indeed, patients will use websites in order to contribute to the generation of positive or negative emotions, such as the emotional betrayal (Joinson et al. 2007) for the latter. Therefore, and further confirmed by the interviews' results:

Hypothesis 6a: Anticipated positive emotions are positively related to desires regarding the participation in virtual patients' communities.

Hypothesis 6b: Anticipated negative emotions are negatively related to desires regarding the participation in virtual patients' communities.

3.2.1.5.4 Trust

In social exchange theory, trust is a core “cost” component of a cost-benefit analysis with respect to social interaction (Roloff 1981). Cost relates to the “negative aspects of engaging in the task” (Eccles and Wigfield 2002). Although trust is often related with the notion of risk (Deutsch 1962; Mayer et al. 1995; Corritore et al. 2003). For interactions that take place in online community contexts, many researchers associate trust concerns with privacy concerns (e.g.; Dong-Hee 2010; Fogel and Nehmad 2009), while the press sometimes reports the unfortunate disclosure of several users' personal data (Read 2006). In fact, in those contexts, patients are likely to be very concerned with the respect of privacy (Goldberg et al. 1997) especially when they interact online with groups of people concerning very private issues, such as health (Coulson 2005; White and Dorman 2001). They are also concerned by the accuracy of information made available (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000) because “trust or lack of trust may be a key factor in determining whether online relationships will thrive and move to

deeper levels” (Joinson et al. 2007, p.43) and foster or hinder the desires to participate in online collective action. Accordingly, in this study we focus on inaccurate medical information and privacy concerns as surrogates of trust.

Indeed, researchers argue that risks induced by trust on the Internet take place “when individuals follow advice that they receive online; if this information is inaccurate, as a variety of costs may be incurred, depending on the domain of the advice (health, travel, finances, etc.)” (Joinson et al. 2007, p.44). Therefore, when the medical information is perceived inaccurate, the reliability of the patients' virtual community is at stake and challenged by users ending up in a lower desire to interact or to follow advices.

Hypothesis 7a: Inaccurate medical information is negatively related to desires regarding the participation in virtual patients' communities.

The purpose of online interaction is closely related and dependent to trust. Online interactions are indeed “conditions that foster high disclosure may also be those that evoke greater trust” (Joinson et al. 2007, p.45) and therefore, higher collective action. When patients have the feeling that their private information can be used by others in an unethical way, this can result in a lower desire to interact in a social way. Therefore, and further supported by the interviews' results:

Hypothesis 7b: Privacy concerns are negatively related to desires regarding the participation in virtual patients' communities.

3.2.1.6 Background Factors

In addition to these variables, we account for the role of a number of background factors in the model. Ajzen indeed argues that “a multitude of variables may be related to or

influence the beliefs people hold, such as: age, gender, ethnicity, socio-economic status, education, nationality, religious affiliation, personality, mood, emotion, general attitudes and values, intelligence, group membership, past experiences, exposure to information, social support, coping skills, and so forth” (Ajzen 2005, p.134) influence individual beliefs. In particular, he has distinguished personal, social and informational factors. Prior research has identified a number of virtual communities’ (Lin 2008) and patients’ (Rahmqvist 2001) characteristics that need to be controlled when examining patients’ interactions on virtual communities. We choose to include several of them in the model in order to control their potential influence on online collective action. Those variables are age, education, the Internet experience of the patients, and gender.

Regarding the latter, however, researchers have found that gender may be less influential in the access to the Internet, other demographics such as age or education and the IT experience lead to disparities (Walsh et al. 2001; Katz and Rice 2002; Joinson et al. 2007).

In order to empirically test the research model, a multi-method approach has been applied (Creswell 2008; Venkatesh et al. 2013).

3.3 Design and Methods

3.3.1 Research design

In order to answer to the research questions and to test the aforementioned hypotheses, we have applied a sequential, mixed-method design (Creswell 2008; Venkatesh et al. 2013). To do so, we followed Venkatesh et al. (2013) guidelines for mixed methods’ approaches in IS. We specifically considered i) the appropriateness of the approach,

given our willingness to both consider the context of patient's online community and provide a holistic understanding of it, ii) our willingness to develop meta-interferences to derive theoretical statements from both qualitative and quantitative results regarding patients' online collective action and iii) our willingness to assess the quality of meta-interferences through integrated findings' assessment in both qualitative and quantitative approaches.

From an epistemological point of view, our approach somewhat goes beyond a 'pure' positivist approach, sometimes depicted as naïve realism "in which reality is comprehensible and knowledge can easily be captured and generalized in a context-free form" (Zachariadis et al. 2010, p.5), or a 'pure' interpretive approach that excludes causal explanation "in early debates in the philosophy of social science concerning understanding versus explanation and on whether reasons could be causes" (Sayer 2000, p.96). Indeed, specifically defining critical realism's scope Zachariadis et al. state:

"Instead of looking for social laws we should be looking for causal mechanisms and how they work. According to critical realists, consistent regularities are only likely to arise under special circumstances in closed systems" (2010, p.5).

We believe critical realism helps addressing some of the ontological and epistemological limitations of positivism Zachariadis et al. (2010), consistent with the way we consider how knowledge is constructed.

Accordingly, we proceeded in two sequential steps. In the first, qualitative step, a partially grounded approach has been applied in order to further investigate online collective action in Web 2.0 contexts. While we believe existing theories provide relevant insights to examine this issue, we also believe they are insufficient to provide a complete

account of online collective action in health contexts. That is why we have decided to ground our research on both the field and theory. This approach allowed us to benefit from emerging insights from the field, while contributing to knowledge in a cumulative way. We conducted a review of the relevant literature on collective action and on patients' interactions on online communities along with interviews with patients from online patients' communities. In practice, the constant back and forth between the patients' inputs, which emerged from the interview analyses and the insights brought by the literature, have participated in knowledge construction consistent with our critical realist approach (Mingers 2000; Mingers 2004).

The second step of our design was the quantitative approach, implemented in order to test the research model. A survey has been conducted with patients who interact on online patients' communities. The key elements of the design for this research are summarized in Table 29 below.

Table 29. Our Multimethod Research Approach		
Approach	Objectives	Procedures
Step 1: Qualitative Approach	<ul style="list-style-type: none"> • Identify the specificities of patients who join virtual communities. • Contextualizing the variables chosen for the research model and survey instrument; ensuring content validity. • Identifying in practice the emerging individual and social determinants of patients joining web-based patients' virtual communities. • Examining the role played by the IT versus information and emotional needs in patient's commitment. 	<ul style="list-style-type: none"> • Ethnographic research approach in order to get preliminary insights on patients' sociological typology as well as motives for online engagement. • 25 preliminary semi-structured interviews) with Doctors and caregivers, health 2.0 experts and web 2.0 experts, users of patients' virtual communities. • 29 subsequent interviews conducted (including the preceding participants) who had to deal with their own health issues or that of relatives.
Step 2: Quantitative Approach	<ul style="list-style-type: none"> • Contextualizing the research model to accurately reflect actual 	<ul style="list-style-type: none"> • Questionnaire development: development of new constructs

patients' interactions with virtual communities.	emerging from interviews, or contextualization of existing constructs from the literature.
<ul style="list-style-type: none">• Measuring patient's interactions with virtual communities and achieving the external validity of the results.	<ul style="list-style-type: none">• Test of the research model on a large population of 10.000 patient web community's users with an online survey.

3.3.2 Qualitative Approach

In the qualitative part, we proceeded with semi-structured interviews (Romelaer 2005) in order to glean any materials that would emerge from patients' testimonies and supplement our theoretical framework.

The interviews were conducted with French Doctors and caregivers, health 2.0 and web 2.0 experts, patients and patients' relatives as shown in Table 30 below. The patients who participated in the study were members of a breast cancer community and parents of autistic children.

The breast cancer community's initial aim is to help patients finding information about their disease, to share their struggle in understanding it, and to help them make decisions thoughtfully, such as which surgical method should be preferable or which practitioner should be recommended, It comprises approximately 10,000 French patients, located all over the world. Participation in the community is anonymous (if desired), free, and the platform is independent of any other renowned social networks.

In contrast, the community of parents of autistic children is a small, closed, Facebook group, which consists of 97 persons. Its aims are similar as those of the breast cancer community members, with a careful focus on privacy protection allowing new entry on demand and acceptance after review only. Considering participants from these two

different communities helped us to increase the variety of the user conditions that we could observe.

Table 30. Interviews		
Interviewees	#	Focus
Doctors and caregivers	5	Feelings and concerns of the patients' population (from a medical standpoint)
Health 2.0 experts	13	Patients' motives for joining health 2.0 IT (from a medical and IT standpoint)
Web 2.0 experts	7	Individuals' motives to join online communities Contrasts between health communities and more traditional communities
Patients	21	Individual and social determinants for joining virtual communities (from a patient standpoint – community of breast cancer patients)
Patients' relatives	8	Individual and social determinants for joining virtual communities (from patients' relatives standpoint – community of parents of autistic children)
Total	<u>54</u>	

Most of the 54 interviewees were female (49) – we conducted 5 males' interviews -, and all were adults. The anonymity of the respondents was guaranteed in order to reduce their apprehension (Podsakoff et al. 2003). The interviews have been recorded and fully retranscribed. The responses provided us primary information about individual motives for online collective action. It also helped us identify the most relevant expectancy values to be included in the research model.

In order to do so, the NVivo9 software was used to proceed to the thematic coding and data mapping (Bazeley 2007) of the interview material. We coded the interviews after having set broad a-priori categories, according to the research model and theoretical background. We also looked for potentially new concepts by examining how well data fit with the conceptual categories identified in the literature (Suddaby 2006). We further allowed new categories to emerge. In this ongoing coding process, we followed a grounded approach (Glaser and Strauss 1967), and hence created new categories from

the interviews themselves. Specifically, we identified and coded, for the most frequent occurrences in the interviews, isolation rupture (White and Dorman 2001), inaccurate medical information (Green 2007; Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000), and privacy concerns (Green 2007; Goldberg et al. 1997; Graber et al. 2002). This process was repeated three times in order to reach theoretical saturation and ensure the nodes' relevance. Recurrent interactions between the two authors of the paper also ensured the accuracy of the coding process. Tables 31.1, 31.2, 31.3, 31.4 and 31.5 below detail the different facets of the constructs that we have identified according to both this process and the literature.

Table 31.1 Social values as the determinants of desires and online collective action

	Relevant Facet	Definition	Illustration*	Author
Social Value	Group Norms	Group norms is the concept of people sharing norms concerning matters of common interest and participate in a system of interlocking roles, influencing each other, and pursuing common goals. (Tajfel 1982)	“Sharing a common vision is often verified at the very beginning. When we browse on a forum, we quickly realize that we share the same vision. You decide to leave because of conflicts about the purpose of the forum.”	(Tajfel 1982)
	Affective Social Identity	<p>"The belongingness hypothesis is that human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships." (Baumeister and Leary 1995, p.497)</p> <p>“In an emotional sense, social identity implies a sense of emotional involvement with the group, which researchers have characterized as attachment or affective commitment.” (Dholakia et al. 2004, p.245;(Massimo Bergami and Bagozzi 2000)</p>	“Well, during my disease, although I was well surrounded by my family, I needed something else. I needed to talk to people, women sharing the same disease.”	(Baumeister and Leary 1995; Dholakia et al. 2004;Massimo Bergami and Bagozzi 2000)
	Cognitive Social Identity	<p>“Interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s), and relatedness without frequent contact will also be unsatisfactory” (Baumeister and Leary 1995, p.497). In the case of patients' communities, websites will be dedicated to one disease only.</p> <p>“In a cognitive sense, social identity is evident in categorization processes, whereby the individual forms a self-awareness of virtual community membership, including components of both</p>	“When it's opened to everyone, as a result, it loses in terms of information. While in a site like Les Impatientes, we know that we will inevitably connect with sharp people sharing our concerns... and it is very reassuring.”	(Baumeister and Leary 1995; Dholakia et al. 2004; Ashforth and Mael 1989)

	similarities with other members, and dissimilarities with non-members.” (Dholakia et al. 2004, p.245; Ashforth and Mael 1989)		
Evaluative Social Identity	“Evaluative social identity is measured as the individual’s group-based or collective self-esteem and is defined as the evaluation of self-worth on the basis of belonging to the community.” (Dholakia et al. 2004, p.245)	“You are loved because sometimes you make them laugh or because they like you as you are... So at this point, you are in charge of the community ... in charge of your commitment in the community.”	(Dholakia et al. 2004)

* Quotes from interviews with Breast Cancer Community’s patients

	Relevant Facet	Definition	Illustration*	Author
	Information Needs	“The Internet was broken down into various communication and information functions: information retrieval, information giving and conversation.” Therefore, information needs comprise the following items: “to get information, to learn how to do things, to provide other with information, and to contribute I know to a pool of information” (Flanagin and Metzger 2001, p.162).	“Yes. In fact, every time I had a question, every time I asked a question, I got an answer.”	(Flanagin and Metzger 2001)
Utilitarian Value	Instrumental Needs	“When social interactions in online communities help participants to accomplish specific tasks, such as solving problem, validating a decision already reached or buying a product” (Grabner-Kräuter 2010, p.509).	“Between doctor’s appointments, we have time to get anxious. On the network, we can speak freely whenever we need it. When girls explain what happened to them even in the reconstruction process, they really know what they’re talking about, almost as well as doctors and other medical professionals.”	(Grabner-Kräuter 2010)
	Isolation Rupture	“With asynchronous communication, participants in online groups have access 24 h a day, 7 days a week, at times most	“Very few friends stay nearby when you are sick. And you do not want to bother them with your	New Dimension

convenient to them” (White and Dorman 2001, p.694) The concept of isolation rupture refers to the possibility for patients to get an in-demand response for interpersonal relationships.	problems ... So, yes, it's much easier to speak with someone who, himself, will understand and hear what you say because he experiences the same thing.”
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* Quotes from interviews with Breast Cancer Community's patients

Table 31.3 Anticipated Emotions values as the determinants of desires and online collective action

	Relevant Facet	Definition	Illustration*	Author
Anticipated Emotions	Positive Anticipated Emotions	“Positive (anticipated) emotions refer to success in achieving a goal” (Perugini and Bagozzi 2001, p.83). In online communities' contexts, it refers to “fun and relaxation through playing or otherwise interacting with others” (Dholakia et al. 2004, p.244).	“Emotions are present, regularly. In fact, when I'm in low spirits, I'm going on the network and it goes away.”	(Perugini and Bagozzi 2001; (Dholakia et al. 2004; Bagozzi et al. 1998; Tsai and Bagozzi 2014)
	Negative Anticipated Emotions	“Negative (anticipated) emotions refer to failures in achieving a goal” (Perugini and Bagozzi 2001, p.83). In online communities' contextual background, it can refer to stress and anxiety through interacting with other patients.	“When a person does his check-up and returns with a negative diagnosis, then you get a punch in your stomach because your fear is coming back and spreading...”	(Perugini and Bagozzi 2001; Bagozzi et al. 1998; Tsai and Bagozzi 2014)

* Quotes from interviews with Breast Cancer Community's patients

Table 31.4 Trust as the determinants of desires and online collective action				
Relevant Facet	Definition	Illustration*	Author	
Trust	Inaccurate Medical Information	“On the Internet, individuals may trust others to provide honest and accurate information” (Green 2007, p.44). In the context of health purposes, there is a risk of dangerous and inaccurate medical information appearing online (Williams et al. 2003; Diaz et al. 2002; Dickerson et al. 2000)	“The big problem on the forum is that only patients participate with their own feelings, with their own knowledge... And they aren't necessarily enlightened patients...”	New Dimension
	Privacy Concerns	“On the Internet, individuals may trust others to keep private information confidential” (Green 2007, p.44). For health purposes, privacy protection may be of relevance due to patients' conditions (Goldberg et al. 1997) as well as the privacy policies of health Web sites (Graber et al. 2002).	“Control is important, as is the confidentiality of data. It was a prerequisite for me, if I was asked my name, I would be gone, because the Internet is risky”	New Dimension

* Quotes from interviews with Breast Cancer Community's patients

Table 31.5 Online Collective Action			
Relevant Facet	Definition	Illustration*	Author
Online Collective Action	Drawing on “the psychological processes underlying attitude-behavior Relationships” (Eagly and Chaiken 1993, p.299), enriches by joint-activity concept (Tuomela 1995; Tuomela 2005) and online context (Dholakia et al. 2004), online collective action indicates the commitment and agreement to be joint-activity from patients' virtual communities users.	“Well, I am determined to act by providing information and answers to people who ask questions, testifying that there is life after cancer. Yes, there is also the testimony that counts. Yes, there is the testimony that you can live well with illness...”	(Dholakia et al. 2004)

* Quotes from interviews with Breast Cancer Community's patients.

The preliminary results of the exploratory, qualitative approach helped us identify the main determinants of online collective action. The subsequent confirmatory,

quantitative approach was expected to help determining whether the model accurately predicts online collective action. We discuss this next.

3.3.3 Quantitative approach

Based on the insights from the qualitative approach, the research model has been conceptualized, enriched and contextualized. Furthermore, the content validity of the model-variables has been improved, as we have identified multiple sub-facets of expectancy values with 4 dimensions for social value (group norms, affective social identity, cognitive social identity, evaluative social identity), 3 dimensions for utilitarian value (information needs, instrumental needs, isolation rupture), and 2 dimension for anticipated emotions values (anticipated positive emotions and anticipated negative emotions). We have also identified 2 dimensions for trust (inaccurate medical information and privacy concerns). We were able to contextualize online collective action and desires.

In practice, and whenever possible, constructs' measures have been adapted from prior research. Following this, a questionnaire has been developed. A survey (Pinsonneault and Kraemer 1993) has then been conducted over the Internet with patients of three different virtual communities in French language. The number of patients registered amounts around 15,000 persons that are not always active, though.

3.3.3.1 Measures

The questionnaire was initially developed in English and then translated into French by experts in both languages. The measures, provided in Tables 32.1, 32.2, 32.3, 32.4 and

32.5, used a seven-point Likert scales (Joinson et al. 2007). Participants were asked to visualize the average participants of their virtual community and to write their names (or pseudos) and a description of each participant up to five persons (See Table 32.1 and Annex 6.3.1.4)

Table 32.1 Constructs and measures for social value

Relevant Facet	Measures	Original Scale
Social Value	Group Norms Five measures How strong would you say the explicit or implicit agreement is among each of the following to interact with on the Internet as a group sometime during the next two weeks or so? Me Member n°1 Member n°2 Member n°3 Whole Community (seven-point “Very weak-Very strong” scale)	(Dholakia et al. 2004)
	Affective Social Identity Two measures How attached are you to the group you mentioned above? (seven-point “Not at all–Very much” scale) How strong would you say your feelings of belongingness are toward the group you mentioned above? (seven-point “Not at all–Very much” scale)	(Dholakia et al. 2004; Allen and Meyer 1996)
	Cognitive Social Identity Two measures Please indicate to what degree your self- image overlaps with the identity of the group of friends as you perceive it (seven-point “Not at all–Very much” scale) How would you express the degree of overlap between your personal identity and the identity of the group you mentioned above when you are actually part of the group and engaging in group activities? (seven-point “Not at all–Very much” scale)	(Dholakia et al. 2004; (Massimo Bergami and Bagozzi 2000)
	Evaluative Social Identity Two measures I am a valuable member of the group (seven-point “Agree–Disagree” scale) I am an important member of the group (seven-point “Agree–Disagree” scale)	(Dholakia et al. 2004; Luhtanen and Crocker 1992)

Table 32.2 Constructs and measures for utilitarian value			
Relevant Facet	Measures	Original Scale	
Utilitarian Value	Information Needs	One measure How often do you use your online group for satisfying the following needs? To get information (seven-point "Never-Always" scale)	(Dholakia et al. 2004)
	Instrumental Needs	Two measures How often do you use your online group for satisfying the following needs? To learn how to do things (seven-point "Never-Always" scale) To solve problems (seven-point "Never-Always" scale)	(Dholakia et al. 2004)
	Isolation Rupture	Two measures How often do you use your online group for satisfying the following needs? To get to know others (seven-point "Never-Always" scale) To feel less lonely (seven-point "Never-Always" scale)	(Dholakia et al. 2004)

Table 32.3 Constructs and measures for anticipated emotions			
Relevant Facet	Measures	Original Scale	
Anticipated Emotions	Anticipated Positive Emotions	Five measures If I am able to interact together on the Internet with the group during the next two weeks, I will feel Relief Contentment Satisfied Proud Self-assured (seven-point "Not at all-Very much" scale)	(Bagozzi et al. 1998)
	Anticipated Negative Emotions	Five measures If I am able to interact together on the Internet with the group during the next two weeks, I will feel Angry Ashamed Sad Depressed Anxious (seven-point "Not at all-Very much" scale)	(Bagozzi et al. 1998)

Table 32.4 Constructs and measures for trust		
Relevant Facet	Measures	Original Scale
Inaccurate Medical Information	Two measures Patients' virtual communities web site provides inaccurate medical information (seven-point "Not at all-Very much" scale)	(Vance et al. 2008)
	There are many errors in the medical information I obtain from the patients' virtual communities web site (seven-point "Not at all-Very much" scale)	
Trust	Four measures I am concerned that the information I submit on the Internet could be misused I am concerned about submitting information on the Internet, because of what others might do with it I am concerned about submitting information on the Internet, because it could be used in a way I did not foresee Being able to control the personal information I provide to a website is important to me (seven-point "Strongly disagree-Strongly agree" scale)	(Dinev and Hart 2004)

Table 32.5 Constructs and measures for desires, intentional collective action, habits, online collective action		
Relevant Facet	Measures	Original Scale
Desires	Three measures I desire to interact together on the Internet with the group I mentioned above during the next two weeks (seven-point "Strongly disagree-Strongly agree" scale) My desire for interacting together on the Internet with the group I mentioned above during the next two weeks can be described as (seven-point "No desire at all-Very, very strong desire" scale) I want to interact together on the Internet with the group I mentioned above during the next two weeks (seven-point "Does not describe me at all-Describes me very well" scale)	(Dholakia et al. 2004)
Intentional Collective Action	Five measures How strong would you say is your intention and the intention of each of the following people to interact with together on the Internet sometime during the next two weeks or so? Me Member n°1 Member n°2 Member n°3 Whole Community (seven-point "Very weak-Very strong" scale)	(Dholakia et al. 2004)

Habits	Three measures Browsing at virtual patients' communities I log onto, is somethingthat makes me feel weird if I do not do it (seven-point "Not at all-Very much" scale) ...I do without thinking (seven-point "Not at all-Very much" scale) ...that has become a routine for me (seven-point "Not at all-Very much" scale)	(Chiu et al. 2012)
Use Frequency	Eleven measures How often do you use your online community Cancer Contribution for satisfying the following needs? To provide others with information To contribute to a pool of information To learn about myself and others To gain insight into myself To generate ideas To impress people To be entertained To relax To make decisions To pass the time away when bored To feel important for others (seven-point "Never-Very often" scale)	(Dholakia et al. 2004)
Online Collective Action	Five measures How strongly committed would you say the following are to interacting together as a group on the Internet sometimes during the next two weeks or so? Me Member n°1 Member n°2 Member n°3 Whole community (seven-point "Very weak-Very strong" scale)	(Dholakia et al. 2004)

Several constructs have been modeled as second order formative constructs with reflective subconstructs. Others are reflective constructs, following both the literature and the insights which emerged from the qualitative study.

For instance, habits is a reflective construct that measures to what extent patients' logging onto patients' virtual community is an automatic behavior. We used the metrics of Chiu et al. (2012) for this construct.

Use frequency is a formative construct that measures how often patients join the virtual communities to satisfy various needs. We used the metrics of Dholakia et al. (2004) for this construct.

Intentional collective action is a formative construct that measures to which degree patients might intend to interact together on the Internet with the group during the next two weeks, based on Dholakia et al. (2004)'s metrics. Similarly, desires is a formative construct that measures to which degree patients might desire to act in the same way, using the same metrics.

Affective social identity, cognitive social identity and evaluative social identity are formative constructs that also used the metrics of Dholakia et al. (2004) to measure: i) how attached are patients to the group, ii) to what degree patient's self-image overlaps with the group and iii) to what extent the patient considers being a valuable member of the group.

Group norms is a formative construct that used the metrics of Dholakia et al. (2004) relating to the shared agreement among patients to participate online in the next two weeks following the question.

Isolation rupture is a reflective construct using the metrics of Dholakia et al. (2004) that measures how often patients connect on virtual communities to feel less lonely.

Information needs and instrumental needs are reflective constructs using the metrics of Dholakia et al. (2004) that measures how often patients connect on virtual communities to: i) get information and ii) solve problems.

Anticipated positive emotions and anticipated negative emotions are formative constructs using the metrics of Bagozzi et al. (1998) that measure whether patients will experience positive or negative feelings while interacting together on the Internet with the group during the next two week following the question.

Inaccurate medical information is a reflective construct based on the metrics of Vance et al. (2008) that measures to what extent patients face errors in the medical information from the patients' virtual communities web site.

Privacy concerns is a reflective construct based on the metrics of Dinev and Hart (2004) that measures, to what extent, patients are concerned that the information they submit on the Internet could be misused.

Finally, online collective action is a formative construct. It measures how committed patients are to interact online, together as a group in the next two weeks following the question. For this construct, we used the metrics of Dholakia et al. (2004).

3.3.3.2 Sampling

Patients suffering from cancer from three different virtual communities were being solicited to participate in the study. The community managers posted the invitation to participate in the survey online that stayed on the sites' homepage during two months for the first community and couple of weeks for the others. In order to reduce the risk of common method bias, the anonymity of the participants was guaranteed, and they were recalled that their answers wouldn't be analyzed individually, and that they wouldn't be identified personally (Podsakoff et al. 2003). There was no reward of any nature offered

in return of their participations. The participants were informed that there were no right or wrong questions and that only their sincere answers were required.

The first community (122 participants), comprised around 10,000 subscribers, is the domain of breast cancer. The second community (102 participants), comprised around 15,000 subscribers, is the domain of thyroid disorders, including thyroid cancer. The third community (45 participants), comprised around 5,000 subscribers, is the domain of cancers.

Overall, 269 participants completed the questionnaire survey. There were 782 clicks on the survey's link, including 282 responses. Out of the 282 responses obtained, 13 were poorly completed and thus deleted due to too many incomplete answers. (See Table 33)

Of the 269 participants, 98% were female. 17% of the participants were in 41-45 range age, 22,1% were in 46-51 range age and 22,1% were in 51-55 range age. Only 2,47% of the participants were self educated. 61,1% of the participants were married, versus 19,8 widowed. 52,2% of the participants had a good skill in the Internet use.

Table 33. Communities' characteristics		
Interviewees	#	Focus
Patients	122	Virtual community of women with breast cancer (10,000 registered)
	102	Virtual community of patients suffering from diseases related to the thyroid gland, including cancers. (15,000 registered)
	45	Virtual community of cancer patients (5,000 registered)
Total	269	

3.4 Analysis

Data analyses were performed via a Partial Least Squares Structural Equation Modeling (PLS-SEM) software, SmartPLS (Ringle et al. 2005; Ringle et al. 2012). The PLS algorithm is particularly appropriate for our model as it involves both reflective and

formative constructs and for the exploratory nature of our research (Straub et al. 2008; Marcoulides et al. 2009; Ringle et al. 2012). We began by examining the measurement properties of the instrument. For this, we conducted typical tests, including convergent validity, discriminant validity, and construct reliability (Boudreau et al. 2001).

3.4.1 Construct Validity and Reliability

3.4.1.1 Convergent Validity

Convergent validity was evaluated by examining the cross-loading values (See Table 33). The results indicate that all items load cleanly on their intended constructs, with values higher than 0,80 for all constructs. Further, the analysis of the outer model loadings allows assessing the significance of item loadings on their intended constructs. It shows that the t-values are higher than 1.96 and hence that all the items do load significantly (e.g., at $p < .05$) on their reference construct. Therefore, we can conclude that convergent validity meets the generally accepted standards (Gefen et al. 2000) for these constructs.

Items	ASI	CSI	D	ESI	H	InfN	IMI	InsN	IR	PC
AFFSOCIDENTIY1	0.922	0.602	0.446	0.470	0.427	0.31	-0.211	0.332	0.366	-0.164
AFFSOCIDENTIY2	0.901	0.561	0.397	0.367	0.227	0.261	-0.148	0.399	0.383	-0.100
CSIDENTITY1	0.534	0.899	0.377	0.324	0.390	0.219	-0.196	0.358	0.434	-0.161
CSIDENTITY2	0.628	0.929	0.446	0.424	0.434	0.35	-0.244	0.450	0.497	-0.239
DESIRES1	0.444	0.431	0.936	0.64	0.578	0.242	-0.272	0.351	0.631	-0.321
DESIRES2	0.458	0.445	0.947	0.634	0.603	0.264	-0.273	0.404	0.651	-0.314
DESIRES3	0.411	0.406	0.950	0.624	0.591	0.240	-0.291	0.406	0.647	-0.309
ESIDENTITY1	0.443	0.387	0.641	0.949	0.638	0.167	-0.258	0.297	0.557	-0.388
ESIDENTITY2	0.432	0.396	0.623	0.947	0.698	0.114	-0.298	0.28	0.560	-0.483
HABITS1	0.287	0.411	0.625	0.692	0.928	0.165	-0.395	0.287	0.557	-0.572
HABITS2	0.338	0.385	0.484	0.614	0.919	0.169	-0.323	0.268	0.485	-0.539
HABITS3	0.386	0.439	0.585	0.609	0.888	0.295	-0.388	0.345	0.556	-0.495
INFO_NEEDS1	0.315	0.317	0.264	0.148	0.228	1	-0.212	0.709	0.422	-0.030
INNAC_MED_INFO1	-0.136	-0.194	-0.215	-0.230	-0.367	-0.206	0.924	-0.258	-0.235	0.36

INNAC_MED_INFO2	-0.224	-0.254	-0.324	-0.310	-0.400	-0.198	0.967	-0.310	-0.296	0.346
INSTR_NEEDS1	0.362	0.389	0.379	0.240	0.265	0.659	-0.245	0.927	0.505	-0.068
INSTR_NEEDS2	0.377	0.437	0.380	0.324	0.344	0.654	-0.321	0.927	0.539	-0.216
ISOL_RUPTURE1	0.396	0.455	0.668	0.658	0.587	0.394	-0.298	0.545	0.925	-0.384
ISOL_RUPTURE2	0.345	0.478	0.563	0.411	0.472	0.372	-0.216	0.474	0.893	-0.249
PRIVACY_CONCERN1	-0.141	-0.123	-0.217	-0.268	-0.348	0.029	0.271	-0.078	-0.215	0.817
PRIVACY_CONCERN2	-0.141	-0.138	-0.241	-0.367	-0.448	-0.034	0.322	-0.119	-0.226	0.892
PRIVACY_CONCERN3	-0.144	-0.175	-0.228	-0.361	-0.459	-0.030	0.366	-0.133	-0.272	0.902
PRIVACY_CONCERN4	-0.096	-0.269	-0.388	-0.502	-0.658	-0.049	0.313	-0.169	-0.421	0.836

Notes: ASI = Affective Social Identity, CSI = Cognitive Social Identity, D = Desires, ESI = Evaluative Social Identity, H = Habits, IMI = Inaccurate Medical Information, InfN = Information Needs, InsN = Instrumental Needs, IR = Isolation Rupture, PC = Privacy Concerns

3.4.1.2 Discriminant Validity

Discriminant validity of reflective constructs is achieved when items from a given construct correlate more highly with their construct than with any other construct. In order to test discriminant validity, we first computed the root square of the average variance extracted for each construct (highlighted on the diagonal of Table 35). We then verified that these values were higher than any off-diagonal values. Since this condition was met, we could thus conclude that reflective constructs have good discriminant validity (Gefen et al. 2000).

Table 35. Discriminant Validity and Reliability

Variables	CR	CA	1	2	3	4	5	6	7	8	9	10
(1) ASI	0.908	0.797	0.911									
(2) CSI	0.910	0.804	0.639	0.914								
(3) D	0.961	0.939	0.463	0.453	0.944							
(4) ESI	0.947	0.888	0.462	0.413	0.670	0.948						
(5) H	0.937	0.899	0.365	0.452	0.626	0.704	0.912					
(6) IMI	0.944	0.886	-0.198	-0.242	-0.295	-0.293	-0.407	0.946				
(7) InfN	1	1	0.315	0.317	0.264	0.148	0.228	-0.212	1			
(8) InsN	0.925	0.837	0.399	0.445	0.410	0.304	0.328	-0.305	0.709	0.927		
(9) IR	0.905	0.792	0.410	0.511	0.68	0.599	0.587	-0.286	0.422	0.563	0.909	
(10) PC	0.921	0.890	-0.146	-0.222	-0.333	-0.459	-0.589	0.370	-0.030	-0.153	-0.354	0.863

Notes: ASI = Affective Social Identity, CSI = Cognitive Social Identity, D = Desires, ESI = Evaluative Social Identity, H = Habits, IMI = Inaccurate Medical Information, InfN = Information Needs, InsN = Instrumental Needs, IR = Isolation Rupture, PC = Privacy Concerns, CR = Composite Reliability, CA =

Cronbach's Alpha.

Items on the diagonal (in boldface) are the square root of average variance extracted (AVE).

3.4.1.3 Construct Reliability

We checked the internal consistency of our constructs with composite reliability (Fornell and Larcker 1981) and Cronbach's alpha measurement. All values for these calculations were higher than 0.70 (Boudreau et al. 2001) demonstrating that conditions for internal consistency are met.

Overall, convergent validity, discriminant validity and reliability analyses showed that our instrument has good psychometric properties.

3.4.1.3.1 Common Methods Variance Analyses

In order to check whether the common methods have influence on the results of the study, we completed the Haman's single factor test as recommended by Podsakof et al. (2003). To do so, we performed a Principal Component Analysis. The results (See Table 36) show that more than one factor emerges from the PCA, which indicates that common method variance is not a serious concern.

Table 36. Transformation Matrix Components

Component	1	2	3	4	5	6	7	8	9	10
1	.500	-.301	.360	.396	-.240	.340	.288	.246	.189	.144
2	.108	.723	.468	-.166	.222	-.032	.223	.268	.117	-.184
3	.452	.320	-.586	.263	.408	.317	-.093	-.035	-.027	.051
4	-.186	-.342	-.245	-.122	.385	-.027	.439	.620	-.147	-.162
5	-.007	-.327	.379	-.026	.744	.021	-.188	-.266	.261	.144
6	-.561	.213	.012	.631	.085	.016	.363	-.159	.001	.276
7	-.224	.014	.275	.173	.045	.474	-.481	.249	-.553	-.137
8	.285	-.073	.110	.469	.106	-.645	-.065	-.043	-.330	-.374
9	-.228	-.012	-.127	.281	-.072	.021	-.348	.257	.664	-.469
10	-.028	-.093	.020	-.059	.003	.376	.378	-.507	-.069	-.664

Extraction Method: Principal component analysis.

Rotation Method: Varimax with Kaiser Normalization

3.5 Results

We tested the aforementioned hypotheses running a bootstrap analysis with 500 resamples. Our model explained a substantial amount of the variance of online collective action ($R^2 = 0.753$), of intentional online collective action ($R^2 = 0.400$) and of desires ($R^2 = 0.628$). The results are highlighted in Table 37.

Table 37. Path Coefficients						
Link	Hypothesis (Validation)	Original Sample	Sample Mean	Standard Deviation	Standard Error	t-Statistics
Affective Social Identity -> Desires	H4a (No)	0.083	0.083	0.067	0.067	1.249
Age -> Online Collective Action	-	0.117	0.094	0.068	0.068	1.736
Cognitive Social Identity -> Desires	H4b (No)	-0.031	0.036	0.078	0.078	0.391
Desires -> Intentional Collective Action	H3 (Yes)	0.632*	0.577	0.282	0.282	2.246
Education -> Online Collective Action	-	-0.034	0.029	0.035	0.035	0.962
Evaluative Social Identity -> Desires	H4c (Yes)	0.245***	0.232	0.072	0.072	3.382
Gender -> Online Collective Action	-	0.000	0.000	0.024	0.024	0.002
Group Norms -> Desires	H4d (Yes)	0.194**	0.201	0.074	0.074	2.634
Habits -> Online Collective Action	H1a (No)	0.028	0.010	0.059	0.059	0.476
IT Experience -> Online Collective Action	-	-0.047	0.040	0.052	0.052	0.910
Inaccurate Medical Information -> Desires	H7a (No)	-0.022	0.017	0.050	0.050	0.445
Information Needs -> Desires	H5b(No)	-0.040	0.039	0.075	0.075	0.540
Instrumental Needs -> Desires	H5c (No)	0.024	0.025	0.098	0.098	0.240
Intentional Collective Action -> Online Collective Action	H2 (Yes)	0.717***	0.710	0.071	0.071	10.085
Isolation Rupture -> Desires	H5a (Yes)	0.333**	0.319	0.083	0.08	4.014
Anticipated Negative Emotions -> Desires	H6b (No)	0.055	0.075	0.050	0.050	1.087
Anticipated Positive Emotion -> Desires	H6a (Yes)	0.122*	0.139	0.061	0.061	1.992
Privacy Concerns -> Desires	H7b (No)	0.013	0.008	0.053	0.05	0.238
Use Frequency -> Online Collective Action	H1b (Yes)	0.168*	0.200	0.077	0.077	2.182

Notes: Variance explained: $R^2(\text{Online Collective Action}) = 0.753$; $R^2(\text{Intentional Collective Action}) = 0.400$; $R^2(\text{Desires}) = 0.628$.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

3.5.1 Relationships between past-adoption behavior and online collective action

As expected in H1b, the use frequency \rightarrow online collective action link was found to be positive and significant ($\beta = 0.168$, $p < 0.05$). However, unexpectedly, the habits \rightarrow online collective action link was not significant ($\beta = 0.028$, n.s. [nonsignificant]), which invalidated H1a.

3.5.2 Relationships between expectancy values and desires

As expected in H4c and H5a, the links evaluative social identity \rightarrow desires ($\beta = 0.245$, $p < 0.001$) and isolation rupture \rightarrow desires ($\beta = 0.333$, $p < 0.01$) were found to be significant. To a lesser extent, in H4d and H6a, the links group norms \rightarrow desires ($\beta = 0.194$, $p < 0.01$) and anticipated positive emotions \rightarrow desires ($\beta = 0.122$, $p < 0.05$) were validated.

The links affective social identity \rightarrow desires ($\beta = 0.083$, n.s.), cognitive social identity \rightarrow desires ($\beta = -0.031$, n.s.), information needs \rightarrow desires ($\beta = -0.04$, n.s.), instrumental needs \rightarrow desires ($\beta = 0.024$, n.s.) and anticipated negative emotions \rightarrow desires ($\beta = 0.055$, n.s.) were not significant, invalidating H4a, H4b, H5b, H5c and H6b.

3.5.3 Relationships between trust and desires

Unexpectedly, the links inaccurate medical information → desires ($\beta = -0.022$, n.s.), privacy concerns → desires ($\beta = 0.013$, n.s.) were not significant, which invalidated H7a and H7b. These results are summarized in Table 38 and Figure 5.

Table 38. Results of Hypotheses Tests		
Hypothesis		Supported?
H1a	Habits are positively related to online action regarding virtual patients' communities	No
H1b	Use Frequency is positively related to online action regarding virtual patients' communities	Yes
H2	Intentional action is positively related to online collective action regarding virtual patients' communities	Yes
H3	Desires are positively related to intentional collective action.	Yes
H4a	Affective social identity is positively related to desires regarding virtual patients' communities	No
H4b	Cognitive social identity is positively related to desires regarding virtual patients' communities	No
H4c	Evaluative social identity is positively related to desires regarding virtual patients' communities	Yes
H4d	Group norms are positively related to desires regarding virtual patients' communities	Yes
H5a	Isolation rupture is positively related to desires regarding virtual patients' communities	Yes
H5b	Information needs are positively related to desires regarding virtual patients' communities	No
H5c	Instrumental needs are positively related to desires regarding virtual patients' communities	No
H6a	Positive emotions are positively related to desires regarding virtual patients' communities	Yes
H6b	Negative emotions are negatively related with desires regarding virtual patients' communities	No
H7a	Inaccurate medical information is negatively related with desires regarding virtual patients' communities	No
H7b	Privacy concerns are negatively related with desires regarding virtual patients' communities	No

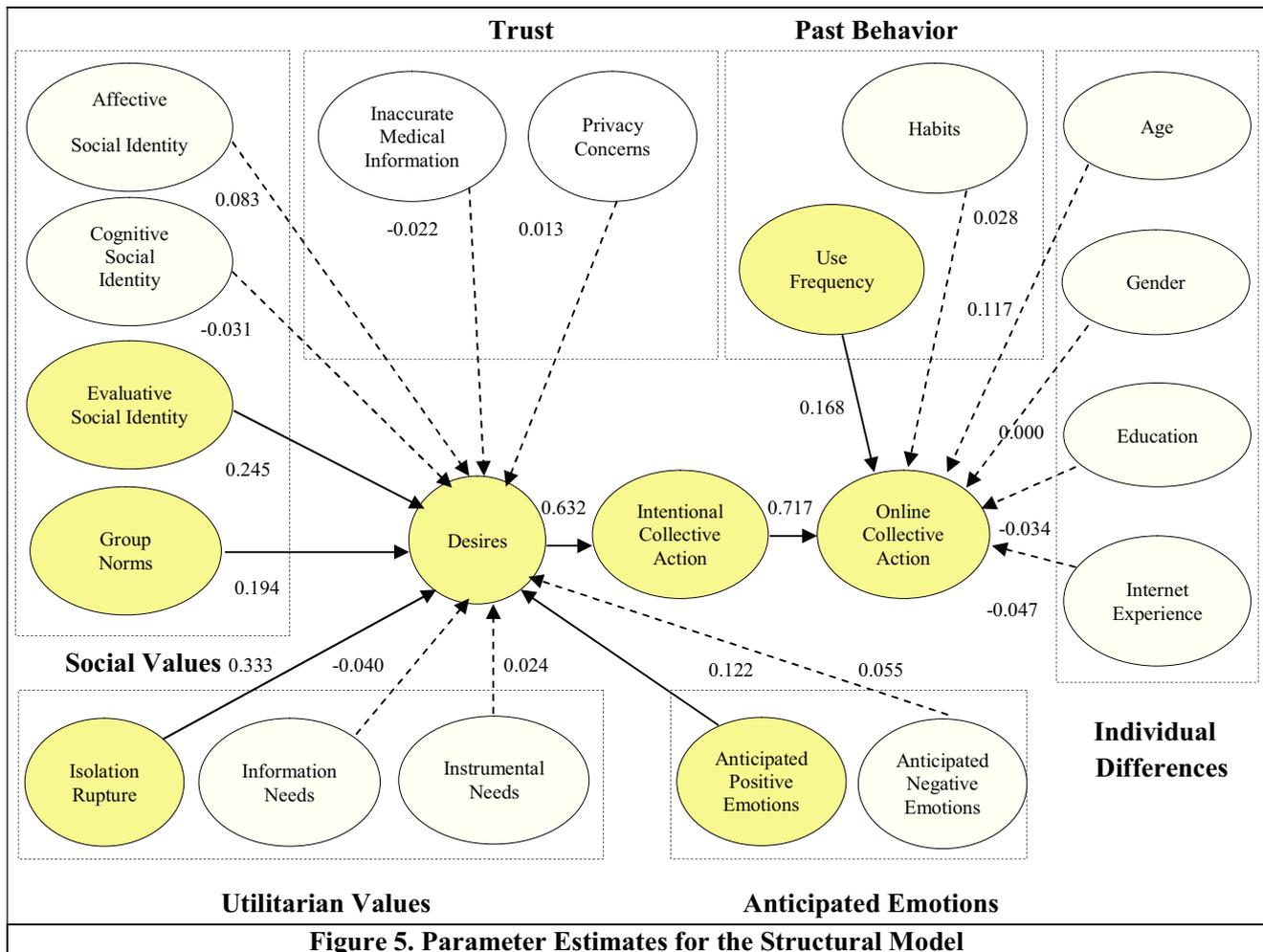


Figure 5. Parameter Estimates for the Structural Model

3.6 Discussion and contributions

Given the context of usage of health virtual communities, the utilitarian perspectives of many of the extent adoption models (e.g., Davis 1989; Venkatesh et al. 2003) are probably not the most relevant for investigating online collective action in the context of health-related virtual communities. In fact, being meaningful for other virtual communities actors is sometimes more important than any economic reward. The

determinants of altruistic action may also reflect the quest for the sense of self, belonging and ownership (Abma and Baur 2012). More specifically, we may, for example, expect that patients differ from other users in more traditional settings of technological interaction. For example, patients may be significantly influenced by emotional factors due to some concerns about their illness. Further, the sensitivity of the information shared – especially when very personal, may for example raise concerns about the trust on the platform.

The purpose of this study was to examine the determinants of online collective action on patients' communities. It makes four major contributions to research and practice.

Firstly, it helps to create a rich, contextualized social media adoption model for health purposes. The multi-method, critical realist approach contributes to the study's relevance - with a qualitative approach that enriches the research model with insights from patients' experiences, and rigor - with a subsequent quantitative study to measure the impacts of the determinants of online collective action. We demonstrate the relevance of combining MGB and EVT for developing a model for examining the determinants of patients' online collective action. Doing so, we enriched the underlying framework of MBG - established by Perugini and Bagozzi (2001) and adapted to virtual communities by Dholakia et al.(2004) - by offering a holistic understanding of the determinants of desires to participate in online collective action based on EVT's (Eccles et al. 1983) tasks values. The qualitative approach allowed us to provide a deep understanding of the context of our research and the quantitative approach enabled us to conceptualize a model, which could be tested or augmented in other fields of inquiry. The quantitative also allows data triangulation. It helps confirm the qualitative field's

findings about desires being a determinant of intentional collective action, itself a determinant of online collective action. Besides, we enhance those findings by identifying the determinants of online collective action. Online collective action is a function of past behavior. Specifically, use frequency, explains this collective action, as a direct determinant, while habits, an automatic behavior activated by the environment (Ortiz de Guinea and Markus 2009), has no influence on OCA. OCA is also a function of intentional collective action.

Desires is a function of social values, utilitarian values, and anticipated positive emotions, in line with the latest findings on virtual communities (Tsai and Bagozzi 2014). However the results show that patients' desires to interact are not significantly constrained by anticipated negative emotions as many patients were either prepared to it or able to cope with it. Similarly, information and instrumental needs were not found to be significant, even if information are exchanged on the platforms, they are not the main reason why patients are willing to interact with each other compared to their needs for isolation rupture or anticipated positive emotions. Specifically, the evaluative component of social identity influences desires to interact online for patients, contrary to the affective and the cognitive ones. This result should be further clarified for any type of communities as, to our knowledge, it has not been demonstrated in other research (Dholakia et al. 2004; Tsai and Bagozzi 2014) and as they may differ depending on the communities' participants.

We then focused on collective action and intention, in contrast with personal action and intention as behavior and behavior's determinant. The results confirmed the importance

of desires and their capability to “convert reasons for action into intention to act” (Tsai and Bagozzi 2014, p.157).

Secondly, this study responds to key challenges in IS adoption research, which has long been examining usage with less consideration paid to other kinds of interactions with and around the IT (Benbasat and Barki 2007b), e.g. online collective action. For example, research has been conducted on the determinants of social networks' usages (Sledgianowski and Kulviwat 2009; Lankton and McKnight 2009; Steinfield et al. 2008; Ross et al. 2009; Mlaiki et al. 2012; Baker and White 2010). However, it has mostly applied lean IT adoption measures (Burton-Jones and Straub 2006; Straub and Burton-Jones 2007), sometimes very far from what is experienced on the field (Straub et al. 1995). Further, it often lacks a contextualized approach, which would enable one to create and to test richer usage-related constructs based on specific common interest exchange on virtual communities - in our case, patients' communities - with narratives and quantitative data. In this process, the critical realist perspective helped us get insights from the field along with a literature review, exploring different arenas and articulating theories relevant for examining patients' online usage – EVT and MGB. Overall, the research helps understand why patients are motivated to act and interact with other patients through technology, and what the role of non-IT determinants is in this process.

From an e-health practice standpoint, a third contribution of this research regards how individuals respond to isolation feelings. They see virtual worlds as a means to reduce perceived isolation and improve their capability to face day-to-day hardships. A major concern is that patients often feel alone, helpless and unmotivated when confronted with

illness. In this context, virtual communities can be viewed as a support for maintaining patients' ties and social relationships. The results of this study are important because they will help Health 2.0 stakeholders to better acknowledge issues such as that of the kind of social community platforms that ought to be designed in order to respond to patients' needs and, therefore, foster their engagement, the social media policy that may or should be applied, the messages that they may diffuse, or the factors they should influence so as to deliver the best social experience possible to patients in virtual communities. Eventually, the study's results will help to more effectively take the disabled and ageing population's health challenges into consideration.

Finally, the research highlights the trust aspects in patients' virtual worlds. The study shows that online collective action among patients is not a matter of trust. Patients are willing to contribute in others' well-being for social, utilitarian values, and positive reasons. Privacy issues and the fear of facing inaccurate medical information do not prevent them from interacting with peers through the online communities. However, these results shouldn't clear Health 2.0 practitioners of any responsibility regarding these issues, for two main reasons. First, the fact that trust does not impact desires means that patients are also likely to interact with an insufficient consideration made to confidentiality issues. Second, during the qualitative phase, patients expressed their need for information control and for online clinical advice that would be performed by health professionals. The first two may imply the need for a more significant medical presence in patients' platforms, which is already the case in many communities, but not systematic. The latter would require making mandatory users' need to log in to be allowed to read forum contents. Those issues also imply that online community

designers should be cautious in integrating appropriate security features on their platforms. A cautious approach should be observed behind these trust issues, with a growing and ageing worldwide population, and growing Internet use.

3.7 Limitations and Future Research

A multi-method qualitative and quantitative approach has been conducted for this research. Interviews have been conducted in order better understand what patients would be more concerned with, and in order to reach semantic saturation. Our specific field of inquiry required this partly inductive approach. Then we conducted a quantitative phase in order to be able to draw conclusions as well as a complete model of patients' online collective action. Although we presented a generic model that can be studied in specific virtual communities and cultural settings' communities within the same epistemological guidelines, we needed, in order to avoid flawed contributions and conclusions' research, to contextualize our work.

Therefore, this research presents limitations which are also opportunities for further investigations.

Firstly, we have developed and tested a research model in a French context, in order to avoid introducing biases from multicultural settings. Though, so doing, the results are probably not generalizable to patients from other countries, as the digital divide between developed and developing countries still exclude some users due to the limitations of the Internet or exclusion of some social strata - with 4 billion people not yet using the Internet, and more than 90% of them located in developing countries (ITU 2014) -, therefore, impacting their collective action, online (Joinson et al. 2007). Therefore,

future research may explore differentiations and/or similarities of behavior of patient's online collective action.

Secondly, the research has been conducted on specific cancer-suffering patients' virtual communities in both the qualitative and the quantitative phase. It would also be relevant to investigate populations other than cancer communities. As well, populations other than patients' communities, sharing diverse concerns or interests, ought to be examined. Therefore, future research can build on the research model of social media adoption. While some variables could be applied as is, others, such as trust, may be adapted with the more holistic concept of cost, which offers a wide range of factors (including trust) to be explored in a given community (Eccles et al. 1983).

Thirdly, the patients' sample comprises a large majority of women. It may therefore not be possible to extrapolate the results to both genders, indeed previous research show that women (65%) are more likely than men (53%) to look online for health information (Pew Research 2011). Future research may hence try to identify variations across genders regarding the determinants of online collective action on patient's online communities.

Finally, the impact of time over social identity or emotions' determinants for patients should be considered depending on the disease evolution. Indeed, patients can become experts or leaders in their own communities, raise their voices and become a role model for newcomers for the sake of these environments. They can also bridge patients-practitioners or pharmaceutical stakeholders' communication gap. Therefore, the study of their attachment to the communities, long after remission in some cases, would greatly benefit to knowledge.

3.8 Conclusions

EVT, MGB's underlying framework, applied to virtual communities, offer important grounding concerning the leading determinants of online collective actions for patients. A multimethod approach has been applied in order to account for the specific context of patients' virtual communities. The community-based background of patient members includes a large number of users, most often weakened by their disease, seeking interaction on these platforms.

Although the emotional dimension remained significant in patients' motives for joining online communities, the findings suggest that the MGB contributed to offer a relevant model for predicting intentional action to engage online. All these variables were validated by the quantitative analysis. However, some utilitarian values, such as information needs and instrumental needs were integrated in the model as they are in the adaption of MGB in Dholakia et al. (2004) past study, but were not validated by our study.

The Internet and patients' initiatives are changing the face of medical practice, previously limited to a top-down approach where health professionals and third parties involved communicated a restricted amount of information to patients. The research suggests that virtual communities are an opportunity to develop virtual spaces for people seeking information and support online.

Arguably, by connecting to virtual communities, patients may improve their quality of life, for to the benefits provided by discussions with others. This is even more the case when those patients cannot interact in more traditional social groups in real life. In this, online communities are likely to bring social benefits such as reduced isolation, which e-

health professionals should leverage. Health professionals and third parties have long been those who communicate (a limited amount of) information to patients in a top-down way. The Web 2.0 fosters online collective action, and subsequently the participation of patients in generating useful content in virtual communities. Eventually this research emphasizes the need for researchers and practitioners to better take into account the ageing population's health challenges. It also shows how patient's virtual communities can help support patient's concerns.

4 - SYSTEM USAGE AND SOCIAL BEHAVIORS IN WEB 2.0 ENVIRONMENTS: THE CONTRIBUTION OF GIFT-GIVING CONCEPTS TO ONLINE COLLECTIVE ACTION ³

³ Laubie, R. (2015). Expectancy Values and Gift-Giving Influences on Patients' Online Collective Action. (*OCIS 2015*), Vancouver for McGill University, Canada, August 7, 2015.

4 SYSTEM USAGE AND SOCIAL BEHAVIORS IN WEB 2.0 ENVIRONMENTS: THE CONTRIBUTION OF GIFT-GIVING CONCEPTS TO ONLINE COLLECTIVE ACTION

4.1 Introduction

In the IS domain, several models have been developed to examine technology adoption and success around the concept of system usage (Hofmann 2002; Bokhari 2005; Straub and Burton-Jones 2007; Burton-Jones and Gallivan 2007; Usluel and Mazman 2009). In Web 2.0 contexts such as online communities, more than system usage, *collective action* reflects the success of technology artefacts (Eysenbach et al. 2004; White and Dorman 2001). While critical in collective action in Web 2.0 contexts, however, little do we know about the characteristics of gift-giving behaviors and how social actors perform it. Accordingly, this study examines the characteristics and dynamics of gift-giving behaviors in online community environments.

The technology acceptance model (TAM) (Davis 1989) is a widely applied framework for describing users' adoption of IT, linking behaviors to attitudes and beliefs, namely ease of use and usefulness "that are consistent in time, target, and context with the behavior of interest" (Wixom and Todd 2005, p.85). Later on, UTAUT (Venkatesh et al. 2003) augments TAM, identifying four determinants (performance expectancy, effort expectancy, social influence, and facilitating conditions) of behavioral intention, itself a determinant of usage.

In spite of the interest of such models for better acknowledging technology adoption, Burton-Jones and Straub (2006) explain that they doubt that usage intentions and behavior in TAM capture the very notion of acceptance. They urge “researchers to provide systematic evidence for which usage measures, if any, are valid proxies for related constructs and to determine which other constructs, if any, are good proxies for system usage” (Burton-Jones and Straub 2006, p.241). Bokhari (2005) further highlights that research does not offer congruent conclusions linking system usage and user satisfaction. Regarding the IS Success Model (Delone and McLean, 2003), Hofmann (2002) warns about the implications of collective phenomena appending a multilevel nature for system usage.

Some researches drew on several of the aforementioned IS adoption models to explain user adoption through the impact of ease of use and usefulness in the Web 2.0 context. They demonstrated that some variables such as usefulness may contribute to the gathering of a critical mass of users (Shin and Kim 2008; Shin 2008; Wu et al. 2008). Nevertheless, the collective phenomena per se are not conceptualized into those models. For example, in the case of corporations: taking into account corporate culture, the support of top management, proper leadership, communication, motivation and training of end-users should be further studied, as explained in the case of web-based collective action (Trkman and Trkman 2009).

Burton-Jones and Gallivan (2007) also emphasize concerns about the lack of consideration for several levels of analysis in a theory such as UTAUT as constructs are conceptualized mostly at the individual level. As a result, for not considering the group

level for example, and in spite of the conceptual strength of all those models for understanding system usage, we believe that, alone, they do not provide a sufficient basis for examining online collective action (OCA) in Web 2.0 contexts.

In sum, those models fail to address four main gaps. First, they all focus on a user-centric approach of the interaction between users and IT, which remains silent on the fundamentally collective nature of the usage and of the benefits of Web 2.0 technologies. In contrast to Web 1.0 IT, Web 2.0 IT usage underlies collective action. For this, conceptualizing Web 2.0 system success through the concept of system usage would not be fully satisfying, as its fundamental benefits lie in the collective use of the technology (Burton-Jones and Gallivan 2007; Rheingold 2003). In this, as argued by Lamb and Kling (2003), users can fundamentally be seen as social actors who interact through technologies and should be treated as such. Benbasat and Barki (2007a) or Straub and Burton-Jones (2007) further explain that existing research on technology adoption and usage has studied a too narrow set of variables around the concept of system usage, (Skageby 2015), that adoption research has hardly sought to examine important mediators or moderators of system usage such as those in the realm of emotions. Accordingly, Burton-Jones and Straub (2006) argue that it is necessary to reconceptualize system usage and call for the development of more contextualized usage variables. Skageby (2015) explains that digital ecosystem offer new perspectives combining gift behaviors and media technologies. Unfortunately, little-to-no indications have been given to better understand how to account for Web 2.0 contexts, and what system usage is in those contexts.

Second, those models do not or hardly account for the role of emotions in the course of individual interactions with technology and whether those positive or negative emotions play a role in the results of IT introductions to people (Beaudry and Pinsonneault 2010). Arguably, as they imply frequent interactions and interdependencies-in-use among people, Web 2.0 technologies are frequent occasions for emotional processes to occur (Tang et al. 2012) and gift-giving behaviors to develop (Skageby 2010). This is especially the case of patients 2.0 contexts, where people are looking for information about their – sometimes severe - health issues (Arnst 2008). By neglecting emotions and gift concepts, “traditional” adoption models such as TAM, UTAUT, or ISM, are insufficient to provide in-depth insights about patients’ interactions with IT.

Third, interestingly, all those models are very silent on the nature of the links among actors of social websites. Social actors interacting on Web 2.0 websites have both instrumental and non-instrumental behaviors led by their desire to share their experience with others. Online collaboration requires social ties between the giver and the receiver and a high level of trust between social actors (Bergquist and Ljungberg 2001). While information is shared for free, intense collective action results in rich and valuable website information content for e-patients. Arguably, the concept of gift may therefore help to further our understanding of those links. However, to our knowledge, IS research has not examined in sufficient depth that concept and the characteristics of gift-giving behaviors in online environments (Bergquist and Ljungberg 2001).

The gift concept is a critical one when examining social actors’ interactions in virtual environments, especially in the medical sphere.

For all those reasons, we argue that the existing theoretical frameworks have to be adapted, specifically concerning the role of gift in online collective action. In order to address those research gaps, our research questions are, therefore:

1. What are the characteristics of gift-giving behaviors in the context of online collective action in virtual communities?
2. How do patients perform gift-giving behaviors in the context of online collective action in patients' virtual communities?

In order to respond to those research questions, a qualitative exploratory study has been conducted. We investigated the role of gifts, from Mauss' (2002) initial perspective, which has earlier been leveraged in works dealing with open source communities, in order to explain the successes of collaborative artefacts, work and outputs (Bergquist and Ljungberg 2001). Interviews with Web 2.0 experts, patients, and patients' relatives, have been conducted. This study provides additional knowledge about gift-giving behaviors and online collective action in the context of patients' virtual communities.

This chapter is organized as follows. In the first section, we discuss the challenges and issues related with system usage in Web 2.0 contexts. We then discuss the gift concepts in the context of online collective action, as applied to Health 2.0 virtual communities and virtual spaces. Following this, we explain the design and methods for the research. The different characteristics of online collective action regarding the gift-giving concepts are then described and discussed. Following this, the contributions and implications of research are emphasized. We then conclude the chapter.

4.2 Theoretical Background

4.2.1 Collective Usage and Collective Action among Social Actors

Collective actions theories have explained human behaviors in diverse environments such as corporate ones (Alter 2010) or social movements (Tarrow 2011). With new information and communication technologies, the concept of collective action needs to be revisited as collective action in actual social contexts differs from *online* collective action (Lupia and Sin 2003).

4.2.1.1.1 Users as Social Actor

Examining such social behavior when studying system usage underlies a social actor approach of the 'system user'. This is why Lamb and Kling (2003) also appeal for a reconceptualization of the user as a social actor, pointing out that:

“the theories that shape this understanding and influence the design and use of ICTs rely primarily on cognitive social psychology and cybernetic models that are contextually underdeveloped leaving nearly all of the organizational and environmental context outside the model”, p.198.

Therefore, users' comprehension needs further in-depth analysis, considering the cognitive processes system usage may require and social dynamics they are faced with (Orlikowski 1992).

Drawing on (Delone 2003) and Morgeson and Hofmann (1999) studies, Burton-Jones and Gallivan (2007) investigated the 'multilevel nature of system usage or collective

usages of information systems, highlighting “the fundamental difference between individual and collective phenomena”, p.663:

“The structure of individual ability refers to scripts, schema, and other cognitive and biological factors, whereas the structure of ability for higher level aggregates not only includes these cognitive and biological factors (since collectives are composed of individuals), but they also involve something more. This something more is the interaction between these individuals” (Hofmann 2002).

Burton-Jones and Gallivan (2007) further posited: “Collective usage is not simply the sum of its parts (i.e., the sum of members' usage) because it also comprises interactions”, p.663.

Going beyond this notion of interdependencies-in-use, they developed a multilevel theory of system usage, where levels are individual, group and organization and dimensions are function of usage, structure of usage and context of usage. Structure of usage is comprised of two sub-dimensions, interdependencies-in-use and form of collective use:

“Because we wish to focus on interactions that are inexorably part of collective usage, rather than general social or task-related interactions, we focus on interdependencies-in-use, that is, dependencies among members of a collective that relate to their use of a system. Accordingly, we suggest that the first step in determining whether collective usage exists is to identify the presence of interdependencies-in-use”, (Burton-Jones and Gallivan 2007, p.663).

Collective usage needs to take into account social value such as interdependencies-in-use (Burton-Jones and Gallivan 2007) that highlight these interactions. These

interdependencies-in-use can be reflected in the gift-giving behaviors as the functioning of virtual communities relies on gift relationships and the gift economy (Rheingold 1995), which have the potential to frame many online collective actions (Skageby 2010). Interactions in online communities are indeed based on foundations other than traditional cost-benefit rationality.

The concept of online collective action, though, still lacks elaboration in the literature. Its nature depends on the virtual community's characteristics, its social identity, its members (Allen and Meyer 1996; M. Bergami and Bagozzi 2000; Luhtanen and Crocker 1992) and its groups norms (Dholakia et al. 2004). Besides, there is interest in the literature for this concept, with the emergence of open source software development and open source revolution (Bergquist and Ljungberg 2001; Bezroukov 1999; Feller and Fitzgerald 2000; Kollock 1999; Mockus et al. 2000) as well as virtual communities' expansion (Skageby 2010; Skageby 2015; Faraj et al. 2015). In the aforementioned prior research, the interdependencies-in-use, which are identified in "collective usage" are poorly reflected in technology system usage theories. In that respect, we believe that gifts theories can improve our understanding of such interdependencies in-use.

We further introduce these concepts below.

4.2.2 Gift Concepts

The gift-giving literature analysis allows to identify concepts that may be relevant for explaining social actors' behavior in virtual communities. Gift-giving behaviors shape

social activities and bounds (Komter 1996) even if they are determined by rational or mechanical rules (A. Komter 2007).

Some research highlight two main perspectives in the concept of gift: the utilitarian one (Mauss 1922 ; Malinowski 2010; Gregory 1982; Bataille 1967; Godbout and Caillé 1992; Alter 2010; Camerer 1988) and the social one (Hyde 2007; Bollier 2001; Skageby 2010) (see Table 39.1, 39.2) . Other researchers highlight the role of emotions depicting individuals' other-orientation motivations in order to contribute to others' well-being in a non-utilitarian way (Ruffle 1999; Komter 2007; Komter 1996). We will describe these three main perspectives in the following sections.

4.2.2.1 Utilitarian Value

The utilitarian perspective of gift-giving behaviors has been studied in different disciplines such as sociology (Mauss 1922; Gregory 1982; Godbout and Caillé 1992; Alter 2010; Camerer 1988) and anthropology (Malinowski 2010, Bataille 1967) (see Table 39.1).

This utilitarian perspective has several preconditions associated with gift-giving behaviors, namely to give, to receive and to repay (Clarke 2007). These preconditions involve the notion of a reciprocal dependence and therefore a return where gifts create a debt for the receiver (Gregory 1982).

Mauss (1922), through ethnographic studies of primitive societies, defined the gift as the action, from a person representative of the community, to give by offering something valuable to someone in order to seal a relationship in a mutual indebtedness. Therefore,

the gift, through its specificities, embodies the power that compels the recipient to give back, in this utilitarian perspective. In this regard, social bounds and relationships are established and maintained as gifts are made and reciprocated with interest.

Alter (2010) highlights the notion of gift-giving in business cooperation, where the gift is never free as it obliges the person who received it. Therefore, altruism is excluded from these environments, leaving room for strategic means that allow individuals to reach their hidden goals. Alter explains that corporate relationships are not all governed by contracts, but by cooperation, in which it is necessary to give, receive and give back. This cooperation induces employees' feelings that exclude pure market logic but still remain rational. Indeed, those who have been helped will have to repay their donor.

Malinowski (2010) further stressed the concept of bond created, especially between individuals, thanks to these gift-giving experiences. Although critics argue that some goods create "a political dependency on inalienable possessions" (Weiner 1992, p.39) drawing on the "paradox of keeping while giving", we believe that these specific cases don't contradict the Mauss and Malinowski general notion of reciprocity as the implicit and core ingredient of a sustainable relation offered by the gift-giving experience (Skageby 2010).

Therefore, and concerning the implication of the utilitarian approach of the concept of gift for online collective action, these theories highlight that giving consists in taking the initiative in the exchange that seals a relationship in a mutual indebtedness. Reciprocity is an implicit and essential condition of the gift-giving experience that will induce the quality and sustainability of collective action.

Table 39.1 Gift Concepts as an Utilitarian Value

Dimension	Area	Definition	Author
Utilitarian Value	Sociology	“If one gives things and returns them, it is because one is giving and returning ‘respects’—we still say ‘courtesies’. Yet it is also because by giving one is giving oneself, and if one gives oneself, it is because one ‘owes’ oneself—one’s person and one’s goods—to others.” (Mauss 1922, p.59)	(Mauss 1922)
	Anthropology	Malinowski (2010) emphasized the reciprocity of exchanges as the demonstration of gratitude between individuals. Gratitude ensures the duration and stability of the trade and its repetition secures the implication of both parts.	(Malinowski 2010)
	Sociology	“Gift exchange is an exchange of inalienable objects between people who are in a state of reciprocal dependence that establishes a qualitative relationship between the transactors” (Gregory 1982, p.16)	(Gregory 1982)
	Anthropology	In Bataille’s theory of consumption, the accursed share is that excessive and non-recoverable part of the economy which highlights the willingness to create a link, to sacrifice something to manifest the desire to create this link.	(Bataille 1967)
	Sociology	Free gift doesn’t exist and altruistic behavior in gift-giving is a missing characteristic. Reciprocal behavior is a core incentive of the gift-giving experience.	(Godbout and Caillé 1992)
	Sociology	The gift is nothing but a strategic means to achieve goals in the corporate environment. Altruistic behaviors or free gifts don’t exist; however, they can be reduced to strict market logic.	(Alter 2010)
	Sociology	“The variety of sociological explanations for gift giving suggests a second explanation, that gifts might serve multiple signaling purposes simultaneously –signaling “willingness” to invest in a relationship while also conveying meaning about the giver’s tastes or identity or beliefs about receivers” (Camerer 1988, p.199)	(Camerer 1988)

4.2.2.2 Social Value

In media and communication literature, gift-giving will benefit to social relationship and bonds, as the foundation of social exchange that will foster community-building processes (Skageby 2010). Indeed, some studies emphasize the human relationships

and emotions within the gift-giving experiences (Chakrabarti and Berthon 2012), highlighting “the connection between giver and receiver is the inescapable backdrop within which a gift-giving experience must be examined” (Larsen and Watson 2001, p. 894). They are closely related to the strength of ties (Granovetter 1983). Bollier (2001) also supports the social value behind the gift-giving experiences, thus contradicting market economy principles, as the members of gift economy value individuals, places and shared experiences and not monetary benefits.

In anthropology and psychology literature, Hyde (2007a) argues that a true gift shouldn't imply any obligation and that the social and personal bounds that connect givers and receivers don't respond to market needs or spheres that remain impersonal by nature. As a result, “it is true that something often comes back when a gift is given, but if this were made an explicit condition of the exchange, it wouldn't be a gift” (Hyde 2007b, p.11). Derrida's work follows this path stating that “for there to be a gift, there must be no reciprocity, return, exchange, counter-gift, or debt” (1992, p.12).

Therefore, and concerning the implication of social value of gift concepts for online collective action, these theories highlight that giving, whether considered as self-centered or other-oriented, when present in a community context creates a dynamic that leads to a sharing spirit supporting online collective action.

Table 39.2 Gift Concepts as a Social Value			
Dimension	Area	Definition	Author
Social Value	Anthropology and Psychology	“If we take the synthetic power of gifts, which establish and maintain the bonds of affection between friends, lovers, and comrades, and if we add to these a circulation wider than binary give-and-take, we shall soon derive society, or at least those societies – family, guilt, fraternity, sorority, band, community – that cohere through faithfulness and gratitude. While gifts are marked by motion and momentum at the level of the individual, gift exchange at the level of the group offers equilibrium and coherence, a kind of anarchist stability.” (Hyde 2007, p.96)	(Hyde 2007a)
	Media and Communication	“Gift economies are potent systems for eliciting and developing behaviors that the market cannot — sharing, collaboration, honor, trust, sociability, loyalty. In this capacity, gift economies are an important force in creating wealth, both the material kind prized by the market and the social and spiritual kind needed by any happy, integrated human being.” (Bollier 2001, p.3)	(Bollier 2001)
	Media and Communication	“Gift economies can indeed support individual selfish motivation and needs, but, when pursued by a larger number of people, converge to form common resources or positive externalities that create a ‘sharing spirit’ that is different from the pure utilitarian rationalism of economic theory” (Skageby 2010, p.172)	(Skageby 2010)

4.2.2.3 Additional Theories and Emotional Value

Other studies highlighted four dimensions of the gift-giving experience (Larsen and Watson 2001) – namely: economic value, functional value, social value, expressive value - essentially serving as “signals of a person’s intentions about future investment in a

relationship” (Camerer 1988, p.180). For example, according to Larsen and Watson, the gift-giving experience is comprised, first, of an economic value where “participants do not give gifts out of altruism, but rather because they expect to receive something at a later date” (Larsen and Watson 2001, p.891). This dimension disputes the concept of pure gifts, where seen as “the logical opposite of commodity exchange and necessarily personal, reciprocal, and socially binding” (Laidlaw 2000, p.618). This dimension may also conflict with the emotionally-loaded intangible aspect, conveyed by the meaning the gift discloses over the tangible object per se (Chakrabarti and Berthon 2012).

Secondly, the gift-giving experience involves a functional value (Sheth et al. 1991), where gifts' utilitarian performance remains the driver of the individuals' perception of the value of gifts. However the functional value is often of minor relevance in gift-giving experiences (Larsen and Watson 2001), and one should not mistake the utilitarian performance of the gift itself for the utilitarian perspective designed by the giver as highlighted above and in Table 39.1, in Mauss and Malinowski's definition of the gift.

Thirdly, the gift-giving experience encompasses a social value, symbolizing and conveying meaning (Camerer 1988), indebtedness and social ties and where “gift exchange is an exchange of inalienable objects between people who are in a state of reciprocal dependence that establishes a qualitative relationship between the transactors” (Gregory 1982, p.101).

Fourthly, the gift-giving experience entails an expressive value as the expression of the giver's self is contained by the gift as a recipient of donor's self-identity (Sherry et al.

1993) as “giving one is giving oneself” (Mauss 1922, p.59) and “to make a gift of something to someone is to make a present of some part of oneself” (Mauss 1922, p.16).

Besides these aforementioned values, researches demonstrated that emotions can also be part of the gift giving experiences (Ruffle 1999) which is not always related to a hidden or instrumental agenda and that are mostly motivated by other-orientation's attributes, whether pure or moderate, where contributing to others' well-being can be considered as primary incentives and rewards without thoughts of a reciprocal obligation (Komter 2007).

Emotions can trigger gift-giving behaviors when the giver anticipates the receiver's positive emotions' effects such as love, happiness or esteem (Belk and Coon 1993; Otnes et al. 1994; Komter and Vollebergh 1997).

As a result of the gift-giving behavior, the giver may feel happiness or pride (Otnes et Beltramini 1996) or avoid the burden of guilt of selfishness (Wolfinbarger 1990)

Therefore, these feelings combined with other positive emotions, such as pride or confidence (Mick et Faure 1998), balance the givers' efforts (Belk and Coon 1993).

4.2.1 Gift Concepts in Online Contexts

Although the different conceptualizations of the gift concepts /behaviors may diverge, the literature provides interesting dimensions of values that can be taken into account in online environments. Indeed, for connected individuals, an additional difficulty lies in the context in which gift-giving behaviors are experienced (i.e., anonymity, exchanges

shared between multiple individuals ...), and, as a result, Mauss (1922) approach, which has been applied to societies from the early 19', may not be directly applicable in online contexts.

Gift-giving experiences on the Internet indeed differ from face to face experiences. For example, the recipient of useful information may be operating under anonymity and never be met again. Therefore a balanced reciprocity performed on a one-to-one basis loses significance and momentum, and the gifts are conducted for the benefit of the group as a whole. This network-wide accounting system (Smith and Kollock 1999) that allows the giver to receive back from another actor of the system introduces the concept of generalized reciprocity (Skageby 2010), which remains unknown or hardly conceivable in real life and offline exchanges. As a result, online gift-giving experiences foster higher generosity, as the giver does not have the guarantee of immediate reciprocation and faces the risk of free-riding behavior that can end up in social dilemmas (Kollock 1998, Yamagishi and Cook 1993, Kollock 1993).

Some researches demonstrate that patients, confined in virtual worlds, can "gift-give" as follows:

- i) although not similar to pure gifts (White and Dorman 2001) their virtual behaviors don't embed an economic value, due to the context itself of their actions,
- ii) while "it is less common for the functionality of a product to be central in gift exchanges" (Larsen and Watson 2001, p.893), patients perform peer-to-peer

healthcare; “lending a hand, lending an ear, lending advice”. Pew Internet research showed that “one in five internet users have gone online to find others who might have health concerns similar to theirs” (Pew Internet 2011).

Besides these behaviors, one should be cautious opposing the anti-utilitarian views - highlighting the rationales of personal relations and altruistic behavior for gift-giving - and the utilitarian views - highlight the rationales of the market, i.e. profit, trade, and exchange for gift giving - (Chakrabarti and Berthon 2012), that sometimes refer to pure gift or free gift (Laidlaw 2000) and that embed implicit conditions that can rarely be explained or met.

Therefore and regarding the virtual context, specifically in health-related communities, studies examining the role of gift in order to understand the functioning of virtual communities, ought to dedicate a close attention to the social dimension of gift-giving behaviors in which “gift giving on the internet gets its social meaning” (Bergquist and Ljungberg 2001, p. 314).

4.2.1.1 Patients' Online Gift-Giving Experiences' Framework

The most cited and core values as applied to online patients are emotional (Ruffle 1999; Komter 2007), social (Berking 1999) and utilitarian ones (Gérard-Varet and Kolm; Skageby 2010). Besides, the three main characteristics of the gift concepts highlighted in the literature, i.e.: i) other-orientation, i.e. helping others in order to enhance their well-being without hidden agenda, ii) bonding value, i.e. developing social relationships, and iii) generalized reciprocity, when the exchange of goods or services create mutual

(Skageby 2010). We can therefore associate what has been observed in the field and demonstrated in the literature. To do so, we can link : i) emotional value with other-orientation concept, ii) social value with bonding value and iii) utilitarian value with generalized reciprocity concept (See Table 40).

Table 40 Online Gift Concepts as Utilitarian, Social and Emotional Values

Dimension	Relevant Facet	Definition	Author	Implication for Online Collective Action
Emotional Value	Gift-Giving Experiences (Other-Orientation)	Draws on the concept of gift, implying a notion of pleasure related with the act of giving and independently of any hidden agenda that would seal a relationship of mutual indebtedness	(Ruffle 1999; Komter 2007)	
Social Value	Gift-Giving Experiences (Bonding Value)	“For gift-exchange is not only the significant form in which archaic societies reproduce themselves; giving and taking are also the elementary activities through which sociability became rich in evolutionary chances, and upon which a community-building process still rests.” (Berking 1999, p.31)	(Berking 1999)	Giving, whether considered as other-orientation self-characteristic, bonding or reciprocal instruments, foster online collective action
Utilitarian Value	Gift-Giving Experiences (Generalized Reciprocity)	“Reciprocity is often the means and vector of mutual self-interest” (Gérard-Varet and Kolm 2000, p.2) “Perspective assumes that the giver expects something in return” (Skageby 2010)	(Gérard-Varet and Kolm; (J. Skageby 2010)	

4.3 Research Design and Methods

This research is focused on two objectives, so better understanding : i) the characteristics of gift-giving behaviors in the context of online collective action in virtual communities and ii) the patients' gift-giving behaviors in the context of online collective action in patients' virtual communities.

In order to reach our research objectives and to identify the most relevant characteristics of gift-giving behaviors in patients' virtual communities, an ethnographic, qualitative

approach (Trauth 2001), has been applied. The steps that have been followed are explained in the Figure 6 below:

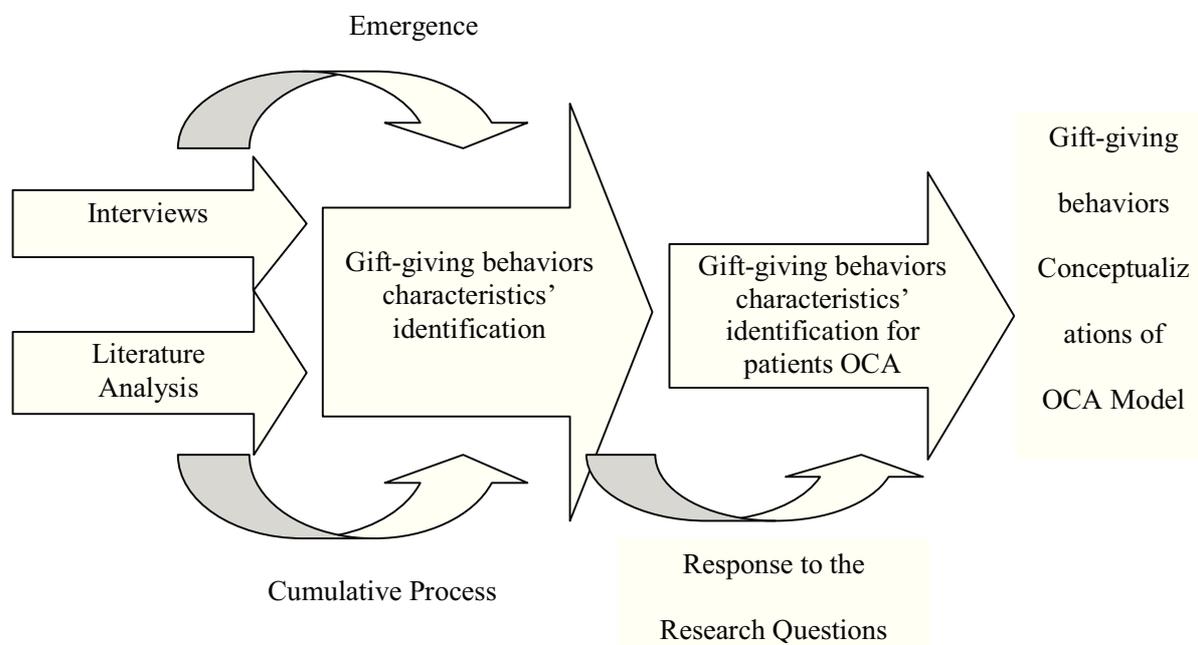


Figure 6 Critical Realist Research Design

4.3.1 Semi-Structured Interviews, Research Field and Participants

We conducted semi-structured interviews (Bryman and Bell 2011; Romelaer 2005) according to accepted approaches (Myers and Newman 2007), taking care of avoiding method bias such as elite bias - for connected patients that wouldn't be too familiar with online usages - or Hawthorne effects - that would result in patients modifying their answers in response to their awareness of being recorded (Parsons 1974).

When engaging in a patients 2.0-related research topic, specific attention should be paid to the diseases addressed by the online communities investigated, as it can potentially influence the results. Preliminary interviews conducted with Doctors, caregivers, Health 2.0 experts and Web 2.0 experts helped us choose the appropriate kind of virtual communities and patients' categories to focus on. The feedback was consensual and chronic or rare diseases were indicated to be suitable for such investigation.

Although we focused on French participants; research performed in the US further confirmed our online community choice. Indeed, Internet users living with chronic disease are more likely than other Internet users to access health information online:

“Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine” (Pew Internet Research 2010).

Understandably, the condition of rare disease patient also amplifies this need to spread their network far and wide and online connection will provide some answers:

“In rare disease communities, each person is an expert in observing the effects of a disease or a treatment on their own or a loved one's body or mind. In this way, rare-disease patients and caregivers who gather together online are an example of a “smart” group...They are diverse and decentralized, yet able to pool knowledge and summarize their observations” (Pew Internet Research 2010).

We therefore led our research to chronic and rare diseases' virtual communities, in compliance with insights brought by testimonies:

“In the selection of virtual communities I would give priority to the chronic or rare diseases. And I think that the networks in connection with rare or orphan diseases are among the most dynamic, one feels the need to find good information and share it with other patients.” (Health 2.0 expert)

Chronic diseases (21 patients) and rare diseases (8 patients' relatives) patients' communities were therefore chosen as backgrounds of our research with 25 females and 4 males online users. Preliminary interviewees were chosen for their command of social medias and connected spaces as well as their expertise of Health 2.0 arena (See Table 41, 42).

Approach	Objectives	Procedures
Qualitative Approach	<ul style="list-style-type: none"> Identify patients which whom we will conduct the interviews. Identifying in practice the emerging characteristics of gift-giving behaviors for patients joining web-based patients' virtual communities. Identifying in practice how connected patients perform their gift-giving behaviors in the context of patients' virtual communities. 	<ul style="list-style-type: none"> Ethnographic research approach in order to gain preliminary insights on patients' sociological typology as well as the characteristics of their gift-giving behaviors. 25 preliminary semi-structured interviews with Doctors and caregivers, Health 2.0 experts and Web 2.0 experts, users of patients' social networks. 29 subsequent interviews conducted with participants who had to deal with their own health issues or that of relatives.

Table 42. Interviews		
Interviewees	#	Purpose
Doctors and caregivers	5	To increase our understanding of the feelings and concerns of the patient population from a medical standpoint.
Health 2.0 experts	13	To increase our understanding of the patient population's activities when joining Health 2.0 IT from a medical and technological standpoint.
Web 2.0 experts	7	To increase our understanding of an individual's activity when joining online communities. To establish contrasts between health communities and more traditional communities.
Patients	21	To contextualize the individual and social activities when joining virtual communities from a patient standpoint.
Patients' relatives	8	To find the individual and social activities when joining virtual communities from the standpoint of patients' relatives.
Total	54	

As a result, a breast cancer virtual community gathering 10,000 patients and a rare disease community for patients' relatives gathering 97 users were studied. Both communities are non-profit associations and operate through a forum for the breast cancer community and using Facebook's features for the rare disease closed group. Members are free to display their identity on the first community and whereas only co-opted users are accepted in the Facebook group.

The interview guides (see Table 43, 44) were built in compliance with DeMarrais (2004)'s prerequisites in order to collect any materials that would emerge from patients'

narratives. It was built to determine segmentation and behaviors of patients' online. Hence, the choices of virtual communities to be studied resulted from the insights brought by these initial interviews, as well as the size and longevity of the virtual spaces. For each group, we stopped conducting interviews when semantic saturation was reached.

Table 43. Interview Guide in Preliminary SDCI	
Questions	Objectives
Is there an existing patient typology for a focus group whether they gather online or offline?	To identify a patient sample to address for the study
Are there patients' networks that are more suitable for some patients than other	To identify a patient's panel that would not be relevant for the study
What would be the patients' activities, online?	To compare the feedback of experts about activities for patients' online against the literature
What would be some hindrances to these online activities?	To compare the feedback of experts about hindrances to patients' online activities against the literature
What about privacy and data protection?	To compare the feedback of experts about hindrances for patients' online activities against the literature
Do you think these portals help patients during the healing process?	To compare the feedback of experts about positive psychology and patients' online activities against the literature

Table 44 indicates the questions patients and patients' relatives were asked regarding the literature's value dimensions investigated.

Table 44. Interview Guide in Patients and Patients' Relatives SDCI	
Questions	Value's Dimension Addressed
Do you feel the need to be informed or inform others on your disease?	
What (other than information) would you seek or give on an online medical portal?	Giving-Help (Other-Orientation/Bonding Value/Generalized Reciprocity) and specificities of those dimensions
Would you say special relations are developed with other patients participating?	

Do you feel the need to be connected to other online patients?

How do you feel when you're connected to people living the same pathologies?

Do you feel pleasure while connected to these participants?

Do you think you're helping people or being helped while connected?

Patients are likely to join online virtual communities for bonding reasons and to get helped. Most emotionally loaded testimonies also suggest an underlying willingness to help others patients:

“Yes. This is extremely important in these communities. Because you become the one who helps. You help because you wish to do so, you need it, just like that...because you can do it and it's important for you to do so just for what it means.” (Breast cancer community patient)

In order to get a more holistic view about how and why patients interact on online communities, we investigated the values as well as these online gift-giving behaviors' specificities among patients gathered on virtual communities.

4.3.2 Data Coding and Analysis

The thematic coding and data mapping (Bazeley and Jackson 2013) was performed with the qualitative data analysis software NVIVO (software version 9 and 10). Using software for coding interviews indeed allows avoiding some of the limitations of manual techniques as:

“proponents of CAQDAS argue that it serves to facilitate an accurate and transparent data analysis process whilst also providing a quick and simple way of

counting who said what and when, which in turn, provides a reliable, general picture of the data” (Welsh 2002, p.5; Morison and Moir 1998; Richards and Richards 1994).

The NVIVO software helped us for the thematic coding and data mapping, allowing us to add new categories emerging from the field and the literature during the whole process which was repeated three times before reaching semantic saturation.

Based on the literature inputs (See Table 40), a first dictionary of themes was obtained by grouping gift-giving behaviors under three categories – namely: other-orientation (emotional value), bonding value (social value) and generalized reciprocity (utilitarian value). We were attentive to any new category that would emerge from the patients’ standpoints through their testimonies. The open codes for gift-giving behaviors in the context of online collective are summarized in Table 45 below.

Table 45 Open Codes for Gift-giving Behaviors in the Context of Online Collective Action	
Dimension	Broad Nodes Generic Designation
Emotional Value	Giving-Help (Other-Orientation)
Social Value	Giving-Help (Bonding Value)
Utilitarian Value	Giving-Help (Generalized Reciprocity)

Overall, we adopted an incremental approach to data gathering, consistent with the critical realist paradigm (Zachariadis et al. 2010; Mingers 2000). In an iterative back and forth process between the research field and literature, we were attentive to any new categories that could emerge from interviewees’ testimonies. We expected to add any

new themes and concepts emerging from the field as well as specific designations of these themes and concepts.

This process resulted in a second version of the dictionary of themes. After the entire coding process and through interview analysis (Bhaskar 1979) the 3 categories for gift-giving behaviors in the context of online collective action were left unchanged. Indeed, SDCI interviews didn't lead to emergent categories with an acceptable occurrence rate to create new ones.

This new dictionary was obtained after we added only the contextual designation for the 3 categories for gift-giving behaviors in the context of online collective action (See Table 46 below). It therefore comprises 3 specific themes – namely: i) emotional support as specificity of generic theme giving-help (other-orientation/emotional value), ii) giving help about practical advices for coping with day-to-day health situation as specificity of generic theme giving-help (bonding value/social value), iii) giving-help about general information (medical or miscellaneous/utilitarian value) as specificity of generic theme giving-help (generalized reciprocity).

Table 46. Open Codes for Gift-giving Behaviors in the Context of Online Collective Action			
Broad Nodes Generic Designation	Broad Nodes Contextual Designation	Key Terms and Phrases	Number of References
Giving-Help (Other- Orientation)	Emotional Support	“so much support”, “seeking consolation”, feelings”, “state of fragility”, “find keen listeners”, ‘ I gave consolation”, “you become the one who helps”	49
Giving-Help (Bonding Value)	About practical advices for coping with day-to-day health situations	“being in a community of patients sharing the same disease”, “share”, “help to better live it”, “good advices”, “communicate on specific information”	35
Giving-Help (Generalized)	About General Information	“We asked each other’s about health topics”, general information”, “we talk about everything”,	31

Reciprocity)	(Medical or Miscellaneous)	“any kind of information”
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We then proceeded to analyses after we gathered enough information in order to reach semantic saturation (Glaser and Strauss 1967). We examined the interview data in an interpretive way where “you want to ‘read’ the interviews for what you think they mean, or possibly for what you think you can infer about something outside of the interview interaction itself” (Mason 2002, p.78). Furthermore we followed the principles for interpretive studies posited by Klein and Myers (1999) such as the principle of abstraction where the researcher relate the idiographic details revealed by the testimonies to more general level concepts. This approach led us to read through the data lines and to reach and understand the actual meaning of what was said. Besides, the multidimensional coding of the data allowed us to assign different codes to same testimonies’ passages (Saldaña 2012).

4.4 Results

The interviews led to important insights, such as the contextual designations for gift-giving behaviors in the context of online collective action. The data analysis confirms the meaningfulness of concepts that are frequently cited by interviewees, such as help-giving that relates to the gift concepts, which are too little in evidence in the literature. The following sections will present the answers to our research questions.

4.4.1 Research Question 1: What are the Characteristics of Gift-Giving Behaviors in the Context of Online Collective Action in Virtual Communities?

Drawing on Bergquist and Ljungberg's (2001) social meaning concept of gift-giving on the Internet in the context of virtual communities - namely other-orientation, bonding value and generalized reciprocity – we confirmed meaningfulness of these three gift-giving categories for online collective action (see 45).

The testimonies also confirmed that these three dimensions refer to the emotional value (other-orientation), social value (bonding value) and utilitarian value (generalized reciprocity) of online gift-giving behaviors.

First, the community members of patients' virtual communities are inclined to support each other through the ups and downs of disease's hardship. It refers to the other-orientation behavior highlighting emotional value to these gift-giving behaviors.

The community members know they will be able to find the support they need online:

“Although my family is there for me, when I'm down, when I seek support, the only suitable option is to reach the girls online. It's so powerful to lighten the burden of my doubts and heal my pains” (Breast cancer community patient)

They know they will be understood by other community members sharing the same concerns:

“We can feel the state of mind and emotions of the girls by the way they answer or don't. It's easy to feel it and support the ones we know. It also very rewarding for the one who gives this help.” (Breast cancer community patient)

In return they are inclined to be there and comprehensive listeners for the sake of others:

“I like and need to help others. It makes me feel useful and it's rewarding to see the effect on others. It's a give and take. It takes back the pride and pleasure of giving.” (Breast cancer community patient)

Second, patients' feel the need to gather online with peers and develop social relationships and bonds, referring to the social value or bonding value of gift-giving behaviors.

“At some point, I really needed to feel less isolated and the only option was to virtually connect. I couldn't leave my home and wanted to exchange with other that would encounter the same matters as I do. I needed to break with the loneliness that comes with the disease.” (Breast cancer community patient)

“When you're too weak to face the outside world you meet others online and you decide to meet sisters who share the same concerns.” (Breast cancer community patient)

“I don't know if feel so closed to others because I meet them online everyday or the other way around. But the bound is really strong” (Breast cancer community patient)

Third, the strong ties between online patients highlight the patients' needs to be connected to their networks, in order to share experiences about the course of their illness and to want to give-help in a utilitarian manner. It refers to generalized reciprocity behaviors.

As a result, patients in needs for information aren't left alone:

“I didn't wait for an appointment with my doctor anymore to find the answer of any information I would need. I know that the community members are here to help me if I need it.” (Breast cancer community patient)

Patients' decision-making process can benefit from others' testimonies resulting in their enlightenment:

“I've learned a lot from the discussions we had about what to do and the disease itself. I feel more equipped to fight my battle against cancer, and in return I can help others to be better informed.” (Breast cancer community patient)

4.4.2 Research Question 2: How do Patients Perform Gift-Giving Behaviors in the Context of Online Collective Action in Patients' Virtual Communities?

Drawing on the characteristics of gift-giving behaviors in the context of online collective action in virtual communities, we then investigated what specific designations of the three sub-categories of giving-help were relevant for connected patients, and how gift-giving was actually performed by connected patients.

Three main contextual designations were identified: i) other-orientation concept relating to the emotional support activity without demand of a return, ii) bonding value concept relating to the information sharing activity about practical advice that will help patients cope with day-to-day health situations, iii) generalized reciprocity concept relating to the flows of general information and social exchange activity, whether it concerns medical knowledge or other purposes.

Other-orientation mainly occurred through the manifestation of emotional support, when patients did care for others with the desire to relieve their suffering and to solace anxieties. The testimonies didn't show any hidden agenda or any expectation of a return. These actions were sufficient for patients to gain social assets and values out of them.

“When I feel down I know that I can get support from females sharing the same problems and, as a result, I do the same. It gives me confidence and makes me feel better.” (Breast cancer community patient)

Bonding-value was illustrated by the sharing of one-to-one advices that fitted specific concerns and matched pertinent needs, that were, most of the time, health-related. The very purpose of these actions was to answer utilitarian patients' needs and help them navigate through the hardship they're enduring.

“Many girls are experienced patients and can give you good advices about your condition that will answer your questions or solve some of your problems. That's very useful and comforting.” (Breast cancer community patient)

Generalized reciprocity referred to the sharing of one-to-many advices and supports. The very purposes of these exchanges weren't consistently health-related and the concept of hidden agenda absent.

“Any matter can be discussed or addressed online on these communities. That's useful and supportive and can be shared with the large majority.” (Breast cancer community patient)

Overall, the results of the categorization of gift-giving behaviors, as shown in table 47, stressed the importance of emotional support in patients' online interaction.

One should notice that among gift-giving behaviors' contextual designations, other-orientation dimension of giving-help is the most frequently quoted form of interaction. Online communities foster and welcome the discussion of sensitive issues, encouraged by peer support, whether performed under anonymity or not.

Table 47. Categorization of Gift-giving Behaviors in the Context of Online Collective Action			
Broad Nodes	Broad Nodes	Illustration	Number of

Generic Designation	Contextual Designation		References
Giving-Help (Other-Orientation)	Emotional Support	“There is so much support in the community. If a person has an anxiety attack in the middle of the night, she can come on the forum and automatically, someone will answer her, because she understands her pain and shares the same feelings.”*	49
Giving-Help (Bonding Value)	About practical advice for coping with day-to-day health situations	“Therefore you understand the importance of being in a community of patients sharing the same disease. We can see how other patients manage everyday problems. There is a lot of advice and help on this.”*	35
Giving-Help (Generalized Reciprocity)	About General Information (Medical or Miscellaneous)	“We asked each other about health topics, we give opinions on practitioners, the good and the less good, the health system, on trials, sometimes on the academic literature. There will always be patients of high expertise to consult in the community.”**	31

* Quotes from interviews with breast cancer community patients

** Quotes from interviews with parents of autistic children

4.4.3 Summary of Results

Among the participants, helping others through emotional support remains the main characteristic of gift-giving behaviors in virtual communities, then creating social links through the sharing of specific health-related information that will help others cope with day-to-day health situations, and, finally, more generalized exchanges of different kinds that will build the foundation of the group reciprocity in compliance with mutual self-interests.

Characteristics related to social behavior have also emerged from interviews, including psychosocial impacts resulting from membership of these communities. Benefits from this commitment are noticeable, namely enhancement of decision-making processes and choices and the role in healing.

The needs and the perceived breaches of these platforms have also been underlined, highlighting the need for moderation of irrelevant comments coupled with a professional medical presence.

4.5 Discussion and Conclusion

This study's central purpose was to examine the characteristics of gift-giving behaviors in the context of online collective action on patients' communities. We did this taking into account the specificities of the chosen patients' community.

Based on the model of goal directed behavior (MGB) (Perugini and Bagozzi 2001) and Dholakia et al. (2004) online resulting study and the gift-giving concepts (Skageby 2010); we highlighted the categories and specific values of gift-giving behaviors (See Table 46, 47).

Patients' testimonies highlighted that online interactions are highly related to the concepts of giving-help in online contexts. Prior research identified three main dimensions of giving-help online: other-orientation, bonding value and generalized reciprocity (See Table 47).

As a result the emotional support, the other-orientation dimension of giving-help contextualized within patients' virtual spaces, prevails. What may be striking is that this dimension of gift-giving behaviors, i.e. the willingness to provide positive emotions, is actually the most frequent social behavior among the actors, according to interviews.

Moreover, the giving-help through practical advice given for coping with day-to-day health situations, as well as general information providing, are the two other ways these gift-giving behaviors are emphasized in patients' feedback.

One should notice that, as they may be acting online in a greater wish to give information than positive emotions, emotional support seems to be predominating in their actual social behavior. Indeed, the need to give help was often expressed where we were expecting the need to get help. This highlights the principles of the gift economy as the foundation and cement of online communities that apply for diverse populations, including patients in the typologies studied.

As a result, patients grouped in large online communities and sharing very similar day-to-day issues, demonstrate behaviors that apply to gift economies and sharing spirit. The cost-benefit rationality does not guide their gift-giving behaviors through other-orientation characteristics. The willingness to help-back, even years after a remission, is not rare and emphasizes the importance for them to contribute to the group. The gift culture, highlighted by Rheingold (1995), is significant for patients' communities, where the bonding between participants is often immediate and especially of relevance, as the disease stigmatizes them.

Consequently, the bonding value and the need to bond profoundly shape their social relationships. New patients reaching the communities are adopted rapidly and with the confidence that s/he, sharing the group illness, belongs to the community. The bond formed is solid and will last for years, and often stays strong after the patient's recovery.

Group norms and its social value are strengthened by social exchange among actors characterized by the reciprocity and gift-giving behaviors. It goes beyond the notion of interdependencies-in-use and reveals the collective form of action. Therefore, the aspects of reciprocity give to the group its social value. Molm et al. (2007, p.200) define reciprocity by two dimensions: i) its instrumental or utilitarian value or human capital, ii) its symbolic and communicative value or social capital, where “the symbolic or communicative value is the value conveyed by the act of reciprocity itself, over and above the instrumental value of the benefit provided”.

Therefore, beyond the benefits provided to others during the act of reciprocity, the action itself, with uncertainty of other's reciprocity, brings value to the group, guides its norms and characteristics of patients' gift-giving behaviors in the context of online collective action.

4.5.1 Contribution

This study makes three major contributions to research and practice.

Firstly, this research highlights the characteristics of online collective action on patients' virtual communities relating to gift-giving concepts. From guidance provided by initial interviews we chose to focus on patient's virtual communities rather than patient's social networks. Indeed, as virtual communities imply strong ties between individuals, bonding value and emotional support, and as the sense of belongingness is a key determinant of gift-giving behaviors, these community virtual spaces for patients were indicated to be

relevant for our study. As a result, we demonstrated that gift-giving behaviors are meaningful endeavors in the context of online collective action in these communities.

Secondly, we performed analyses beyond the frame offered by traditional IS adoption models, which do not see users as social actors and do not frame interdependencies-in-use. We contextualized IT use in the e-health domain, and contributed to the analysis of gift-giving behaviors of patients, enabling the drawing of online collective actions specificities using both literature and field knowledge. Using a critical realist design helped us get insights from the field along with a literature review exploring different arenas and combining complete theories well suited for patients' online usage (Field Theory, MGB and the gift concepts). This helped to understand what kind of actions and interactions with others patients were performing online through technology, but driven by determinants other than the IT tools themselves. Traditional system usage research and IT artifacts offer a very partial view of how social actors interact in web 2.0 contexts. For that purpose, multidisciplinary knowledge from social psychology, sociology and anthropology is also needed in order to examine the various facets of online collective action, in given online communities populations.

Thirdly, we were able to reveal contextual designations behind patients' gift-giving behaviors. Indeed, from the literature we already discovered that the functioning of virtual communities relies on gifts as a way of: i) helping others and their well-being (other-orientation), ii) developing strong ties (bonding value), iii) creating mutual satisfaction which doesn't depend on who gives or who gets as long as exchanges endure (generalized reciprocity). So, the present research offers the contextual designations for

these three dimensions in the context of patients' communities. The values that emerged from the field were compliance with literature underlying framework and are as follows: i) emotional support activity (other-orientation), ii) sharing information about practical advice (bonding value), iii) giving general information and social exchange activity (generalized reciprocity).

4.5.2 Limitations and Future Research

This research has several limitations. Those limitations are also opportunities for further investigations.

Firstly, we targeted French patients in order to avoid introducing biases from multicultural settings, as multiculturalism can influence people, and in particular self and group identity (Fernback and Thompson 1995). Future research may explore differentiations and/or similarities of behavior of patient's online collective action.

Secondly, preliminary interviews suggested focusing on specific patients' virtual communities. It may also be relevant to investigate populations other than the breast cancer community and a community of parents of autistic children, whether mixed or exclusive types of patients gathered on the same platform. It may also be advisable to explore communities gathering users that share different concerns or interests, from shared hobbies or passions to communities of professionals comprised of persons in the same occupation or industry.

Thirdly, our patients interviewed were mostly female. Extending this study to both genders or exclusively to male patients may drive interest for comparing results.

4.5.3 Conclusion

The gift concepts and MGB's underlying framework, applied to virtual communities, offer important conceptual foundations for examining the characteristics of gift-giving behaviors on patients' online communities.

Although the emotional dimension remained meaningful in patients' motives for interacting online, the gift concepts complete the lack of an explanation, highlighting the notion of help-giving and the social value, predominant in their actions.

These above-mentioned aspects contribute to expand the development of virtual spaces for people seeking information and support online. The Internet and patients' initiatives contribute to make medical practice evolve. While previously limited to a top-down approach where health professionals and third parties communicated a restricted amount of information to patients, online communities allow a greater access to information and more relational support.

Hopefully, by connecting to virtual communities, patients will have an improved quality of life, due to the benefits provided, which are often different from those they would get from traditional social groups operating in real life. We urge researchers and stakeholders to contribute to further research in this domain. The current research helps to better take into account the ageing population's health challenges and emphasizes how patient's virtual communities can help support patient's concerns.

5 – DISCUSSION AND CONCLUSION

5 DISCUSSION AND CONCLUSION

This study's central purposes was: i) to examine the underlying determinants of online collective action on patients' communities, ii) to conceptualize a model that predicts intentional action and subsequently online collective action during users' interactions and iii) to identify the characteristics of gift-giving behaviors in the context of online collective action, given the specificities of a patients' community typology that was chosen for this purpose.

Based on the Field Theory of Lewin (1947), the Expectancy-Value Theory (EVT) (Eccles et al. 1983), the model of goal directed behavior (MGB) (Perugini and Bagozzi 2001) and Dholakia et al. (2004) online resulting study; together with insights and knowledge accumulated from the field (Bhaskar 2010); we conceptualized a model to predict online collective action on patients' virtual communities (See Figure 4). Based on the gift concepts (Skageby 2010) and the implications of collective phenomena for system usage (Benbasat and Barki 2007; Straub and Burton-Jones 2007; Burton-Jones and Gallivan 2007; Usluel and Mazman 2009), we determined the characteristics of online collective action regarding the gift-giving concepts (See Table 48).

Table 48. Research Issues

	§2	§3	§4
Theories	<ul style="list-style-type: none"> Expectancy-value – EVT (Eccles et al. 1983), the model of goal directed behaviors - MGB (Perugini and Bagozzi 2001) and Lewin (1947) Field Theory. 	<ul style="list-style-type: none"> Expectancy-value – EVT (Eccles et al. 1983) and the model of goal directed behaviors - MGB (Perugini and Bagozzi 2001) theorizing. <u>First model</u> creation that predicts intentional action and subsequent online collective action during users' interactions with patients' virtual communities. 	<ul style="list-style-type: none"> Gift-giving utilitarian value (Mauss 1922 ; Malinowski 2010; Gregory 1982; Bataille 1967; Godbout and Caillé 1992; Alter 2010; Camerer 1988), Gift-giving social value (Hyde 2007; Bollier 2001; Skageby 2010) and Gifting concepts as social behavior when online (Skageby 2010).
Approaches	Qualitative	Quantitative	Quantitative
Research Questions	<ul style="list-style-type: none"> What are the individual and social driving and restraining forces of patients' online collective action? 	<ul style="list-style-type: none"> What are the relevant expectancy values during the course of patients' interactions with virtual communities? Do these expectancy values predict patients' desires and intentions regarding virtual communities' usage, and subsequently their engagement with online collective action? 	<ul style="list-style-type: none"> What are the characteristics of gift-giving behaviors in the context of online collective action in virtual communities? How do patients perform gift-giving behaviors in the context of online collective action in patients' virtual communities?

5.1 Coming back to the research questions

In order to respond to the research questions, a mixed method has been applied (Creswell 2008; Venkatesh et al. 2013). Qualitative, partially grounded, exploratory approaches have been applied in the current research. Interviews have been conducted with doctors and caregivers, Health 2.0 and Web 2.0 experts, patients and patients' relatives. A survey has then been conducted with 269 participants in patients' online

communities. The objectives and procedures of our mixed methods approach adopted for this research are summarized in Table 49 below.

Table 49. Multimethod Research Approach			
Approach	Objectives	Procedures	Sample
Qualitative Approaches	<ul style="list-style-type: none"> Identify the specificities of patients who join virtual communities Contextualizing the variables chosen for the research model and survey instrument; ensuring content validity Identifying in practice the emerging individual and social determinants of patients joining web-based patients' virtual communities Examining the role played by the IT versus information and emotional needs in patient's commitment Identify the characteristic of online collective action and its contextual designation for patients 	<ul style="list-style-type: none"> Ethnographic research approach in order to get preliminary insights on patients' sociological typology as well as motives for online engagement 25 preliminary semi-structured interviews) with Doctors and caregivers, health 2.0 experts and web 2.0 experts, users of patients' virtual communities 29 subsequent interviews conducted (including the preceding participants) who had to deal with their own health issues or that of relatives 	<ul style="list-style-type: none"> 5 doctors and caregivers 13 Health 2.0 experts 7 Web 2.0 experts 21 patients. 8 patients' relatives
Quantitative Approach	<ul style="list-style-type: none"> Contextualizing the research model to accurately reflect actual patients' interactions with virtual communities Measuring patient's interactions with virtual communities and achieving the external validity of the results 	<ul style="list-style-type: none"> Questionnaire development: development of new constructs emerging from interviews, or contextualization of existing constructs from the literature Test of the research model on a large sample of patient web community's users with a cross-sectional, online survey 	<ul style="list-style-type: none"> 122 patients from a virtual community in the domain of breast cancer. 102 patients from a virtual community in the domain of thyroid disorders, mainly thyroid cancers 45 patients from a virtual community in the domain of cancers

When engaging in a patients 2.0-related research topic, we knew that the study would require specific attention on the diseases to be addressed. The preliminary interviews with experts suggested which way we should focus. The feedback was consensual and chronic or rare diseases were indicated to be suitable for such investigation.

Although we decided to focus on French participants, research performed in the US confirmed this choice, with Internet users living with chronic disease being more likely than other Internet users to access health information online:

“Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine” (Pew Internet Research 2010).

Understandably, the condition of rare disease patient also amplifies this need to spread their network far and wide and online connection will provide some answers:

“In rare disease communities, each person is an expert in observing the effects of a disease or a treatment on their own or a loved one’s body or mind. In this way, rare-disease patients and caregivers who gather together online are an example of a “smart” group...They are diverse and decentralized, yet able to pool knowledge and summarize their observations” (Pew Internet Research 2010).

Although this research was conducted in both communities, one should recall that, out of the 37 interviews, 8 were performed on a rare disease community patient family member, 21 on a breast cancer community patient.

5.1.1 Discussion on Research Question 1: What are the individual and social driving and restraining forces of patients' online collective action?

Among the segmentation of the driving forces for online collective action (utilitarian value, social value and anticipated positive emotions), the information needs, the belongingness needs, the exclusive value and the positive emotions were the most quoted by the interviewees. On the other hand and concerning the restraining forces of patients' online collective action inaccurate medical information, privacy issues and negative emotions were frequently enunciated by the patients. All these variables were therefore tested in a subsequent quantitative analysis.

5.1.2 Discussion on Research Question 2: What are the relevant expectancy values during the course of patients' interactions with virtual communities?

The social media adoption model for patients highlighted the determinants of patients' online collective action, namely i) evaluative social identity and group norms for social values, ii) isolation rupture for utilitarian values and iii) anticipated positive emotions for anticipated emotions. The exclusive value (cognitive social identity) that was reported during the interviews wasn't proven significant by the quantitative analysis. However, for this value as well for the other determinants tested in our research, we advise them to be tested for any type of communities as the results may differ from one to another.

5.1.3 Discussion on Research Question 3: Do these expectancy values predict patients' desires and intentions regarding virtual communities' usage, and subsequently their engagement with online collective action?

MGB (Perugini and Bagozzi 2001) and EVT's (Eccles et al. 1983) theoretical frameworks allowed us to build a social media adoption model in the context of patients' virtual communities where desires is a determinant of intentional collective action, itself a determinant of online collective action. We also identified that use frequency is also a determinant of patients' online. We intentionally focused our approach on a specific type of community helping us to determine what type of other than IT incentives motivate patients to act and interact online; therefore answering to key questions in IS adoption research.

5.1.4 Discussion on Research Question 4: What are the characteristics of gift-giving behaviors in the context of online collective action in virtual communities?

Bergquist and Ljungberg's (2001) theory, implying that the concept of giving-help online is comprised of three dimensions - other-orientation, bonding value and generalized reciprocity – was confirmed by patients' testimonies. Among all actions performed online by patients, the most recurrent occurrences were concerning this very concept of

giving-help, even if, we could have expected the opposite considering the patients in the need for help, fighting for their health.

5.1.5 Discussion on Research Question 5: How do patients perform gift-giving behaviors in the context of online collective action in patients' virtual communities?

To the previous results, we could add contextual designations to patients' online behaviors; namely: i) other-orientation concept relating to the emotional support activity without demand of a return, ii) bonding value concept relating to the information sharing activity about practical advice that will help patients cope with day-to-day health situations, iii) generalized reciprocity concept relating to the flows of general information and social exchange activity, whether it concerns medical knowledge or other purposes.

Out of these three contextual designations, patients' testimonies show that emotional support is of the utmost importance, as highlighted in Table 47.

5.2 Contribution

The purpose of this study was to examine the underlying determinants of online collective action on patients' communities, as well as to highlight the characteristics of gift-giving behaviors in virtual communities. Regarding the findings, it makes four major contributions to research and practice that are highlighted in Table 50.

Table 50. Contributions for Theory and Practice

Theory	
<ul style="list-style-type: none"> • The study helps to create a richer social media adoption model for health purposes that can also be tested in its generic form to other shared interests' communities. • We demonstrate the relevance of combining MGB and EVT for developing this model for patients' communities in order to better examine the determinants of patients' online collective action. • The qualitative approach allowed us to provide a deep understanding of the context of our research and the quantitative approach enabled us to build theories that can be confronted in other fields of inquiry. • We confirm the field's findings about desires being a determinant of intentional collective action, itself a determinant of online collective action. 	<ul style="list-style-type: none"> • This study contributes to responding to key challenges in IS adoption research, which has mainly examined usage without considering sufficiently other kinds of interactions with and around the IT (Benbasat and Barki 2007), e.g. online collective action. • The critical realist perspective helped us to understand why patients are motivated to act online and interact with other patients through technology, highlighting insight from the field, while contributing to knowledge in a cumulative way. • We contextualized IT use in the e-health domain, and contributed to the analysis of gift-giving behaviors in the context of online collective action, highlighting gift-giving behaviors online as well as contextual designations to patients' online action.
Practice	
<ul style="list-style-type: none"> • From an e-health practice standpoint, this research concerns how virtual worlds can help to reduce perceived isolation and to improve patients' condition and day-to-day hardships. • The results of this study are important because they will help Health 2.0 stakeholders to better acknowledge issues such as that of the kind of social community platforms that ought to be designed. • Eventually, the study's results will help us to more effectively take the disabled and ageing population's health challenges into consideration. 	<ul style="list-style-type: none"> • The study shows that the need for patients to contribute to the others' well-being is rooted in their behavior and of the utmost importance. • The study shows that, despite that trust aspects, privacy concerns and their fear of facing inaccurate medical information, they still intend to interact with peers through the online communities. • During the qualitative phase, insightful comments were received, such as the need for information control, the need for online clinical advice that would be performed by health professionals and the wish to leave virtual spaces closed.

5.3 Conclusion

The gift concepts, EVT, MGB, following Lewin's underlying framework, applied to virtual communities, offer important information concerning the leading determinants of online collective actions for patients and its contextual designations. However some adjustments have to be made to fit our field of enquiry in patients' virtual communities. Indeed, our community-based background of patient members includes a large number of users, most often weakened by their disease, seeking interaction on these platforms.

Although the emotional dimension remained meaningful in patients' motives for joining online communities, the findings suggest that the MGB failed to offer a relevant model for predicting intentional action to engage online. The gift concepts complete the lack of an explanation concerning the activities performed online and the social value comprised of determinants such as evaluative social identity and group norms, the utilitarian value comprised of the determinant isolation rupture and the anticipated emotions via the anticipated positive emotions were proven significant in their relation to desires regarding virtual patients' communities.

These above mentioned aspects contribute to expand this trend of developing virtual spaces for people seeking information and support online. The Internet and patients' initiatives are changing the face of medical practice, previously limited to a top-down approach where health professionals and third parties involved communicated a restricted amount of information to patients.

We hope that by connecting to virtual communities patients will have an improved quality of life, due to the benefits provided, which are often different from those they would get from traditional social groups operating in real life. We hope that researchers

and stakeholders will contribute to this problem-solving, as this research has helped to better take into account the ageing population's health challenges and emphasized how patient's virtual communities can help support patient's concerns.

6 - ANNEXES

6 ANNEXES

6.1 Interview Guides

6.1.1 Conceptualizing and Predicting Online Collective Action in Patients' Virtual Communities

Table 6. Interview Guide in Preliminary SDCI	
Questions	Objectives
Is there an existing patient typology for a focus group whether they gather online or offline?	To identify a patient panel to address for the study
Are there patients' networks that are more suitable for some patients than other	To identify a patient's panel that would not be relevant for the study
What would be the patients' motives for online engagement?	To compare the feedback of experts about determinants for patients' online engagement against the literature
What would be some hindrances to engagement?	To compare the feedback of experts about hindrances to patients' online engagement against the literature
What about privacy and data protection?	To compare the feedback of experts about hindrances for patients' online engagement against the literature
Do you think these portals help patients during the healing process?	To compare the feedback of experts about positive psychology and patients' online engagement against the literature

Table 7. Interview Guide in Patients and Patients' Relatives SDCI	
Questions	Value's Dimension Addressed
Do you feel the need to be informed on your disease?	Information Needs
Where do you go to find medical information?	Inaccurate Medical Information
Do you think online medical information is relevant?	
What (other than information) would you seek on an online medical portal?	Instrumental Needs, Positive Emotions, Belongingness Needs, Exclusive Value, Overcoming Isolation

Would you say special relations are developed with other patients participating?	
Do you trust online medical portal participants?	Belongingness Needs, Group Norms
Do you feel the need to be connected to other online patients?	
Do you mind your testimonies being exposed online?	Privacy Protection
How do you feel when you're connected to people living the same pathologies?	Positive Emotions, Negative Emotions
Do you feel pleasure while connected to these participants?	
Do you think you're helping people while connected?	Giving-Help
Do you feel your participation in the debate useful?	
What would be the ideal patients' community?	Other emergent dimensions
Is it easy to find what you are looking for on the patients' virtual community web site?	
Is the patients' virtual community web site attractive?	

6.1.2 System Usage and Social Behaviors in Web 2.0

Environments: the Contribution of Gift-Giving

Concepts to Online Collective Action

Table 43. Interview Guide in Preliminary SDCI	
Questions	Objectives
Is there an existing patient typology for a focus group whether they gather online or offline?	To identify a patient sample to address for the study
Are there patients' networks that are more suitable for some patients than other	To identify a patient's panel that would not be relevant for the study
What would be the patients' activities,	To compare the feedback of experts about

online?	activities for patients' online against the literature
What would be some hindrances to these online activities?	To compare the feedback of experts about hindrances to patients' online activities against the literature
What about privacy and data protection?	To compare the feedback of experts about hindrances for patients' online activities against the literature
Do you think these portals help patients during the healing process?	To compare the feedback of experts about positive psychology and patients' online activities against the literature

Table 44. Interview Guide in Patients and Patients' Relatives SDCI

Questions	Value's Dimension Addressed
Do you feel the need to be informed or inform others on your disease?	
What (other than information) would you seek or give on an online medical portal?	
Would you say special relations are developed with other patients participating?	Giving-Help (Other-Orientation/Bonding Value/Generalized Reciprocity) and specificities of those dimensions
Do you feel the need to be connected to other online patients?	
How do you feel when you're connected to people living the same pathologies?	
Do you feel pleasure while connected to these participants?	
Do you think you're helping people or being helped while connected?	

6.2 Questionnaire

6.2.1 *The Determinants of Online Collective Action in Patients' Virtual Communities: the Contribution of Social, Utilitarian and Emotional Influences in an Extended Model of Goal-Directed Behavior*

6.2.1.1 Informed Consent Form Introduction

Thank you for answering the questions on this questionnaire. Please do not sign this questionnaire, as all responses will be kept strictly anonymous and confidential. For statistical purposes, we really need your frank and honest responses, so that we can gain a real understanding of group interactions on the Internet. We expect people to differ in their true reactions and we ask you to be totally honest. We are looking for your own reaction and feel confident with them, as they are no wrong answer but your true feelings.

6.2.1.2 Confidentiality

All data obtained from participants will be kept confidential and will only be reported in an aggregate format (by reporting only combined results and never reporting individual ones). All questionnaires will be concealed, and no one other than the primary investigator and assistant researchers listed below will have access to them. The data collected will be stored in the HIPPA-compliant, Qualtrics-secure database until it has been deleted by the primary investigator.

6.2.1.3 Questions about the Research

If you have questions regarding this study, you may contact Raphaëlle Laubie, at rlaubiester@gmail.com

6.2.1.4 Questionnaire

Imagine that you are logging on to the Internet to engage in the group interaction.

Visualize the average participants of your online group. Then write your first name (or pseudo) and a description of each participant that you think of in the table below. You may include up to, but not necessarily, five participants that come to mind.

Names or pseudos

My name or pseudo: _____

Participant 1's name or pseudo: _____

Participant 2's name or pseudo: _____

Participant 3's name or pseudo: _____

Participant 4's name or pseudo: _____

Participant 5's name or pseudo: _____

Several of the following questions will refer to this group above described.

1.1.1. How strong would you say the explicit or implicit agreement is among each of the following to interact with on the internet as a group:

	Very weak (1)	(2)	(3)	Moderate (4)	(5)	(6)	Very Strong (7)
Me (1)	<input type="radio"/>						
Group Member Number 1 (2)	<input type="radio"/>						
Group Member Number 2 (3)	<input type="radio"/>						
Group Member Number 3 (4)	<input type="radio"/>						
Whole Group (5)	<input type="radio"/>						

1.1.2. How strong would you say the explicit or implicit agreement is among each of the following to interact with on the internet as a group sometime during the next two weeks or so? And how strong is the agreement of the whole group?

	Very weak (1)	(2)	(3)	Moderate (4)	(5)	(6)	Very Strong (7)
Me (1)	<input type="radio"/>						
Group Member Number 1 (2)	<input type="radio"/>						
Group Member Number 2 (3)	<input type="radio"/>						
Group Member Number 3 (4)	<input type="radio"/>						
Whole Group (5)	<input type="radio"/>						

Q 1.2.1 How strong would you say is your intention and the intention of each of the following people to interact with together on the internet sometime during the next two weeks or so? And how strong is the whole group intention?

*Please note the difference between **desires** and **intentions**. While intentions control the action, desires are only conducive to the course towards it.*

	Very weak (1)	(2)	(3)	Moderate (4)	(5)	(6)	Very Strong (7)
Me (1)	<input type="radio"/>						
Group Member Number 1 (2)	<input type="radio"/>						
Group Member Number 2 (3)	<input type="radio"/>						
Group Member Number 3 (4)	<input type="radio"/>						
Whole Group (5)	<input type="radio"/>						

Q 1.2.2 How strongly committed would you say the following are to interacting together as a group on the internet sometimes during the next two weeks or so? And how committed is the whole group?

	Very weak (1)	(2)	(3)	Moderate (4)	(5)	(6)	Very Strong (7)
Me (1)	<input type="radio"/>						
Group Member Number 1 (2)	<input type="radio"/>						
Group Member Number 2 (3)	<input type="radio"/>						
Group Member Number 3 (4)	<input type="radio"/>						
Whole Group (5)	<input type="radio"/>						

Q 2.1 How attached are you to the group? (Belongingness Needs)

	Not at all attached: I have no positive feelings toward the group (1)	(2)	(3)	Moderately attached (4)	(5)	(6)	Attached very much: I have very positive feelings toward the group (7)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q 2.2 How strong would you say your feelings of belongingness are toward the group?

	Not at all strong (1)	(2)	(3)	Moderately strong (4)	(5)	(6)	Very strong (7)
(1)	<input type="radio"/>						

Q 2.3 "I am a valuable member of the group."

	Does not describe me at all (1)	(2)	(3)	Describes me moderately well (4)	(5)	(6)	Describes me very well (7)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q 3.1 "I prefer the online group to be dedicated to patients sharing the same disease"

	Strongly Disagree (1)	(2)	(3)	Neither (4)	(5)	(6)	Strongly Agree (7)
(1)	<input type="radio"/>						

Q 3.2 "It wouldn't be beneficial for the online group to be composed of sub-groups of patients with different diseases."

	Strongly Disagree (1)	(2)	Neither (3)	(4)	Strongly Agree (5)
(1)	<input type="radio"/>				

Q 4.1 How often do you use your online group for satisfying the following needs?

	Never (1)	(2)	(3)	Sometimes (4)	(5)	(6)	Always (7)
to get information (Information Needs) (1)	<input type="radio"/>						
to gain insight into myself (Information Needs) (2)	<input type="radio"/>						
to learn how to do things (Instrumental Needs) (3)	<input type="radio"/>						
to solve problems (Instrumental Needs) (4)	<input type="radio"/>						
to provide others with information (Giving Help) (5)	<input type="radio"/>						
to contribute to a pool of information (Giving-Help) (6)	<input type="radio"/>						
to get to know others (Isolation Rupture) (7)	<input type="radio"/>						
to feel less lonely (Isolation Rupture) (8)	<input type="radio"/>						

to learn about myself and others (9)	<input type="radio"/>						
to play (10)	<input type="radio"/>						
to generate ideas (11)	<input type="radio"/>						
to impress people (12)	<input type="radio"/>						
to be entertained (13)	<input type="radio"/>						
to relax (14)	<input type="radio"/>						
to make decisions (15)	<input type="radio"/>						
to pass the time away when bored (16)	<input type="radio"/>						
to feel important (17)	<input type="radio"/>						

Q 5.1 "The patients' virtual communities web site is attractive"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 5.2 "I like the look and feel of the patients' virtual communities web site"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 6.1. "It is easy to find what I am looking for on the patients' virtual communities web site"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 6.2 "The patients' virtual communities web site offers a logical layout that is easy to follow"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 7.1 "If I am able to interact together on the Internet with the group during the next two weeks, I will feel”:

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
Relief (1)	<input type="radio"/>						
Contentment							
(2)	<input type="radio"/>						
Excited (3)	<input type="radio"/>						
Delighted							
(4)	<input type="radio"/>						
Happy (5)	<input type="radio"/>						
Glad (6)	<input type="radio"/>						
Satisfied (7)	<input type="radio"/>						
Proud (8)	<input type="radio"/>						
Self-assured							
(9)	<input type="radio"/>						

Q 8.1 "Patients' virtual communities web site provides inaccurate medical information"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 8.2 "There are many errors in the medical information I obtain from the patients' virtualcommunities web site"

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 9 9.

	Strongly disagree (1)	(2)	(3)	Neutral (4)	(5)	(6)	Strongly agree (7)
I am concerned that the information I submit on the Internet could be misused (1)	<input type="radio"/>						
I am concerned about submitting information on the Internet, because of what others might do with it (2)	<input type="radio"/>						
I am concerned about submitting information on the Internet, because it could be used in a way I did not foresee (3)	<input type="radio"/>						
Being able to control the personal information I provide to a website is important to me. (4)	<input type="radio"/>						

Q 10.1 "Connecting on the virtual patients' communities can make me feel" :

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
Angry (1)	<input type="radio"/>						
Frustrated (2)	<input type="radio"/>						
Guilty (3)	<input type="radio"/>						
Ashamed (4)	<input type="radio"/>						
Sad (5)	<input type="radio"/>						
Disappointed (6)	<input type="radio"/>						
Depressed (7)	<input type="radio"/>						
Worried (8)	<input type="radio"/>						
Uncomfortable (9)	<input type="radio"/>						
Anxious (10)	<input type="radio"/>						
Agitated (11)	<input type="radio"/>						
Nervous (12)	<input type="radio"/>						

Q 11.1 Browsing at virtual patients' communities I log onto, is something ...

...that makes me feel weird if I do not do it

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

... I do without thinking

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

...that has become a routine for me

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 12.1.1 “I desire to interact together on the Internet with the group I mentioned above during the next two weeks”:

	Strongly disagree (1)	(2)	(3)	Neither (4)	(5)	(6)	Strongly agree (7)
(1)	<input type="radio"/>						

Q 12.2.1 “My desire for interacting together on the Internet with the group I mentioned above during the next two weeks can be described as”:

	No desire at all (1)	(2)	(3)	Moderate desire (4)	(5)	(6)	Very, very strong desire (7)
(1)	<input type="radio"/>						

Q 12.3.1 “I want to interact together on the Internet with the group I mentioned above during the next two weeks”:

	Does not describe me at all (1)	(2)	(3)	Describes me moderately well (4)	(5)	(6)	Describes me very well (7)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q 13.1.1 Please express the degree to which you might intend to interact together on the Internet with the group mentioned above during the next two weeks:

	Extremely unlikely (1)	(2)	(3)	Neither (4)	(5)	(6)	Extremely likely (7)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q 13.2.1 "I intend that our group interact on the Internet together sometimes during the next two weeks":

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

13.3.1 "We intend to interact on the Internet together sometime during the next two weeks":

	Not at all (1)	(2)	(3)	Moderately (4)	(5)	(6)	Very much (7)
(1)	<input type="radio"/>						

Q 14.1 On the following scales, please express your attitude toward interacting together on the Internet with the group you identified above sometime during the next two weeks:

	Extremely foolish (1)	(2)	(3)	Neither (4)	(5)	(6)	Extremely wise (7)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Extremely harmful (1)	(2)	(3)	Neither (4)	(5)	(6)	Extremely beneficial (7)
(1)	<input type="radio"/>						

Q 15.1 Please answer the following questions about yourself.

	Strongly disagree (1)	(2)	(3)	Neither (4)	(5)	(6)	Strongly agree (7)
I like helping people by providing them with information about medicine (1)	<input type="radio"/>						
My friends think of me as a good source of information when it comes to medicine (2)	<input type="radio"/>						
I like helping people by providing them with information about how I live my disease, my treatment, its side effects (3)	<input type="radio"/>						

Q 15.2 Please rate the degree to which each statement is characteristic or true of you.

	Extremely uncharacteristic (1)	(2)	(3)	Neither (4)	(5)	(6)	Extremely characteristic (7)
It takes me time to overcome my shyness in new situations (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have trouble working when someone is watching me (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get embarrassed very easily (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't find it hard to talk to strangers (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel anxious when I speak in front of a group (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Large groups make me nervous (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q 16 Do you know your tumor grade? If, so, please, could you indicate it :

1 (1)	2 (2)	3 (3)	Unknown (4)	keep it	not
-------	-------	-------	-------------	---------	-----

					confidential (5)	concerned (6)
(1)	<input type="radio"/>					

Q 17.1 How many times in the past two weeks did you interact together on the Internet with the group?

Q 17.2 How many hours do you spend on average when you interact together on the Internet with the group?

Q 17.3 How many times did you interact together on the Internet with the group you identified above in a typical two week period over the past 6 months?

Q 18 Please indicate your age:

Q 19 Please indicate your gender:

- Male (1)
- Female (2)

Q 20 Please indicate your nationality:

Q 21 Please indicate your level of education:

	Self-educated (1)	CAP (2)	BEP (3)	BAC (4)	BAC+1 (5)	BAC+2 (6)	BAC+3 (7)	BAC+4 (8)	BAC+5 (9)	More than BAC+5 (10)
(1)	<input type="radio"/>									

Q 22 Please indicate your marital status:

	Married (1)	Widowed (2)	Divorced (3)	Separated (4)	Never married (5)
(1)	<input type="radio"/>				

Q 23.1 How would you define your skill in Internet use?

	Poor or none (1)	(2)	(3)	Fair (4)	(5)	(6)	Very good (7)
(1)	<input type="radio"/>						

Q 23.2 How would you evaluate your skill using information online?

	Poor or none (1)	(2)	(3)	Fair (4)	(5)	(6)	Very Good (7)
(1)	<input type="radio"/>						

Q 23.3 How often do you use the Internet ?

	Never (1)	(2)	(3)	Sometimes (4)	(5)	(6)	Very often (7)
(1)	<input type="radio"/>						

6.3 Researcher Profile

6.3.1 Teaching Experience, Corporate Experience and Education

I am fortunate to work in the health sector since 2006.

Early, before the creation of Facebook and Twitter, my business partners, themselves health professionals and " 2.0" visionaries, created a virtual community where health professionals could discuss their daily practice. Working with them gave me early on extensive knowledge about virtual communities' day-to-day functioning and an interpretive willingness to conduct research in this field.

Besides these activities, I always valued teaching experiences and was lucky to be given these opportunities by prestigious institutions.

My corporate experience and education are summarized in tables 50, 51, 52.

Table 51. Researcher Profile – Teaching Experience

Institutions	Period	Position Held	Expertise
La Sorbonne University	Since 2015	Corporate Lecturer	Entrepreneurship
Dauphine University	Since 2012	Corporate Lecturer	Web 2.0, Open Innovation, Social Media
EM Lyon	Since 2011	Corporate Lecturer	Web 2.0, Open Innovation, Social Media
ESCP Europe	Since 2011	Affiliate Professor	Web 2.0, Open Innovation, Social Media, Health 2.0
	2009 - 2011	Corporate Lecturer	Web 2.0, Open Innovation, Social Media

HEC Geneva	2009	Corporate Lecturer	Organizational Behavior & Coaching
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Table 52. Researcher Profile - Corporate Experience

Organizations	Period	Position Held	Achievements
HEXAP Registry, applicant for .med, Domain Name Industry, HealthCare Industry	2012 – 2017	Co-Founder, President	- Fundraising - Brand and online policy creation - Sales & Services development
ABCDENT Media, e-Business and Social Network, HealthCare Industry	2008 – 2017	Partner, Strategy & Operations Manager	- Strategic and worldwide operational development - New brands creation - Sales & Services development
PROMOPIXEL Web Agency & Registry	2008 – 2017	Partner, Strategy & Operations Manager	- Strategic and worldwide operational development - New brands creation - Sales & Services development
AB AGENCY Digital Agency, HealthCare Industry	Since 2006	Founder & Executive Manager	- First Entrepreneurial Experience - Sales & Services development - Health ongoing training accreditation integration
ZODIAC AEROSPACE (ACC LA JONCHERE) Aerospace Equipments Manufacturer	2003 – 2007	Group Purchase Manager	Strategic and operational development of processes rationalization (Lean, Supply chain...) - Board Member
		Executive Director of Security Group's Division	- Development and implementation of a new B.U in medical and dental field, for block surgery security
		International Sales Manager of Security Group's Division	- Rationalization of the distributor network - Development of sales in video increase of 25% over 3 years
SWISS LIFE (Wargny) Bank	1998 – 2002	Financial Markets Operator / Financial Analyst / Financial Consultant	
SEPTEC Consulting Agency	1996 – 1998	Junior Consultant CCTV Solutions & Luxury Products North America	

Table 53. Researcher Profile - Education

Institutions	Degree
Paris Dauphine University	Executive DBA
ESCP Europe	Executive MBA
Paris VIII	MSc. Organizational Behavior
UFR Sciences Nantes	MSc. Physics

6.3.2 Presentations and Publications in Conferences with Peers Reviews

Convinced that the exchange within the academic world and that peers reviews would greatly be beneficial for my work, I very early on wished to present my work in progress in conferences. I had already participated in some of them as an entrepreneur and in the field of Health 2.0 and it is not uncommon in health industry meetings to mix genres between startups and academic research. I had the chance to present my work in five conferences, including three oral presentations (ICEMS2011, MedX2012 and ICIS2012) (See Table 53).

Table 54. Researcher Profile – Presentations and Publications in Conferences with Peers Reviews

Institutions Conferences - Journal	Period Reference	Authors	Title
Association Information et Management	May 20, 2016	Laubie, R., Elie-Dit-Cosaque, C.	"Conceptualizing and Predicting Online Collective Action in Patients' Virtual Communities: the Influences of Utilitarian Values, Social Values and Anticipated Emotions"
OCIS Doctoral Consortium	August 7, 2015	Laubie, R.	Expectancy Values and Gift-Giving Influences on Patients' Online Collective Action.
Association Information et Management	December 15, 2013	Laubie, R., Elie-Dit-Cosaque, C.	System Usage and Social Behaviors in Web 2.0 Environments: Conceptualizing and Predicting Online Collective Action.
International Conference on Information Systems	December 16-19, 2012	Laubie, R., Elie-Dit-Cosaque, C.	Exploring and Predicting Online Collective Action on Patients' Virtual Communities: a Multi-method Investigation in France.
Stanford University MedX	September 28-30, 2012	Laubie, R.	Examining the Impact of Hedonic Value and Trust on Patients' Communities Online Action: an Extended Model of Social Networks Goal-Directed Behavior.
Harvard University Medicine 2.0	September 15-16, 2012	Laubie, R.	Expectancy-Value Model of Patients' Virtual communities. The Determinants of Desires for Online Collective Action.
Stanford University Medicine 2.0	September 16-18, 2011	Laubie, R.	Understanding the Determinants of Online Collective Action. The Case Study of Patients Communities.
Case Western Reserve University International	June 2-5, 2011	Laubie, R.	Extended Model of Social Networks Goal-Directed Behavior. The Role of Anticipated

Conference on Engaged Management Scholarship			Emotions and Habits.
Expansion Management Review	2011, n°143, pp.24-31	Laubie, R.	Le Patient Connecté ou les Métamorphoses de la Santé

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Résumé

Au cours des dernières années, les communautés virtuelles de patients se sont énormément développées sur l'Internet. Ces communautés permettent des échanges fréquents entre les patients, qui peuvent partager des informations liées à la santé dans un environnement interactif. Alors que beaucoup s'accordent sur l'opportunité représentée par ces communautés pour ses utilisateurs, les connaissances sur ce qui détermine l'action collective en ligne des patients ainsi que sur les fondamentaux de l'action collective en ligne dans ces espaces virtuels sont relativement peu développées. En conséquence, ce travail doctoral examine les raisons pour lesquelles les patients interagissent entre eux et comment ils procèdent. En nous appuyant sur le modèle du comportement orienté vers un but, la théorie de la valeur de l'attente, la théorie des forces du champ, les concepts de dons et les interviews menées, nous avons développé un modèle qui examine les interactions en ligne des patients dans un contexte d'action collective en ligne. Une approche multi-méthode, qualitative et quantitative, permet d'explorer les interactions des patients et de mesurer les déterminants de l'action collective en ligne sur ces espaces virtuels. L'analyse qualitative de 54 entretiens menés avec des patients, des proches de patients, des professionnels de la santé 2.0, des médecins et des soignants permet d'affiner le modèle de recherche, qui a ensuite été testé au travers d'une enquête quantitative auprès de 269 patients. Cette recherche contribue à la recherche en systèmes d'information en augmentant nos connaissances sur la dynamique individuelle et les interactions qui entourent les communautés de patients en ligne.

Mots Clés

Patients 2.0, Santé 2.0, Communautés Virtuelles, Action Collective en Ligne, Concepts de Dons, Théorie des Forces de Terrain, Théorie de la Valeur de l'Attente, Modèle de Comportement Orienté vers un But, Émotions, Systèmes d'Information en Santé, Adoption, Médias sociaux, Réalisme Critique

Abstract

Over the last few years, virtual patients' communities have been developing tremendously over the Internet. These Web 2.0 communities allow frequent interactions among patients, who can share health-related information within an interactive environment. While many agree on the opportunity represented by those communities for its users, we know very little about what determines patients' online collective action, specifically on virtual communities as well as the fundamentals of online collective action in these virtual spaces. Accordingly, this doctoral work examines why patients interact with others and how they interact on topics related to their disease through these virtual communities. Drawing on the goal-directed behavior (MGB), the expectancy-value (EVT) theories, the field force theory, gift concepts and field interviews, we have developed a model for examining patients' online interactions and identified gift-giving behaviors in the context of online collective action. A multi-method, qualitative and quantitative approaches, enables us to explore patients' interactions and measures the determinants of online collective action on these virtual spaces. The qualitative analysis of 54 interviews conducted with patients, patient's relatives, Health 2.0 professionals, doctors and caregivers allows refining the research model, which has then been tested through a survey handled with 269 patients, members of patient's communities. This research contributes to IS research by increasing our knowledge regarding the individual dynamics and interactions that surround online patients' communities.

Keywords

Patients 2.0, Health 2.0, Virtual Communities, Online Collective Action, Gift Concepts, Field Theory, Expectancy Value Theory, Model of Goal-Directed Behavior, Emotions, Health Information Systems, IT Adoption, Social Media, Critical Realist