Patient empowerment in the digital age - Description and interest of an international online community of patients: Carenity

Swiss Digital Health
June 15th, 2018
Agenda

1 - What is a digital patient community?

2 - Patient Insight solutions

3 - Use cases and publications

4 - Conclusions
What is a digital patient community?

The rise of online patient communities
Main discussion topics on digital patient communities

- Information on drugs, disease, and symptoms
- Impacts of disease and drugs on patient’s quality of life
- Patient rights, navigating healthcare bureaucracy
- Relation with HCPs and patient care pathway
Carenity: the largest multi-lingual, multi-disease online patient community

- Company incorporated in 2011
- 300,000+ patients and carers
- 1,200+ chronic diseases (1 disease per community)
- 6 countries: US, France, UK, Germany, Spain and Italy
- 300+ studies and 50+ scientific publications focusing around RWE, PRO, and patient-centricity
A fast-growing cohort of 300k+ patients and carers across main therapeutic areas (+5k members per month)

Main therapeutic areas

- Diabetes: 50,000
- CV: 40,000
- Rheumatisms: 35,000
- Oncology: 20,000
- Autoimmune: 20,000
- CNS: 20,000
- Respiratory: 30,000
- Mental health: 30,000
- Virology: 15,000

But also numerous communities in Rare Disease areas (e.g. Fabry, Gaucher, Acromegaly…)

Members as of May 2018
Our Mission: engage online patient communities to generate real-world insights and improve medical research

A social platform for patients

- Connect
- Share
- Learn
- Act
- Track

Empower Patients

Carenity Solutions

- Custom studies
- Subscription-based solutions
- AI / Natural Language Processing
- Clinical trial optimization

A digital cohort for life sciences partners

- Access
- Communicate
- Survey
- Validate
- Demonstrate

Guide Healthcare Industry
Services offered to Carenity members

Experience sharing and support

Forums, newsfeed, private messages

Health news and information

Articles, experts videos, patient testimonials

Personalised patient dashboard

Online surveys

Online surveys, discussion groups…

What do you think about your treatment?

What are your main sources of information?

Tips for a better diet with breast cancer
Our commitments

- De-identified data and confidentiality
- Free sign-up
- Data hosted on secure servers within the European Union
- No resale of our database (email, IP addresses…)
- Total transparency about funding and business model
- Collaborative model with sharing of survey results with members
- Daily moderation of online discussions and ethics charter
- Scientific and Ethics committee with 12 renowned HCPs
Real-world patient insights provide beneficial outcomes for both patients and the pharma industry business

Patient Centricity?
Patients now have a direct impact on the success of drugs and health-related services

What is a digital patient community?
Real-world patient insights provide beneficial outcomes for both patients and the pharma industry business

**Patient Centricity?**
Patients now have a direct impact on the success of drugs and health-related services

- **Medical**: Improve cost effectiveness of clinical trials by better taking into consideration the patients’ experience and accelerating recruitment on trial.

- **Market access**: Price and reimbursement of new drugs are increasingly **correlated to their clinical benefits in real life, patient preference and also on their positive impact on patients’ quality of life.**

- **Communication**: Chronic patients are active, informed, and **publicly share their opinion on medical products and services.**

- **Commercial**: 7/10 patients say they played a direct role in the choice / discontinuation of their therapy.

- While often overlooked as a stakeholder, **patients are motivated to participate in Medical research**

- Healthcare players need to source data directly from the patients, **without the filter of HCPs**

*What is a digital patient community?*
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Our Patient Insight Solutions

Patient insights bring value at each phase of the drug life cycle

<table>
<thead>
<tr>
<th>Targeted groups</th>
<th>Medical / R&amp;D / ClinOps</th>
<th>Market access HEOR</th>
<th>Post launch</th>
</tr>
</thead>
</table>
| **Scope**       | • R&D development for new drugs  
                  • Clinical Trial Optimization  
                  • Recruit and retain patients in clinical trials  
                  • Ask patients to define target product profile  
                  • Use real-life input for trial design and enrolment  
                  • Screen, recruit and retain patients in clinical trials  
                  • Help doctors address patient unmet needs  
                  • Patient profile segmentation  
                  • Patient journey mapping  
                  • Drug Utilization study  | • Plan launch for new drugs  
                  • Demonstrate benefits of existing drugs  
                  • Use RWE data to support:  
                    • Patient segmentation  
                    • Value generation (preference, QoL,)  
                    • P&R  
                    • Continued product acceptance & adherence  | • BU / Product / Sales  
                  • Market research / BI  
                  • Late Phase  |

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Our Real-World Evidence solutions

Custom

- Carenity questionnaire®
  - One-shot questionnaire

- Carenity Monitor®
  - Barometer

- Carenity Listen®
  - Conversation analysis

Subscription-based

- Carenity Study®
  - Multi-client studies

- Patient Treatment Monitor®
  - Treatment monitor

- Patient Live®
  - Express survey
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Objective: Experiences and expectations of patients and relatives with non-Hodgkin lymphoma (NHL)

Project duration: 3 months

Sample size: 50 respondents

Case Study: Oncology – Marketing Care pathway, services and info needs & expectations

Diagnosis

Patients feedback
51% complain about the support provided

Top patient feelings
Ashamed: 10%  Anxious: 30%  Shocked: 26%  Angry: 24%  Challenged: 38%  Scared: 28%

Treatments

Main fears concerning the treatment
- Side effects: 53%
- Dying: 40%
- Treatment ineffectiveness: 22%

Top 3 missing services
1. Psychological support
2. Medical info about NHL
3. Discussion with NHL specialists

Relapse

Support during relapse
- Support received: 21%
- No support: 30%
- Support support: 49%

Offer and usefulness
Support for returning to work is one of the most frequently proposed services (32%). However, it is only 5th most useful service (68%).

On the contrary, medical support is not always offered but is the most useful service (88%).

Remission

Top expected information

- Patients’ experience: 90% (37), 80% (33), 70% (30)
- Medical news: 68% (28), 73% (30)
- Existing treatments: 56% (23), 49% (20)
- Practical advice: 49% (20), 66% (27)
- Treatment process: 39% (16), 32% (13)
- Enough info: 32% (13), 27% (11)

Key learnings

- There are important expectations all along the patient care pathway.
- Medical information at the start of the treatment and psychological support in case of relapse are top priorities.
- Patients and relatives would like to share more personal experience.

Levers / ROI

- Developing services and information media adjusted to patients’ needs, to facilitate their NHL and treatment management.
- Prioritization of services: newsletters / NHL-specialized websites, reinforcing psychological monitoring, videos of patient testimonies.
Objective: Evaluate spendings not reimbursed by health insurance and measure impact of these costs and patients/carers financial resources.

Sample size: n=300 respondents – MS patients and carers

When: Q4-2016

Measure the out-of-pocket in MS

<table>
<thead>
<tr>
<th>HCP most met</th>
<th>Out of pocket: YES/NO</th>
<th>Level of out of pocket</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologist</td>
<td>No 71% Yes 29%</td>
<td>1 to €5: 53%</td>
</tr>
<tr>
<td>General practitioner</td>
<td>No 52% Yes 48%</td>
<td>6 to €10: 10%</td>
</tr>
<tr>
<td>Ophtalmologist</td>
<td>No 49% Yes 51%</td>
<td>10 to €20: 7%</td>
</tr>
<tr>
<td>Urologist</td>
<td>No 62% Yes 38%</td>
<td>15%</td>
</tr>
<tr>
<td>Specialized nurse</td>
<td>No 92% Yes 8%</td>
<td>20 to €30: 10%</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>No 66% Yes 34%</td>
<td></td>
</tr>
<tr>
<td>Internal medicine specialist</td>
<td>No 93% Yes 7%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Avg. (Median)
- €20,8 (€7,5)
- €6,5 (€2,5)
- €23,6 (€15)
- €9,8 (€2,5)
- €4,3 (€2,5)
- €10,5 (€2,5)
- €1,5 (€1,5)

Out of pocket: YES/NO

=> Results will be published at ISPOR 2017
Results of Carenity studies are shared with the scientific community

Journal: BMJ Innovations
Publication date: March 2017
Sample: 1103 patients and caregivers
Title: Defining patient centricity with patients for patients and caregivers: a collaborative endeavour
Authors:
- G Yeoman: AstraZeneca Pharmaceuticals, Melbourn, UK
- P Furlong: Patient Project Muscular Distrophy, Hackensack, New Jersey, USA
- M Seres: 11Health, Borehamwood, Hertfordshire, UK
- H Binder: Corvista, Cheshire, UK
- H Chung: AstraZeneca Pharmaceuticals, Gaithersburg, Maryland, USA
- V Garzya: AstraZeneca Pharmaceuticals, Melbourn, UK
- R RM Jones: Formerly AstraZeneca Pharmaceuticals, Macclesfield, UK

Use cases and publications
Results of Carenity studies are shared with the scientific community

Journal: Lupus (international)
Publication date: September 2015
Sample: 521 patients and caregivers
Title: Characteristics and information searched for by French patients with systemic lupus erythematosus: A web-community data-driven online survey

Authors:
• B Meunier : service de Médecine Interne, Hôpital de la Conception, Université Aix-Marseille, Marseille, France
• N Jourde-Chiche : service de Néphrologie, Hôpital de la Conception, Université Aix-Marseille, Marseille, France
• J Mancini : service de Biostatistiques et Technologie de l’Information et de la Communication (BIOSTIC), Hôpital de la Timone, APHM; Université Aix-Marseille, UMR S912, Inserm, IRD, SESSTIM, Marseille, France
• M Chekroun : Carenity, Paris, France
• F Retornaz : service de Médecine Interne, Hôpital Européen, Marseille, France
• L Chiche : service de Médecine Interne, Hôpital Européen, Marseille, France.
Results of Carenity studies are shared with the scientific community

Patient empowerment in the digital age. Description and analysis of multiple sclerosis patients’ engagement in a European online community of patients: Carenity

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5Facultad de Medicina, Universidad de Santiago, Santiago, Chile
6Facultad de Medicina, Universidad de Chile, Santiago, Chile

Abstract

Patient empowerment is widely recognized as a desirable goal of modern healthcare systems, to improve quality of life of patients suffering chronic conditions. Online virtual communities allow patients to benefit from the support and knowledge of other contributors, but it is still unclear how it may help patients coping with complex health issues. Our objective was to describe and analyze patients’ perceptions and benefits they receive from these online interactions. We evaluated the responses to an online survey by 256 patients suffering from Multiple sclerosis registered on Carenity, an online social network. Only 19% of patients shared this experience with their physician. Perception of privacy has not changed for 82.2% of respondents. Patient’s motivation for joining the platform, and their valuation of the interactions with other patients, allowed us to identify peer-to-peer communication as one of the key aspects of the new definition of patient empowerment in the digital age.

Introduction

Patients’ active involvement in decisions concerning their health has been considered a desirable goal for decades.

Journal: JAMIA

Publication date: September 2015

Sample: 256 patient

Title: Patient empowerment in the digital age. Description and analysis of multiple sclerosis patients’ engagement in a European online community of patients: Carenity

Authors:

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Results of Carenity studies are shared with the scientific community

Rare 2013 - Montpellier  SFD 2015 - Bordeaux
SFD 2015 - Bordeaux  SFD 2015 - Bordeaux  SFD 2016 - Lyon

Ispor 2013 - Dublin  Ispor 2014 - Amsterdam  Ispor 2016 - Vienna

SFR 2014 - Paris
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Conclusions

Digital transformation: the beginning…

Connected Health tools

Big Data

Multisource analysis
Your contacts

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- Doctorate in Pharmacy, MS degree Health System Assessment
- 2001-2015: Senior Director Business Operations - MAPI RWE
- 2015-2017: Head of Late Phase & RWE - Zeincro
- 2018: Business Development Director – Carenity

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Understand the patient’s view to improve patient’s life

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