HIV Patient’s Journey
Patient’s journey methodology

Maria Giulia Marini, 29 ottobre 2013
Between *disease* management and *illness* awareness

*Disease* is the side of the mechanics, the performance and the causal effects of treatments bound primarily to the functionality of the "body" or even more of a “target organ”. Hence the Disease Management program, the Process Reengineering.

*Illness* concerns the conscious or unconscious perception that the subject has of the disease, how is the living with, thus transforming the patient from object of care to a human subject who feels and thinks and perceives the disease.

*By Arthur Kleinmann:* in 2006 Kleinman received the Lifetime Achievement Award from the Society for Medical Anthropology, and in 2004, he was awarded the Doubleday Medal in Medical Humanities by University of Manchester. In 2007 he received an award in the medical humanities at Imperial College in London.
Redefining global health-care delivery

The framework introduces the notion of care delivery value chains that apply a systems-level analysis to the complex processes and interventions that must occur, across a health-care system and over time, to deliver high-value care for patients with HIV/AIDS and co-occurring conditions, from tuberculosis to malnutrition. To deliver value, vertical or stand-alone projects must be integrated into shared delivery infrastructure so that personnel and facilities are used wisely and economies of scale reaped.

Michael Porter  The lancet, September 2013
The current Italian situation: Patto per la salute – The Health Pact

Among the priorities of the NHS, the Italian Health Minister ranks transparency: "I am of the opinion that the ability of public institutions to make transparent the decision-making processes and results, initiating mechanisms of involvement of citizens and civil society stakeholders, and to the basis of the new way of thinking about public action” should be accessible to everyone, because only in this way will ensure the choice of patients and we can evaluate the capacity of health facilities."

With regard to the standard cost of the National Health Service, "the goal is not just getting a saving in economic terms, but also check whether the federal system will be able to maintain the same level of protection of health and bridge the gap that exists today between the different regional realities."
“The term 'patient journey' refers to the experiences and processes the patient goes through during the course of a disease and its treatment (BMJ 2011)”

“Process mapping enables the reconfiguring of the patient journey from the patient’s perspective in order to improve quality of care and release resources.”(BMJ 2010)
Benefits of process mapping

- Picture of a patient pathway which is a complex process, undertaking the journey from a patient’s perspective

- Overview of activities and collaboration among professionals during the course of treatment

- Identification and selection of the most critical activities to achieve the goals of care;

- Definition of quality standards and optimization the process of care

- Comparison of physician and patients perceptions about quality and management of care

- Less wastes for management of care (order versus chaos).
HIV Patient’s Journey project: objectives

- build and validate the HIV patient's journey
- promote the use of Italian HIV Ministerial Guidelines during the patient’s journey
- include the patient's experience in all phases of the journey
- identify most critical areas to management and the emotional impact
- define the skills and tools needed to optimize the management of HIV patient
- promote a new approach "illness centered" and not only «disease centered» in the management of HIV infection
HIV patient’s journey: method

Assessment
Advisory meeting
Sharing with patients Community
Sharing with scientific Community
Validation Advisory meeting
Issue of Patient’s Journey
Phase 1: assessment

- Scouting of relevant documentation (Guidelines, desk research, audio-visual materials)

- Define the Scientific Committee: Prof. Adriano Lazzarin, Prof. Massimo Andreoni.

- Define a board of medical specialists in infectious and tropical diseases (representative of main structures in the management of HIV over Italy) and representatives of the Associations (ANLAIDS, Nadir Onlus, Plus, NPS Italy Onlus)

- Sharing the project with a KOLs group

- Visit a Department of Infectious and Tropical Diseases to learn the basic knowledge of the therapeutic reference and context.

- Define an instrument for assessment (questionnaire)
Scientific commettee
• Prof. A. Lazzarin ; Prof. M. Andreoni

HIV physicians:
• A Ammassari, Roma
• A Castagna, Milano
• S Rusconi, Milano
• AM Cattelan, Rovigo
• M Celesia, Catania
• G D’Ettorre, Roma
• G Orofino, Torino

Patients ans people associations:
• GM Corbelli, Anlaid
• M Errico, NPS
• S Marcotullio, NADIR
• S Pieralli, Plus

Coordination commettee:
• MG Marini, (F.ISTUD) Milano
• L Reale, (F.ISTUD) Milano
Phase 2: advisory meeting

Advisory Meeting (14-15 Marzo) a Baveno, ISTUD Foundation

- Sharing the results of the Assessment
- Sharing the methodology of consensus building
- Mapping the journey of HIV patient (based on what actually happens) through flow chart.
- Analysis of the activities
- Identification of critical issues and additional proposals
- Reflection about the "ideal type" of journey but linked with the feasibility concept
- Preparation of a first draft of patient journey
Phase 3: sharing with patient’s Community

In NADIR annual seminar the draft of HIV Patient's Journey was presented. Goal was to collect comments and feedback from patient's experience on the various phases of the journey.

ISTUD Foundation thereafter prepared a new proposal updated of HIV Patient's Journey including deeper the focus on «the living with» the condition...
Phase 4: sharing with scientific community

**Italian Conference on AIDS and Retrovirus - ICAR, pre-course HIV patient’s journey**

Presenting an updated proposal of prototype of HIV Patient's Journey in order to submit the instrument to the scientific community. Goal is to collect comments and feedback from the physician experience on the various phases of the journey, ISTUD Foundation will prepare a new proposal updated Patient's Journey including a deepening coming from the «physician’s eye».
Phase 5: Sharing with Pharmacists and Nurses

Meeting with SIFO and AIMI

Presenting an updated proposal of prototype of HIV Patient's Journey to delegates of SIFO and AIMI. Goal is to collect comments and feedback from the these actors and close the gap with these additional stakeholders.
HIV patient’s journey: summary

Flow chart 1: The inclusion in the structure of care
Flow chart 2: The first visit
Flow chart 3: The second visit
Flow chart 4: The hospitalization
Flow chart 5: Follow Up with treatment
Flow chart 6: Follow Up without treatment
Flowchart - Symbology

HIV patient’s journey has been realized through the development of FLOW - CHART.

- **Start / end of the flow**
- **Actions/activities**
- **Emotions**
- **decision-making that generates two possible paths**
- **Production / storage of a document**
- **Directions of the flow**