



No profit federation of  
associations

Founded in 2002

Based in Milan

>50 Regional and local  
Association in Italy

>9K Volunteers

All board members are ostomates or  
incontinent persons

WHO WE ARE



Pier Raffaele Spina, Bruxelles 17th November 2023



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••• ✕

We guarantee the rights of incontinent  
and ostomised persons

We support and promote projects  
at national and regional level

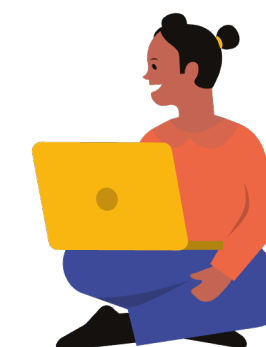
We collaborate with Scientific  
Societies, Institutions, Associations,  
Companies

We promote social information and  
communication campaigns

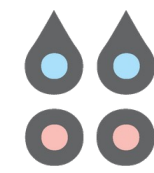
Lobbying action

Promote advocacy

## WHAT WE DO



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Learning from the past to avoid same mistakes

Patient centricity approach in NHS&RHS

Creating new practices to improve and innovate processes

Creating new knowledge through studies and publications

Patient Experience Value for Health Systems

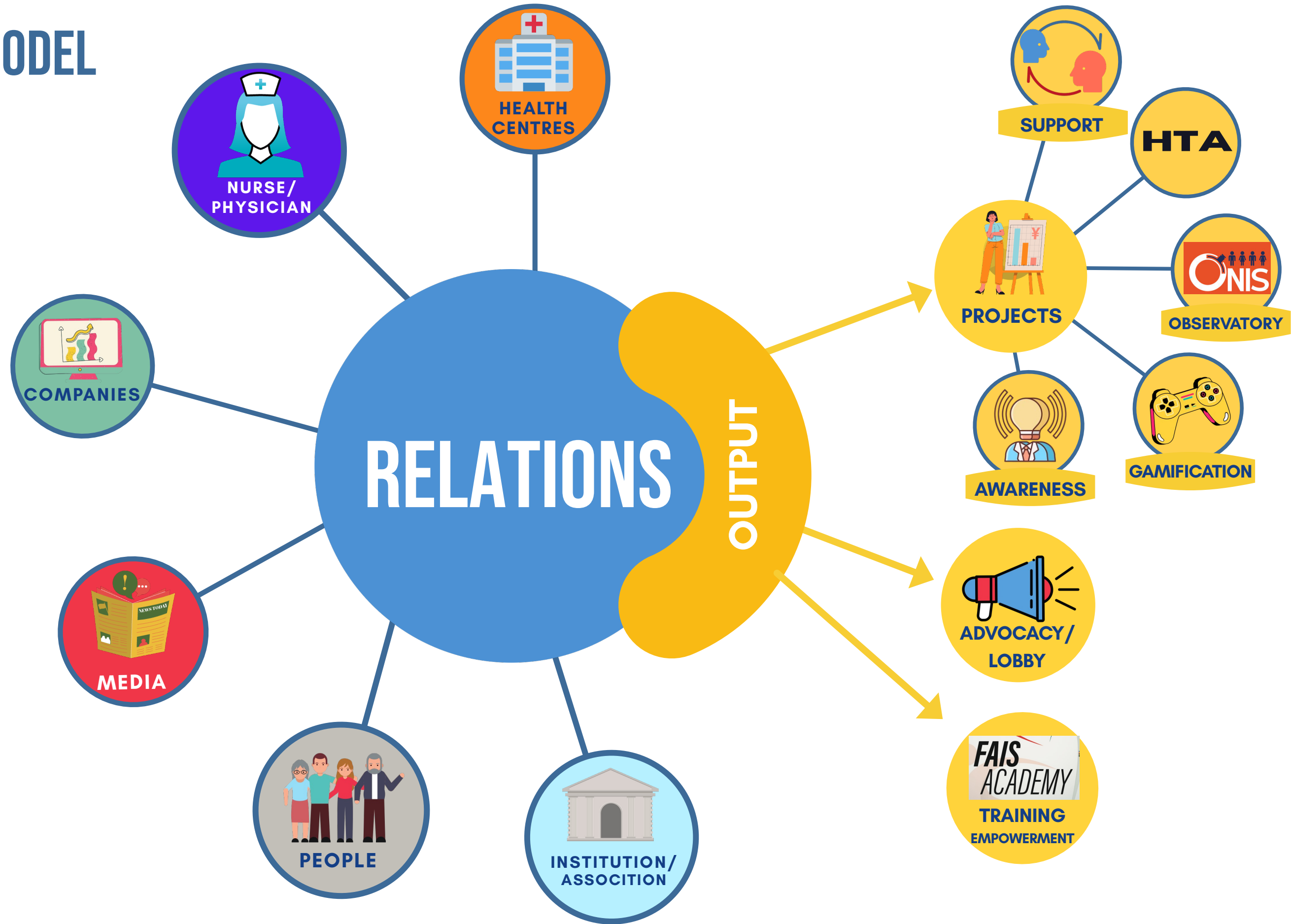
# OUR VISION & STRATEGY



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# OUR MODEL





# THE FIRST HTA STUDY IN EUROPE ON A SERVICE



May 2020

UNIVERSITÀ CATTOLICA del Sacro Cuore  
**ALTEMS**  
ALTA SCUOLA DI ECONOMIA  
E MANAGEMENT DEI SISTEMI SANITARI

**Valutazione multidimensionale e multidisciplinare del servizio di consegna domiciliare dei presidi medici per stomia e incontinenza**

Cicchetti A, Rumi F, Fiore A, Furfaro S, Palmeri M, Orsini F, Refolo P, Sacchini D, Spagnolo AG.

MAGGIO 2020

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March 2022



June 2021

HTA 2021 ANNUAL MEETING  
**Manchester**  
UNITED KINGDOM

UNIVERSITÀ CATTOLICA del Sacro Cuore  
**ALTEMS**  
ALTA SCUOLA DI ECONOMIA  
E MANAGEMENT DEI SISTEMI SANITARI

**Applying HTA For Home Care Services: The Case Of Products And Services For Ostomy And Incontinence**

Rumi F<sup>1</sup>, Fiore A<sup>1</sup>, Furfaro S<sup>1</sup>, Sacchini D<sup>2</sup>, Refolo P<sup>2</sup>, Midolo E<sup>2</sup>, Spagnolo A<sup>2</sup>, Orsini F<sup>1</sup>, Palmeri M<sup>1</sup>, Cicchetti A<sup>1\*</sup> Alta Scuola di Economia e Management dei Sistemi Sanitari (ALTEMS), Rome Rome, Italy

<sup>2</sup> Institute of Bioethics and Medical Humanities - Università Cattolica del Sacro Cuore, Rome Rome, Italy



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## ... KEY POINTS TO SOLVE

Few data on ostomates and incontinents

Differences between regions on health policy

Territorial problems with bureaucracy and tenders

No institutional awareness campaign

Insufficient representation of patient associations in decision-making processes



Always 75,000 ostomates for 20 years, is that possible?

21 different regional health systems

Free choice of device and suitability

Complex, slow bureaucracy

No regulation of access to consultations with Institutions/payers





Production of communication campaigns makes it possible to reach the general public. It is the first step in introducing our priorities

In the last five years we have implemented 15 projects at national level, in different fields. 3 of them were sponsored by the Fondazione Pubblicità Progresso

## OUR PROJECTS

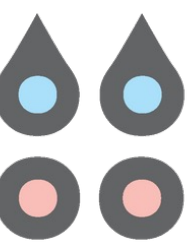


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## ONIS - NATIONAL OBSERVATORY ON INCONTINENCE AND OSTOMY



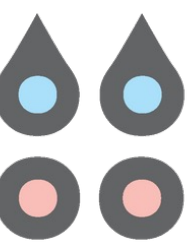
Launched in 2022 it is the first observatory in the field promoted by a patients' association. The Observatory's objective is to monitor the performance of regional policies and their ability to look at the rights of incontinent and ostomized people. In this context, the role of the patients' association is decisive and in some respects innovative in terms of approach methodology and scope of research. On the ONIS steering committee there are representatives of institutions (Ministry of Health and more), scientific societies (SICCR, AIUG, etc.), associations (FNOPI, Cittadinanzattiva, etc.), and representatives of the Welfare DGs of the Campania, Veneto, Piedmont and Lazio Regions have also joined. Observatory published already two scientific reports.

[www.onisitalia.net](http://www.onisitalia.net)



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Internal advanced training project for volunteers from all member associations. The aim is to guarantee continuous training to provide effective tools for those who work in the area for others. There will be 48 hours of training per year divided into training modules on topics such as knowledge of relevant regulations, state of the art of national/regional policies in favour of incontinent and ostomised persons, communication, fundraising, new technologies. The development programme also provides the participation of volunteers from other associations in the training sessions. The FAD service is also guaranteed to those attending the academy courses. Participation in the courses is totally free of charge.

[www.faisacademy.it](http://www.faisacademy.it)





# STOMY CRAFT



## Ostomy Bag Management

Learn how to manage the medical device as you face enemies and build new worlds.



## Relationship With The Caregiver

Participate in various challenges with your caregiver and cultivate your mutual trust together.



## Proper Nutrition

Recognize food that make you feel good and give you strength and energy to defeat your enemy.



## Community

Play with people from all over the world, meet new friends and safely share your doubts.

Learning how to handle the ostomy pouch while facing enemies and building new worlds. Participating in various challenges with their caregiver and cultivating mutual trust together. Recognising foods that make one feel good and give strength and energy to defeat the "enemy". Playing with people from all over the world, meeting new friends and safely sharing their doubts.

StomyCraft is also a phygital project: the video game is flanked by physical components including a LEGO accessory

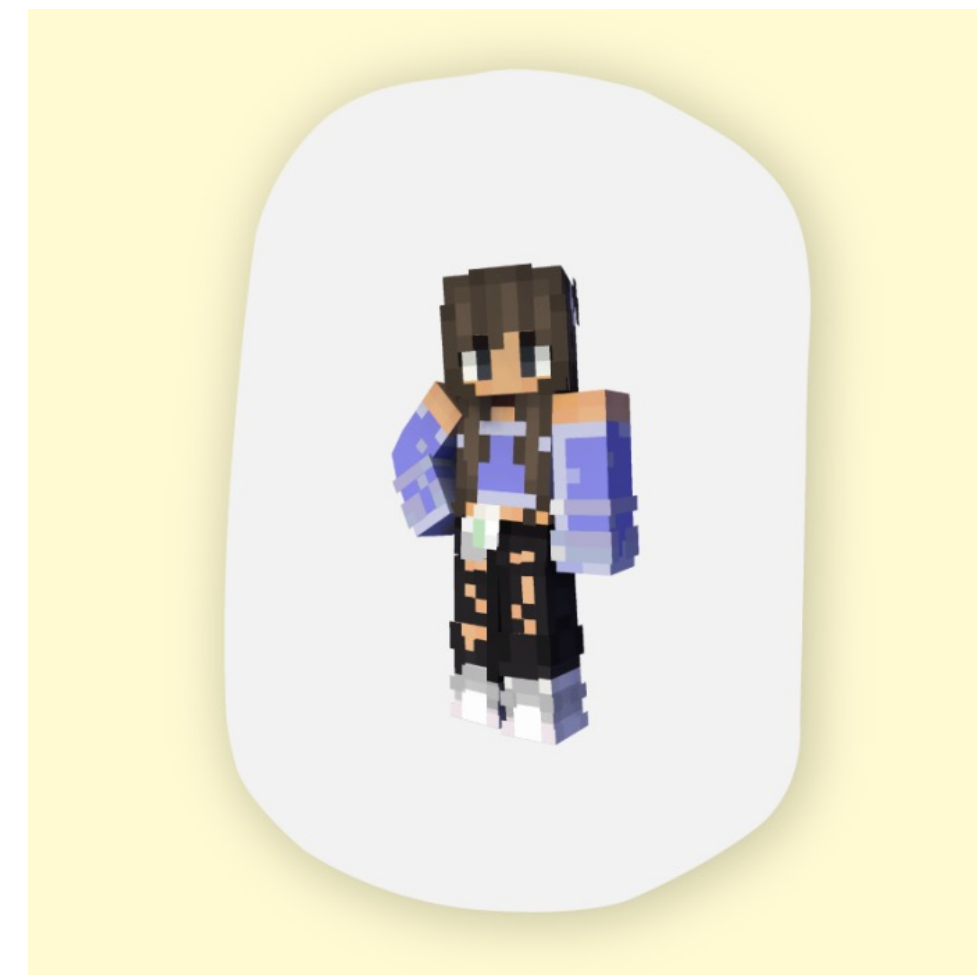


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# STOMYCRAFT



StomyCraft is also a phygital project: the video game is flanked by physical components including a LEGO accessory. A cover bag that can be customised with the image of one's choice, so as to improve the acceptance of the paediatric patient's condition, who will be able to carry his favourite heroes with him at all times. Finally, a console, installed at a reception point or outpatient clinic, to allow paediatric patients to try out the game while waiting for examinations and check-ups.







# #SIAMO UN'OPERA D'ARTE - 2023



# THANK YOU

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