

Co-creation approach at the Institut Jules Bordet with patients-experts, artists and professionals

OEI Oncology Days 44
June 15th 2022, Valencia

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Outline

- ♦ Institut Jules Bordet
- ♦ Patient involvement
 - ♦ Model and inspiration
 - ♦ IJB “Patients & Partners” program
- ♦ From patient involvement to co-creation
 - ♦ First experiences...
 - ♦ The B.CaRe Project
- ♦ Conclusion

Institut Jules Bordet

- ♦ Brussels (BE)



Outpatient visits : 86.000
(incl. 11.000 prevention)

One day admissions : 27.000 (chimio)

Inpatient admissions : 5.780
(2019)

160 beds to become soon 250
(2022)



Member of L'Hôpital Universitaire de Bruxelles (H.U.B)



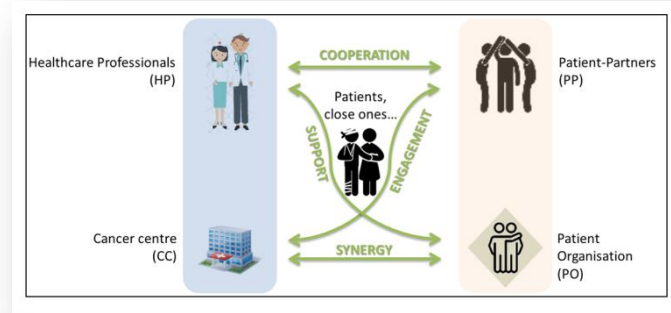
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Patient Involvement



OEI – ECPC Partnership (2016)



OEI Model of PI (2017)

OEI Collaboration for Good Practices with Patients (CGPP) working group (2017)



OEI Patient Day (2019, 2021)

IJB « Patients & Partners » program



- ♦ (2017)
- ♦ Based on the OECI-ECPC model & support from AJB
- ♦ Involvement program:
 - ♦ Processes for selection (projects) and involvement (pro & pat)
 - ♦ Convention templates
 - ♦ Involvement and reporting guidelines, assessment
- ♦ Projects : organization, communication, literacy projects...

Patient involvement in research @ IJB

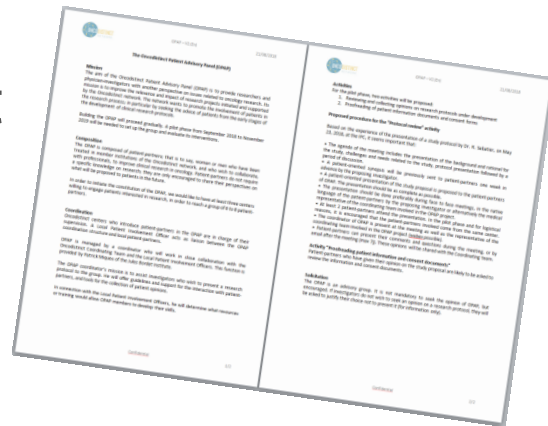
- ♦ June 2017 First patient involvement experience in research with the IREN consent tool: <http://iren-tool.be> (**OECI** pilot-project)
- ♦ Sept. 2017 Participation to the “South East London Consumer Research Panel for Cancer” @ **King’s Heath Partners** with Ambi Williams
- ♦ Mai 2018 “Test session” @ **Paoli-Calmettes Institute** in Marseille with Martine Bouyssié (Oncodistinct Network)
- ♦ Dec. 2018 Launching PISARO

PISARO group

PISARO: « **P**atients of the Institute **S**upport **A**nd improve **R**esearch in **O**ncology »

Advisory group of patients “interested” in clinical research and available to :

1. Review and provide opinions on research protocols under development
2. Proofread patient information documents and consent forms



PISARO group

- ♦ IJB « Patient Involvement » process
 - ♦ « **Patients & Partners** » program
- ♦ Current members(5)
 - ♦ 4/5 are patient organisations' members
- ♦ Conventions with individuals (not organizations)
 - ♦ (collaboration agreements: « mutual engagement, confidentiality, GDPR...)
- ♦ **3** years of existence - **14** meetings - **9** research projects evaluated - **8** reports produced - **5** trainings* for P&P - 3 papers on PISARO - **1** consultancy contract



2019: PI in “routine”...



VAINCRE



Comité de soutien des patients du
groupe de l'ELCWP (European Lung
Cancer Working Party)



Les patients, ces experts

Des groupes de malades, comme les entendeurs de voix et des personnes atteintes de la maladie de Huntington, militent pour la prise en compte, par le milieu médical, d'un savoir fondé sur le vécu. Ils brouillent les frontières entre normal et pathologique.

LE MONDE SCIENCE ET TECHNO | 12.09.2016 à 18h03 • Mis à jour le 14.09.2016 à 12h09 | Par Catherine Mary



La JAP (2019)

Patient organizations' Day

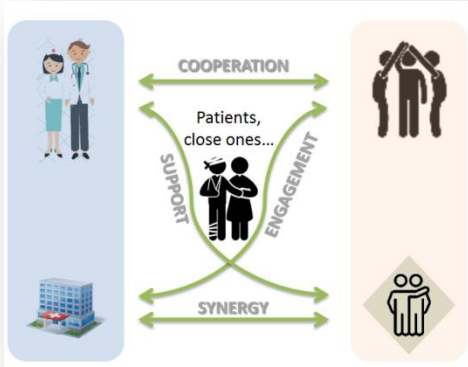
2020

- COVID-19 changed priorities
- Public and patient involvement has been sidelined
- Difficulty to maintain contact and communication with POs

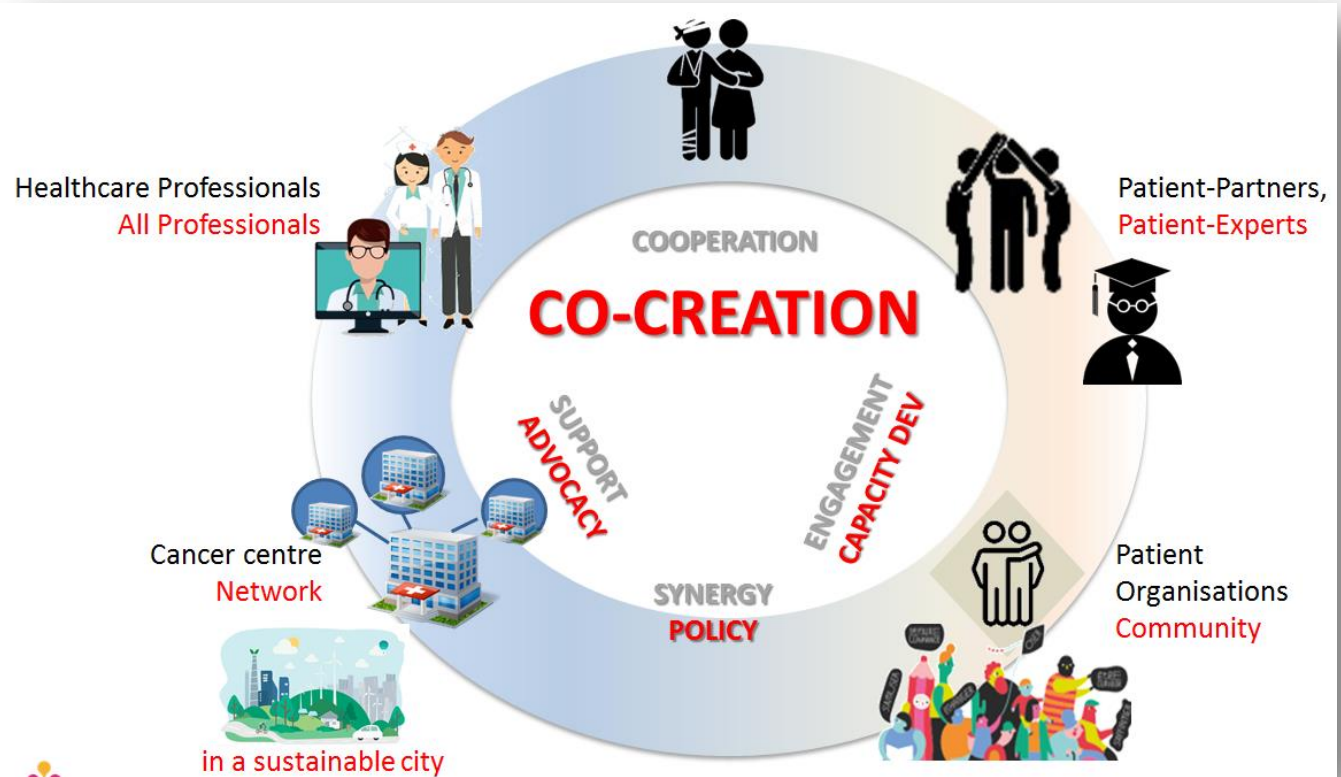
But...

- Evolution of the OECl Model of Patient Involvement
- Brussels Innoviris “Co-Create” Call

Evolution of the patient involvement model



INSTITUT
JULES BORDET
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Co-creation projects Urban Resilience in BXL

Co-CREATE Call in 2020

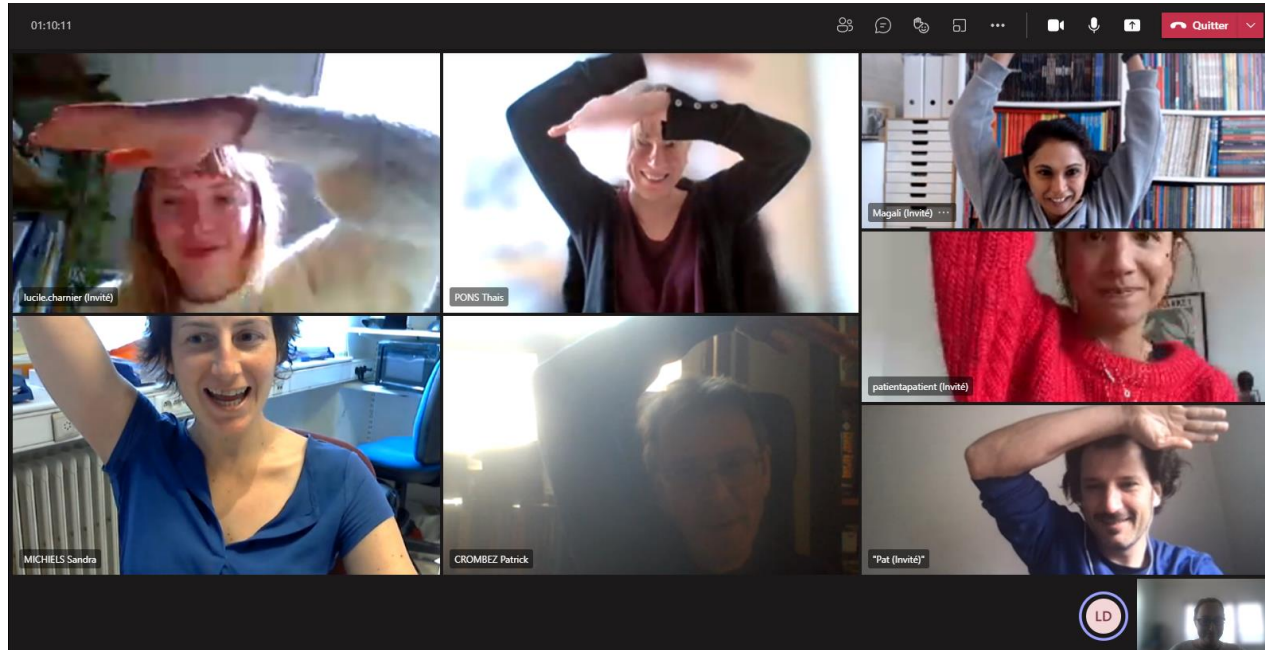
Raising the capabilities of the city of Brussels to co-evolve by launching a transformation, following a crisis/a collapse or a deep modification of its environment!

<https://www.cocreate.brussels/>

MD –Gynecologist

Artist – Art-
therapist

Health
Anthropologist
(Diversity)



Survivor
Health/Life coach
Coll. w IJB since 2019

Survivor
Patient-Expert

Head Nurse (Research)

Researcher
Social Sciences

The crisis

- Lack of time
- Lack of/incorrect allocation of resources
- Biological vs. holistic medicine
- Paternalistic system

De-humanization of
cancer care

- Break in the life course
- Increased social inequalities
- Loss of income/employment
- Depersonalization of the patient
- Mental health of relatives

- Suffering at work
- Absenteeism
- Burnout
- Shortage
- Weakened health sector
- Disempowerment of institutions

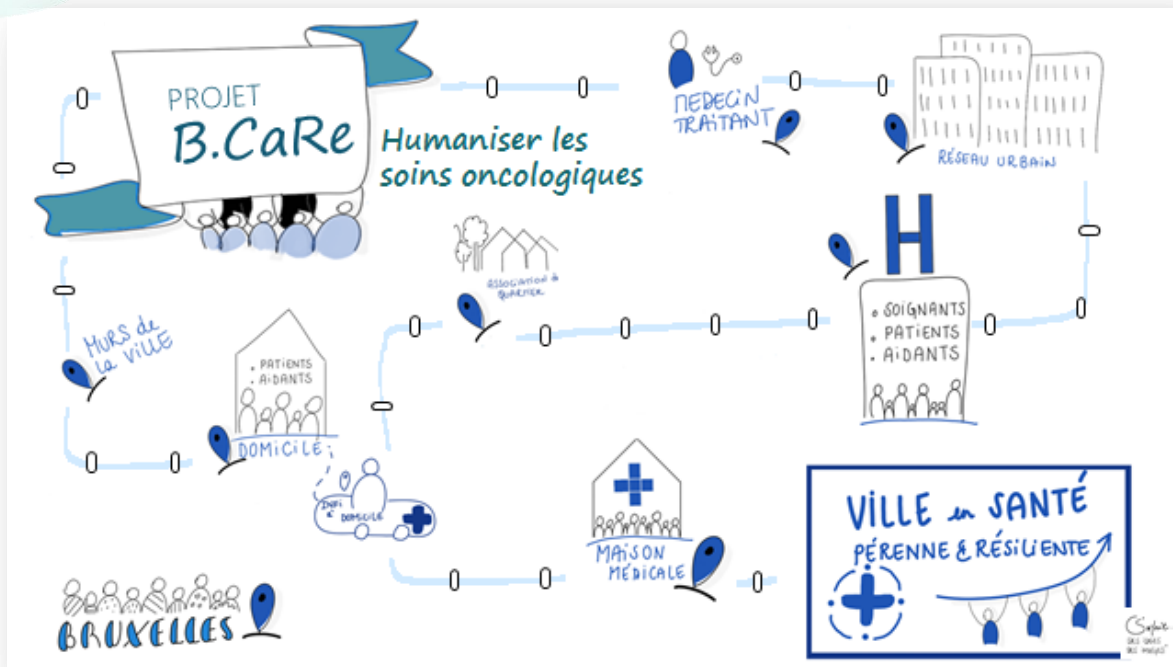
Decrease in quality of care

(© Consortium B.CARE)



Projet B.CaRe

Humaniser les soins en oncologie: cherchons ensemble!



4 year project - Start 1 nov 2021

(© Consortium B.CARE)



Projet B.CaRe

Humaniser les soins en oncologie: cherchons ensemble!

ULB



Céline Mahieu
Collaborations
interprof., bien-être au
travail



Florence Horicks
Coordinatrice



Fabian Defraigne
Collab. 1ère-2ème
ligne



Yves Coppieters
Santé Publique



Thaïs Pons
Support



TRAVAIL&CANCER



Magali Mertens
Coaching, retour au travail



Laura Lozano
Infirmière



Quentin Vanderhofstadt
Médecin Généraliste



Ingrid Theunissen
MD, oncologie intégrative



Mariangela Fiorente
Action Lymphome WB



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Sandra Michiels
Interculturalité,
inégalités sociales



Patrick Crombez
Inf. oncologie-hémato



Patrick Miqueu
Collaborations Patients



Anh Thi Nguyen
Patiente Experte



Lucile Charnier
Artiste

+

Collectif d'Artistes
Et d'Art-thérapeutes

Objectives



1. Smoother therapeutic pathways and networking to support patients
2. Development of professional well-being tools in the healthcare field
3. Support for the hospital-city transition and collaboration between 1st and 2nd line care teams
4. Recognition and/or integration of non-healthcare professionals to restore the link and the human element in therapeutic relations and the organization of care

=> Local networks allowing for concerted care and support for patients with real teamwork between carers and local resources

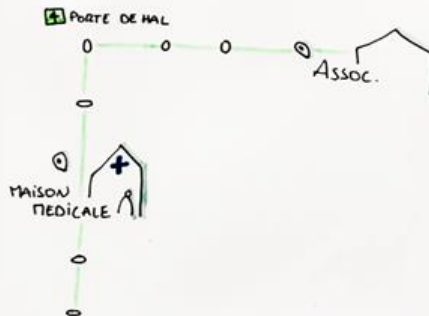
=> Ownership by citizens of their cancer journey and well-being



Urban biographies

PROFILES HUMANIZATION

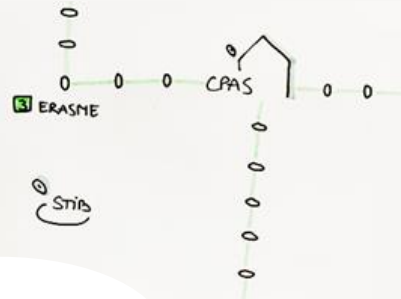
- Biographical profiles
- Sharing experiential knowledge



The Allies of Care

HUMANIZATION OF RELATIONSHIPS

- Inclusion of « non-carers » in care team
- Art/PP/... interventions



B·CaRe

CONCERTED SUPPORT APPROACH ON A TERRITORY

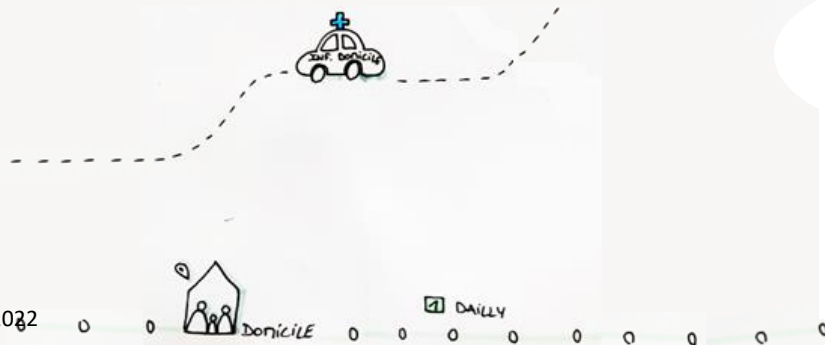


Transition in the city

CARE PATHWAY HUMANIZATION

- « City-oriented » oncology coordinating nurses

OECI44 - June 15th 2022



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Wellbeing @Workplace

HUMANIZATION OF PLACES

- Quality of professional life
- Coaching & Disability Management

B.CaRe – “The Allies of Care”

- ♦ *Caring of the carers who take care*
- ♦ Building interprofesionnal care teams with patient-experts, artists, non-healthcare employees...
- ♦ Bringing new resources for patients and healthcare professional
- ♦ Developing a *culture* to support the development of interprofessional collaborative patient-centered care

B.CaRe – “The Allies of Care”

- ◆ Phase 1 : Exploration (6 months)
- ◆ In practice...
- ◆ Questionning dimension of interprofessional care:
 - ◆ values and ethics, roles and responsibilities, interprofessional communication, cooperation and teamwork...
- ◆ First results:
 - ◆ Individual patient support with patient-expert
 - ◆ Individual artistic workshops with artist-singer

Conclusion

- ◆ From consultation, to involvement and starting co-creation: amazing journey!
- ◆ Collective human intelligence
 - “a team of cooperating agents can solve problems more efficiently than when those agents work in isolation”*

*“No one knows everything,
but everyone knows something”*

Thank you !



+ all colleagues @Bordet



+ Patient-partners, patients and their relatives



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