# STH INTERNATIONAL CONFERENCE ON ONCOLOGY AND CANCER RESEARCH



**Elodie Neumann-Michel** <sup>a</sup> , Geneviève Petitpierre <sup>b</sup>, Amaëlle Otandault <sup>a</sup>, Elisangela Olivier <sup>a</sup>, Marc Palpacuer <sup>a</sup>, Anaïs Lecluse <sup>c</sup>, Xavier Heber-Suffrin <sup>d</sup>, Brigitte Trétarre <sup>a e f</sup>, Chris Serrand <sup>g</sup>, Daniel Satgé <sup>a</sup>

- <sup>a</sup> Oncodefi, Parc Euromédecine, Montpellier, France
- <sup>b</sup> Department of Special Education, University of Fribourg, Fribourg, Switzerland
- <sup>c</sup> Association "Nous Aussi", France
- d Établissement et service d'aide par le travail L'Envol, UNAPEI 34, Castelnau-le-Lez, France
- <sup>e</sup> Herault Tumor Registry, Montpellier, France
- f CERPOP Constitutive Team, UMR 1295, Inserm, University of Toulouse III Paul Sabatier, Toulouse, France
- g Department of Biostatistics, Clinical Epid<mark>emi</mark>ology, Public Health and Methodological Innovation CHU Nîmes, Nîmes, France
- h Desbrest Institute of Epidemiology and Public Health, UMR UA11, INSERM, University of Montpellier, Montpellier, France

# Improving participation and knowledge of people with intellectual disabilities in cancer screening: the PAM study

### **Background**

In persons with intellectual disability (PID) breast, colon and cervical cancers are frequent and often diagnosed late. Yet, they show a lower participation in organized cancer screenings. Purpose: The participatory research PAM (Prevention/Screening-Adults-Measure) evaluated the ability of PID to understand and memorize information on cancer screening and put into practice these three screenings.

## Methodology

A randomized controlled trial evaluated the efficacy of an adapted instructional module (IM) on adults with mild and moderate ID. The tested group received information on cancer screening while the control group received a placebo module on oral hygiene. The IM included a slideshow, a workshop using screening kits and latex organs (breast) to palpate abnormalities, discussion time, a game and a film specially created for the study. An "easy-to-read-and-understand" questionnaire on screenings was completed four times by participants: 15 days before the IM, the day of IM, 3 months and 1 year after.

ISBN: 978-1-917892-23-0



# STH INTERNATIONAL CONFERENCE ON ONCOLOGY AND CANCER RESEARCH

#### Results

The study included 608 PID from 38 institutions in the South of France. The day of the IM, three months, and one year after the intervention, experimental group participants showed significantly improved cancer screening knowledge (p<0.001) compared to controls. The intention to participate in screenings was increased on the intervention date (p<0.001), and observed as a trend at one year (p=0.068). Study attrition was only 19% after one year, showing an active interest of PID in cancer screening.

#### Conclusion

This research provides strong evidence supporting adapted and direct interventions for people with intellectual disability to increase their knowledge and participation in organized cancer screening. Study supported by the French National cancer institute (INca).

## Biography

Elodie Neumann-Michel is a cancer nurse and researcher working currently at Oncodefi association Montpellier France, dedicated to cancer care in people with intellectual disabilities. Qualified in 2004, she worked as a nurse in cancer and palliative care departments in Paris, then at the Montpellier cancer center. Holder of a master's degree in health research (Montpellier School of Medicine) she worked during three years on the PAM study which evaluated health learning in people with intellectual disabilities.

ISBN: 978-1-917892-23-0