

Enjeux et barrières à l'implication de patients-partenaires en recherche en soins palliatifs.

Guillaume Economos, MD, M.Sc.

Centre de Soins Palliatifs Lyon Sud – HCL

Equipe de recherche EPiCEA



- ***Liens d'intérêts déclarés par l'intervenant :***

Absence de lien d'intérêts déclarés par l'intervenant

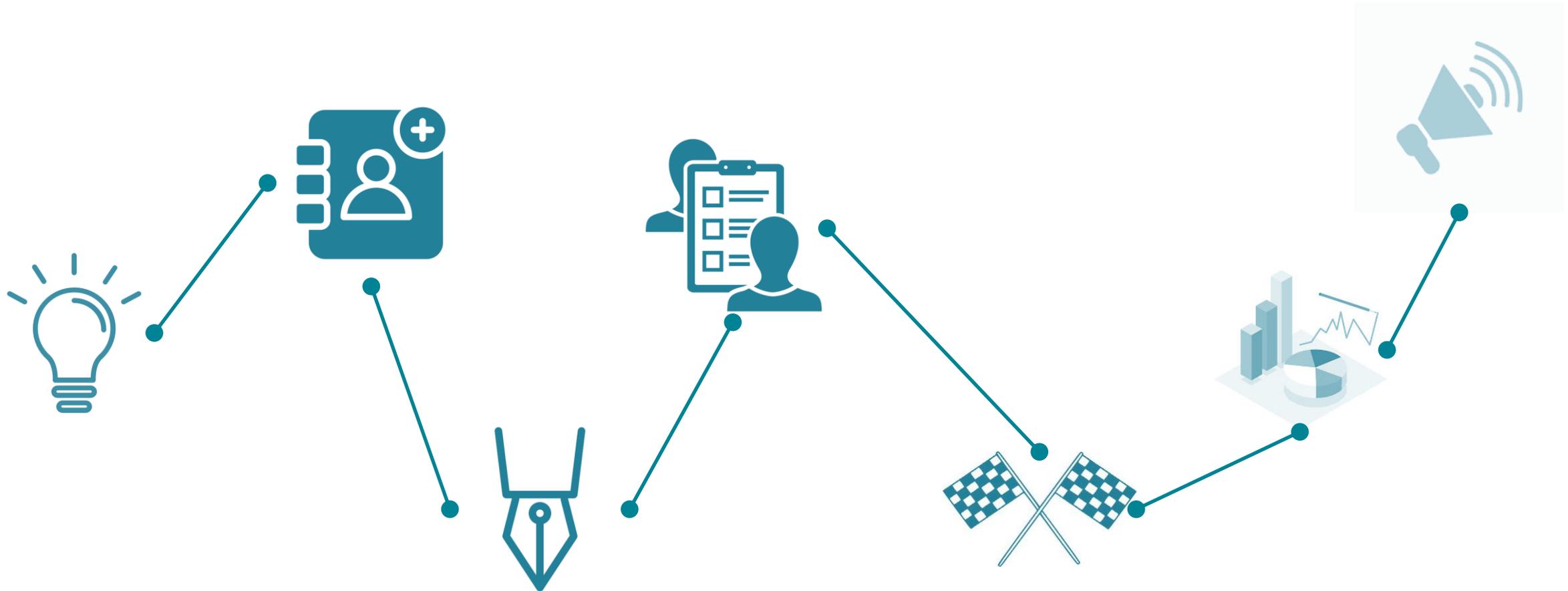
I- Mise en œuvre des projets participatifs.

II- Enjeux spécifiques aux contextes palliatifs.

- Les sciences participatives:²

Forme de production de connaissances scientifiques auxquelles des acteurs non scientifiques-professionnels, qu'il s'agisse d'individus ou de groupes, participent de façon active et délibérée.

² -Houllier F, Merilhou-Goudard J-B. Les sciences participatives en France [Internet]. 2016 p. 63 p. Available from: <https://hal.inrae.fr/hal-02801940>



Impliquer les patients dès l'idée...

- **Rendre le sujet pertinent pour la population cible.**



Impliquer
précocement un PPI

Recherche
communautaire³

3 - Riffin C, Kenien C, Ghesquiere A, Dorime A, Villanueva C, Gardner D, et al. Community-based participatory research: understanding a promising approach to addressing knowledge gaps in palliative care. *Ann Palliat Med.* 2016;5:218–24.



Faire jouer les réseau des patients

- Faciliter le recrutement ultérieur dans certaines populations



ACCESSCare Research :
King's College London

Faire co-construire le projet et/ou relire le protocole

Patient and public involvement in the design of clinical trials: An overview of systematic reviews



Amy Price MA (Open) MSc (Open) MSc(Oxon) DPhil Student (Oxon) PhD ✉, Loai Albarqouni MSc MD PhD, Jo Kirkpatrick BSc, Hons (Open) Post Grad Certificate Psych (Open), ... [See all authors](#) ▾

- Faciliter l'acceptation de l'intervention
- Augmenter le recrutement
- Faciliter l'implémentation
- Augmenter la validité des données collectées

➤ Obtenir certains financements...





Horizon Europe
 Programme Guide

Version 1.1
 19 July 2021

Disclaimer
 This guide is aimed at assisting applicants. It is provided for information purposes only and is not intended to replace consultation of any applicable legal sources. Neither the Commission nor the Executive Agencies (or any person acting on their behalf) can be held responsible for the use made of this guidance document.



Citizen, civil society and end-user engagement: Provide clear and succinct information on how citizen, civil society and end-user engagement will be implemented in your project, where/if appropriate. The kinds of engagement activities will depend on the type of R&I activity envisaged and on the disciplines and sectors implicated.

This may include: *co-design activities* (such as workshops, focus groups or other means to develop R&I agendas, roadmaps and policies) often including deep discussion on the implications, the ethics, the benefits and the challenges related to R&I courses of action or technology development; *co-creation activities* (involving citizens and/or end-users directly in the development of new knowledge or innovation, for instance through citizen science and user-led innovation); and *co-assessment activities* (such as assisting in the monitoring, evaluation and feedback to governance of a project, projects, policies or programmes on an iterative or even continual basis).

The extent of engagement in the proposal could range from one-off activities alongside other methodological approaches to being the primary focus or methodological approach of the project itself. Engagement will require resources and expertise and is therefore often conducted by dedicated interlocutor organisations or staff with relevant expertise. More detailed information on these activities and useful resources developed over the course of Horizon 2020 can be found in the relevant section below.

Impliquer le patient en tant que représentant de l'étude (champion / facilitateur) ⁴

- Faciliter la mise en œuvre de l'étude
- Favoriser le recrutement

4 - Gray-Burrows KA, Willis TA, Foy R, Rathfelder M, Bland P, Chin A, et al. Role of patient and public involvement in implementation research: a consensus study. *BMJ Qual Saf.* 2018 Oct;27(10):858–64.

Faire relire les données et résultats

- Avoir d'autres modes d'interprétation des données ⁶
- Avoir des éléments de discussion
- Augmenter la validité des données ⁷

Health Expectations
Open Access

An International Journal of Public Participation
in Health Care and Health Policy

6

Patient involvement in qualitative data analysis in a trial of a patient-centred intervention: Reconciling lay knowledge and scientific method

Julia Frost PhD, Senior Lecturer Health Services Research¹  | Andy Gibson PhD, Associate Professor in Patient and Public Involvement, Health and Social Sciences² | Faith Harris-Golesworthy, Patient and Public Involvement Representative³ | Jim Harris, Patient and Public Involvement Representative³ | Nicky Britten PhD, Professor of Applied Health Care Research⁴

7 Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis from the patient perspective using focus groups

Michaela Coenen^{1,2}, Alarcos Cieza¹, Tanja A Stamm^{1,3}, Edda Amann¹, Barbara Kollerits¹ and Gerold Stucki^{1,2,4}



Diffuser les résultats des études

- Diffuser via les associations de patients
- Diffuser via les groupes de pairs
- Diffuser via les réseaux sociaux



LA LIGUE

CONTRE LE CANCER



- **Le patient partenaire en soins palliatifs, quelles réticences?** ⁹

? Inquiétudes sur la balance bénéfice /risque

? Patient en état de fragilité / faiblesse / vulnérabilité

? Peur de la charge liée à l'étude

? Peur liée au retentissement psychologique

9 -Blum D, Inauen R, Binswanger J, Strasser F. Barriers to research in palliative care: A systematic literature review. Progress in Palliative Care. 2015 Apr;23(2):75–84.

Talking With Terminally Ill Patients and Their Caregivers About Death, Dying, and Bereavement

Is It Stressful? Is It Helpful?



Ezekiel J. Emanuel, MD, PhD; Diane L. Fairclough, DPH; Pam Wolfe, MS; Linda L. Emanuel, MD, PhD

Table 2. Terminally Ill Patient and Primary Caregiver Reports of Stress and Helpfulness Experienced in Participating in an In-Person Survey on Death and Dying*

Variable	Terminally Ill Patients		Caregivers of Terminally Ill Patients	
	Initial Survey (N = 988)	Follow-up Survey (n = 650)	Initial Survey (N = 893)	Postbereavement Survey (n = 256)
Stress				
A great deal	1.9	3.1	1.5	9.4
Some	7.1	7.2	8.4	16.4
Little or none	88.7	87.6	89.7	73.4
No response	2.3	2.2	0.4	0.2
Helpful				
Very	16.9	14.0	19.1	16.8
Somewhat	29.6	25.4	34.3	24.6
Little or none	49.6	58.9	44.9	56.3
No response	3.9	2.8	1.7	2.3

*Values are given as percentages.

10 -Emanuel EJ, Fairclough DL, Wolfe P, Emanuel LL. Talking With Terminally Ill Patients and Their Caregivers About Death, Dying, and Bereavement: Is It Stressful? Is It Helpful? Arch Intern Med. 2004 Oct 11;164(18):1999.



Dying persons' perspectives on, or experiences of, participating in research: An integrative review

Melissa J Bloomer, Alison M Hutchinson, Laura Brooks and Mari Botti



« Quel est le point de vue et expériences des personnes mourantes participant à des projets de recherche? »

Valorisation du fait de participer à des projets de recherche, même en l'absence de bénéfice personnel

Une personne mourante ne doit pas être présumée vulnérable de fait

Peut être profitable indirectement par une satisfaction à aider les autres, contribuer à la société, à la sciences et aux futures soins

11 -Bloomer MJ, Hutchinson AM, Brooks L, Botti M. Dying persons' perspectives on, or experiences of, participating in research: An integrative review. Palliat Med. 2018;32:851-60.

- Alternatives au patient-partenaire...

Une parade est l'utilisation des anciens patients (Survivors) des groupes de patients (La Ligue) ou des membres de la famille.



European Cancer
Patient Coalition



Family Caregiver Participation in Palliative Care Research: Challenging the Myth

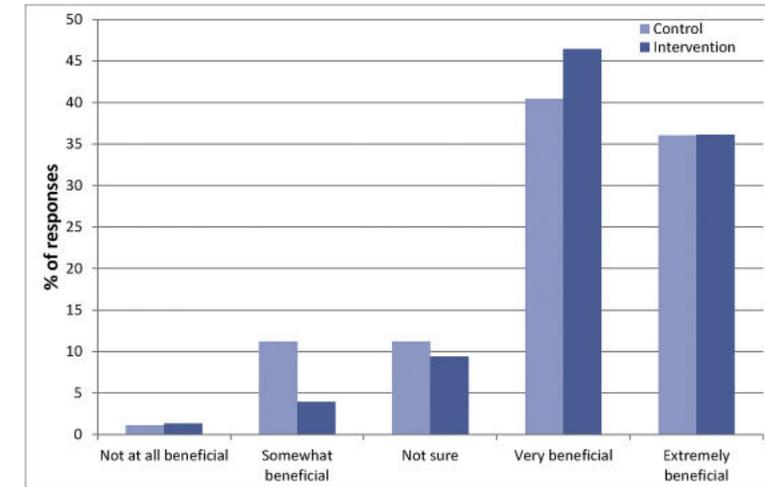


Samar Aoun, PhD, MPH, BSc(Hons), Susan Slatyer, PhD, BNurs(Hons), RN, Kathleen Deas, RN, and Cheryl Nekolaichuk, PhD(R.Psych)

School of Nursing, Midwifery and Paramedicine (S.A., S.S., K.D.), Curtin University, Perth; Centre for Nursing Research (S.S.), Sir Charles Gairdner Hospital, Perth, Western Australia, Australia; and Division of Palliative Care Medicine (C.N.), Department of Oncology, University of Alberta, Edmonton, Alberta, Canada

Table 2
Summary of Themes and Corresponding Subthemes

Theme	Subthemes
Theme 1: intrapersonal—inward directed	<ul style="list-style-type: none"> - Prompting contemplation and reflection: “Making you think” - Gaining insight and awareness of support needs: recognizing the “emotional and physical side of caring”
Theme 2: connection with others—outward directed	<ul style="list-style-type: none"> - Feeling acknowledged and valued: “Feeling as if you matter” - Feeling less isolated: “Letting people in” - Improving support for future caregivers: “Making a difference for others” - Enhancing service improvement: “Needing documented evidence”
Theme 3: interpersonal—participant-researcher relationship	<ul style="list-style-type: none"> - Expressing a “caring tone” - “Listening to my heart” - Respecting “my free will”



12 -Aoun S, Slatyer S, Deas K, Nekolaichuk C. Family Caregiver Participation in Palliative Care Research: Challenging the Myth. Journal of Pain and Symptom Management. 2017;53:851–61.





Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation



Halle Johnson^{1*} , Margaret Ogden^{2*}, Lisa Jane Brighton¹ ,
 Simon Noah Etkind¹, Adejoke O Oluyase¹ , Emeka Chukwusa¹,
 Peihan Yu¹, Susanne de Wolf-Linder³, Pam Smith², Sylvia Bailey²,
 Jonathan Koffman¹  and Catherine J Evans^{1,4}

- Faciliter l'implication des PPI en soins palliatifs:

-  Créer et maintenir des relations patient-soignant-chercheur

-  Être flexible sur le niveau d'engagement du patient

-  Sélectionner les bonnes personnes



Figure 2. Revised principles to inform public involvement in palliative care and rehabilitation research.

13 -Johnson H, Ogden M, Brighton LJ, Etkind SN, Oluyase AO, Chukwusa E, et al. Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation. Palliat Med. 2021;35:151–60.



Merci pour votre attention.

Guillaume.economos@chu-lyon.fr