



Barrières et facilitateurs de la recherche clinique en CHSLD et en UCDG :

Comment en faire davantage grâce aux perspectives des multiples parties prenantes impliquées dans la recherche sur le vieillissement?

Midi-maillage - Centre d'excellence sur le vieillissement de Québec

2024.12.12

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Géiatre, épidémiologiste et chercheur CHUM/CRCHUM



Divulgation du présentateur

- Liens avec des commanditaires :
 - Commercial : expert médical d'Eugeria
 - Subvention à la recherche : UdeM, FRQS, IRSC et Fondation Saputo
 - Bureau des conférenciers/honoraires : aucun
 - Brevet : aucun
- Conflits d'intérêt potentiels :
 - Quoc Dinh Nguyen est détenteur de parts dans l'entreprise Eugeria, compagnie offrant des produits et services pour les personnes âgées atteintes de troubles cognitifs et leurs proches.

Thèmes de la présentation

- **Barrières et facilitateurs de la recherche clinique en CHSLD :**

Comment en **faire davantage** grâce aux perspectives des **multiples parties prenantes impliquées** dans la recherche sur le **vieillissement**?

- Plus largement
 - *Comment adapter la recherche à la population gériatrique?*
 - Population – intervention – méthodes statistiques et IA – outcomes

Objectifs et plan de la présentation

- Souligner l'importance de la recherche clinique dans la population âgée
- Présenter les barrières et les facilitateurs identifiées, et **leur importance**
- Présenter des canevas pour avancer
- Faire des ponts avec vous, vous entendre



Pourquoi cette étude 1?

- Sous-représentation des personnes âgées

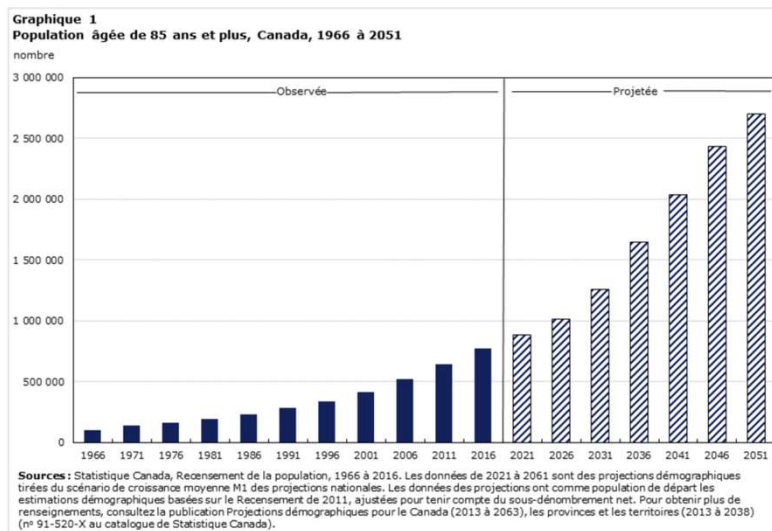


Table 5. Comparison of Age and Female Representation in Randomized Clinical Trials and Population Prevalence

	Median Age in Trials, y	Median Age in NHANES and GBD, y	Gap, y	Women in Trials (Mean %)	Female Prevalence in NHANES and GBD, %	Gap, %
All conditions	63.0	...		33.0	...	
Coronary artery disease	62.0	67.0	-5.0	27.4	54.6	-27.2
Heart failure	64.0	70.0	-6.0	27.4	52.8	-25.4
High vascular risk	60.2	...		49.1	...	
Diabetes mellitus	60.0	61.0	-1.0	37.2	55.0	-17.8
Hypertension	63.0	60.0	3.0	46.2	48.0	-1.8
Atrial fibrillation	68.9	70.5*	-1.6	33.3	42.1	-8.8
Other	66.0	...		35.0	...	

GBD indicates Global Burden of Disease; and NHANES, National Health and Nutrition Examination Survey 2015–2016.

*Estimates from the 2010 GBD standardized to the 2010 US population.

Pourquoi cette étude 2?

- Sous-représentation durant la pandémie
 - Clinique
 - Impact

Prendki et al. *BMC Geriatrics* (2020) 20:538
<https://doi.org/10.1186/s12877-020-01954-5>

BMC Geriatrics

RESEARCH ARTICLE

Open Access

A systematic review assessing the under-representation of elderly adults in COVID-19 trials



Virginie Prendki^{1,2,3*}, Noam Tau^{4,5}, Tomer Avni^{5,6}, Marco Falcone⁷, Angela Huttner^{2,3}, Laurent Kaiser^{2,3}, Mical Paul⁸, Yaara Leibovici-Weissmann^{5,9†}, Dafna Yahav^{5,10†}, on behalf of ESCMID Study Group for Infections in the Elderly (ESGIE)

- **12 RCTs**
 - Âge moyen = 56 ans
 - Consentement substitué, n = 1
 - Analyse 65+, n = 1
 - Exclusion cognition, maladies chroniques
 - Pas d'outcomes gériatriques
- Vaccination
 - Âge moyen = 45 ans
 - 1.7% 75+

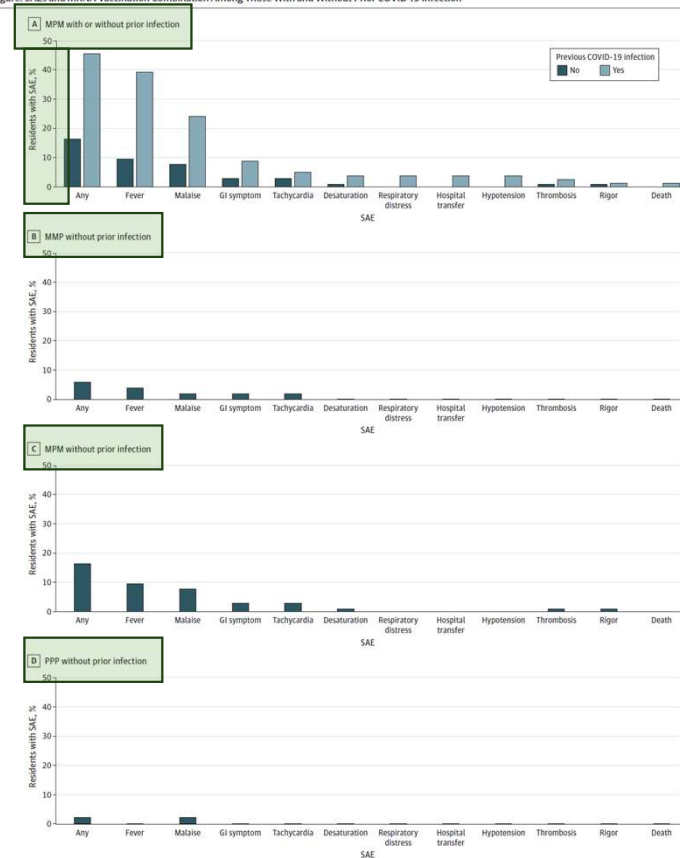
Pourquoi cette étude 3?

- Généralisabilité, transportabilité et validité externe – *EBM*
 - *Efficacy* ou *effectiveness*
 - Intervention applicable?
 - Effets secondaires
 - Outcomes pertinents à la population gériatrique

Safety and Adverse Events Among Long-term Care Residents Receiving a Third COVID-19 mRNA Vaccine Booster Dose in Quebec

Xi Sophie Zhang, MD, MSc; Andréanne Moreau, MD; Diana Cruz-Santiago, MD; Stéphanie Langevin, MD, MSc; Quoc Dinh Nguyen, MD, MPH, PhD

Figure. SAEs and mRNA Vaccination Combination Among Those With and Without Prior COVID-19 Infection



Ce qu'on sait et ce qu'on sait moins

- Su
 - Modèles recherche gériatrique: 5T et 5M
 - Target population
 - Team
 - Tools
 - Time
 - Tips
 - Mind
 - Mobility
 - Medications
 - Multicomplexity
 - Matters most to me
 - Barrières connues et bien décrites en CHSLD

Lam et al. *BMC Geriatrics* (2018) 18:242
<https://doi.org/10.1186/s12877-018-0934-9>

BMC Geriatrics

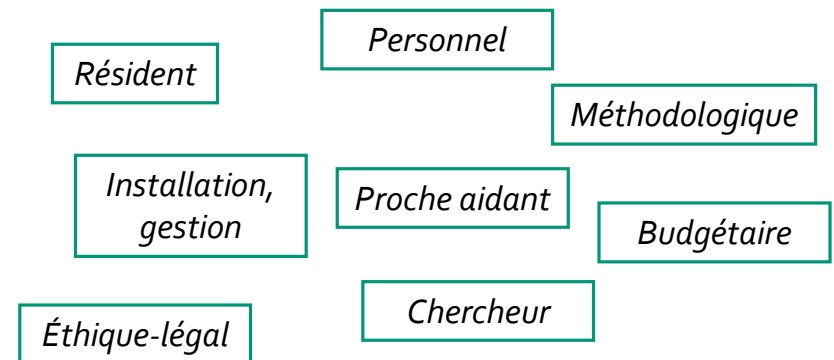
RESEARCH ARTICLE

Open Access

Challenges of conducting research in long-term care facilities: a systematic review

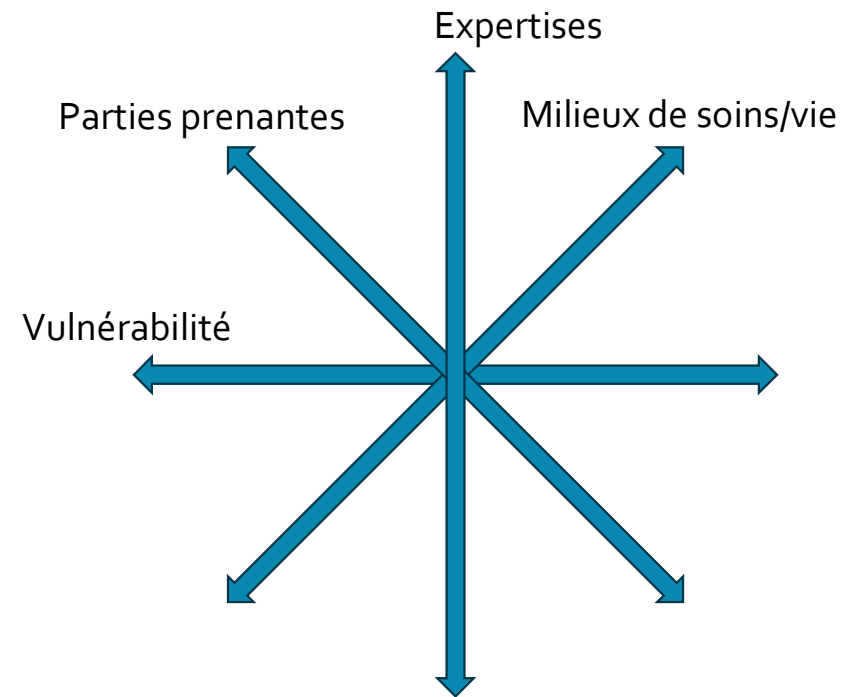


Helen R Lam¹, Selina Chow^{1,2}, Kate Taylor¹, Ronald Chow¹, Henry Lam¹, Katija Bonin¹, Leigha Rowbottom¹ and Nathan Herrmann^{1,2*}



Ce qu'on sait et ce qu'on sait moins

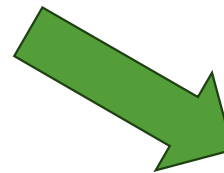
- Moins su – **Comment mettre ça ensemble?**
 - Hétérogénéité de la population âgée
 - Comparaison CHSLD et UCDG
 - Variabilité questions de recherche
 - Multiplicité des parties prenantes
 - Perspectives de chacune



Est-ce réaliste ou optimal de produire une liste de barrières, facilitateurs, recommandations pertinentes partout?

Notre objectif

- **Cadre conceptuel** à l'intersection
 - Qui est important?
 - Quels sont les thèmes importants?
 - À quelles étapes de la recherche?
 - UCDG vs CHSLD



Canevas pour mener la recherche localement

Ce qu'on a fait

1. Scan environnemental → *Préliminaire*
2. Revue systématique → *Matériel brut*
3. Synthèse quantitative

→ Sortir les parties prenantes, les étapes de recherche et les thèmes

Scan environnemental

- Perspectives sur parties prenantes, étapes, thèmes
 - 7 membres du personnel
 - 6 chercheurs cliniques
 - 6 chercheurs non cliniques
 - 2 gestionnaires
 - 1 patient partenaire
 - 1 personnel de recherche
 - 1 représentant réseau de recherche

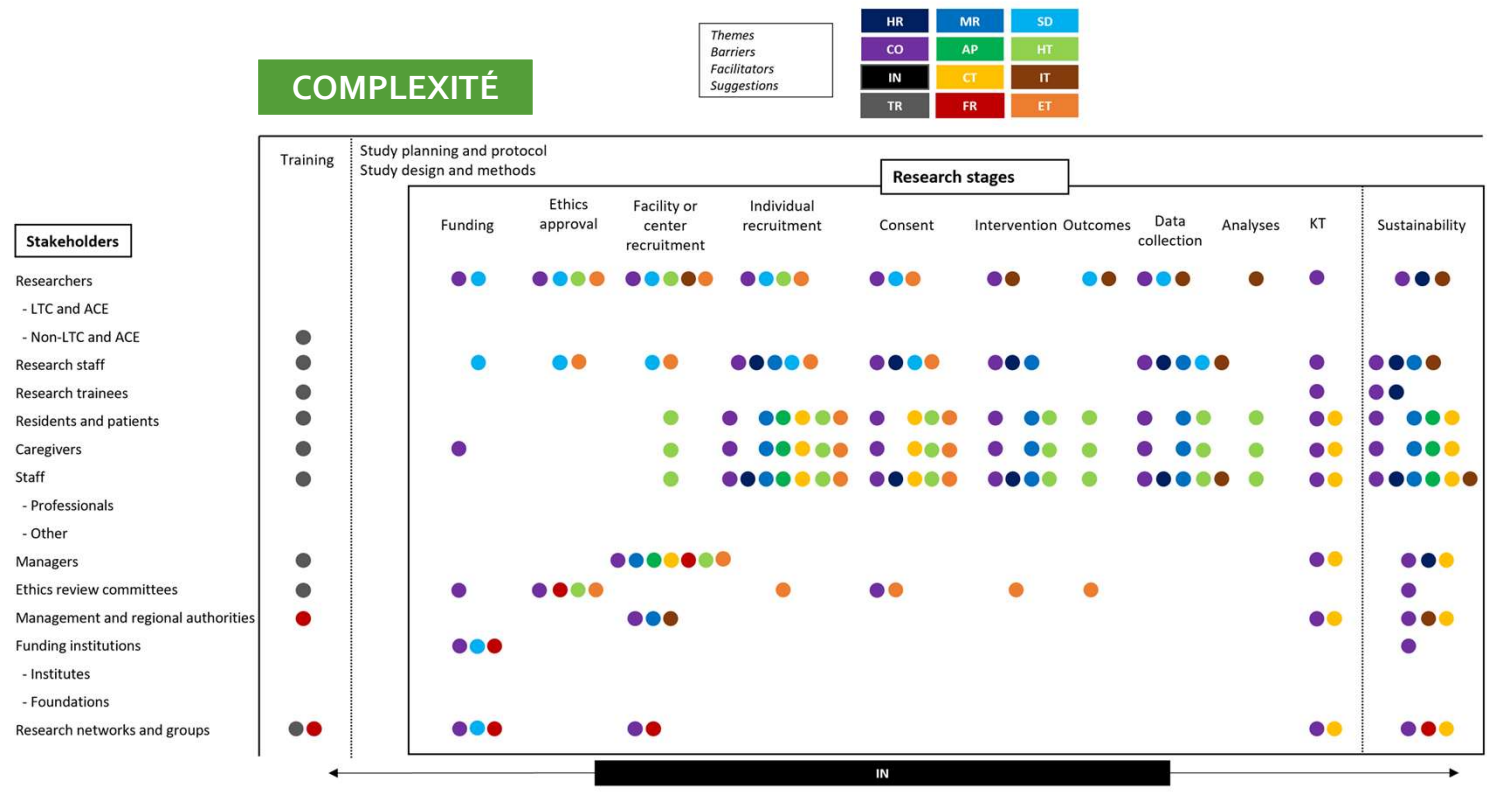


Supplementary Table 1. Initial stakeholders and research stages

Initial stakeholders
Researchers based in LTC and GAC
Researchers in general
Research staff
Residents and patients
Caregivers
Staff (professionals)
Staff (others)
Ethics review committees
Managers
Management and regional authorities (e.g., central offices)
Research networks and groups
Funding agencies and institutes
Foundations
Trainees
Initial research stages
Training
Study planning and protocol
Study design and methods
Funding
Ethics approval
Facility or center recruitment
Individual recruitment
Consent
Intervention
Data collection
Outcomes
Analyses
Knowledge transfer
Sustainability

Cadre conceptuel préliminaire

Supplementary Figure 1. Initial conceptual framework and interaction map



Revue systématique

- 2000-2021, sur méthodes processus de recherche UCDG et CHSLD
- 7014 abrégés →
132 complets →
68 inclus

Supplementary Table 3. Characteristics of articles included in systematic mapping review

Year (n = 68)	
2000-2004	9 (13%)
2005-2009	17 (25%)
2010-2014	16 (24%)
2015-2019	17 (25%)
2020-2021	9 (13%)
Jurisdiction	
United States of America	30 (45%)
United Kingdom	23 (34%)
Europe	6 (9.0%)
Australia and New Zealand	4 (6.0%)
Asia	3 (4.5%)
Canada	2 (3.0%)
Methodology	
Review	23 (34%)
Qualitative	21 (32%)
Quantitative	9 (14%)
Mixed	7 (11%)
Methods	8 (12%)
Population	
Long-term care	51 (75%)
Geriatric acute care or mixed	27 (25%)

COMPLEXITÉ

Table 1 Research stakeholders, stages, and transversal themes		
12	Research stakeholders	17
	Research team	*Alignment
	Residents and patients	
	Caregivers	Appropriation
	Staff	
	Facilities and centers	Collaboration
	Ethics review committees	Communication and trust
	Managers	Ethics
	Management and regional authorities	
	Research networks and groups	
	Funding agencies and institutes	
	Foundations	Fragmentation
	Trainees	
		*Funding
		*Governance
		Heterogeneity
		Human resources
		Inefficiency
		Information technologies
		*Legal and regulations
		Material resources
		*Reputation
		Standardization
		Training

Defining and related concepts

Fit between project objectives and the perception and needs of stakeholders

Project ownership, mobilization, buy-in, local leadership and championing

Interdisciplinary work, team, Relationship, positive perception

Ethical issues and considerations, capacity, consent (including proxy), autonomy, power of attorney, privacy, confidentiality

Isolation, centralization, network, coordination

Grants, securing funds, costs for research

Central authority, administrative and operations rules, corporate responsibility

Variability in population and centers, personalization, adaptability, adjustments, feasibility and logistics with specific population

Staff shortage, staff turnover

Duplication, redundancy, delays, friction, and obstacles

Implementation and availability of technology, digital data infrastructure

Legislation, statutes, legal protection

Physical space, equipment

Public perception, threats to reputation

Harmonization, consensus, guidelines, best practices, simplification

Knowledge, lack of knowledge, uncertainty

Notes. *These themes were identified in conducting the systematic review

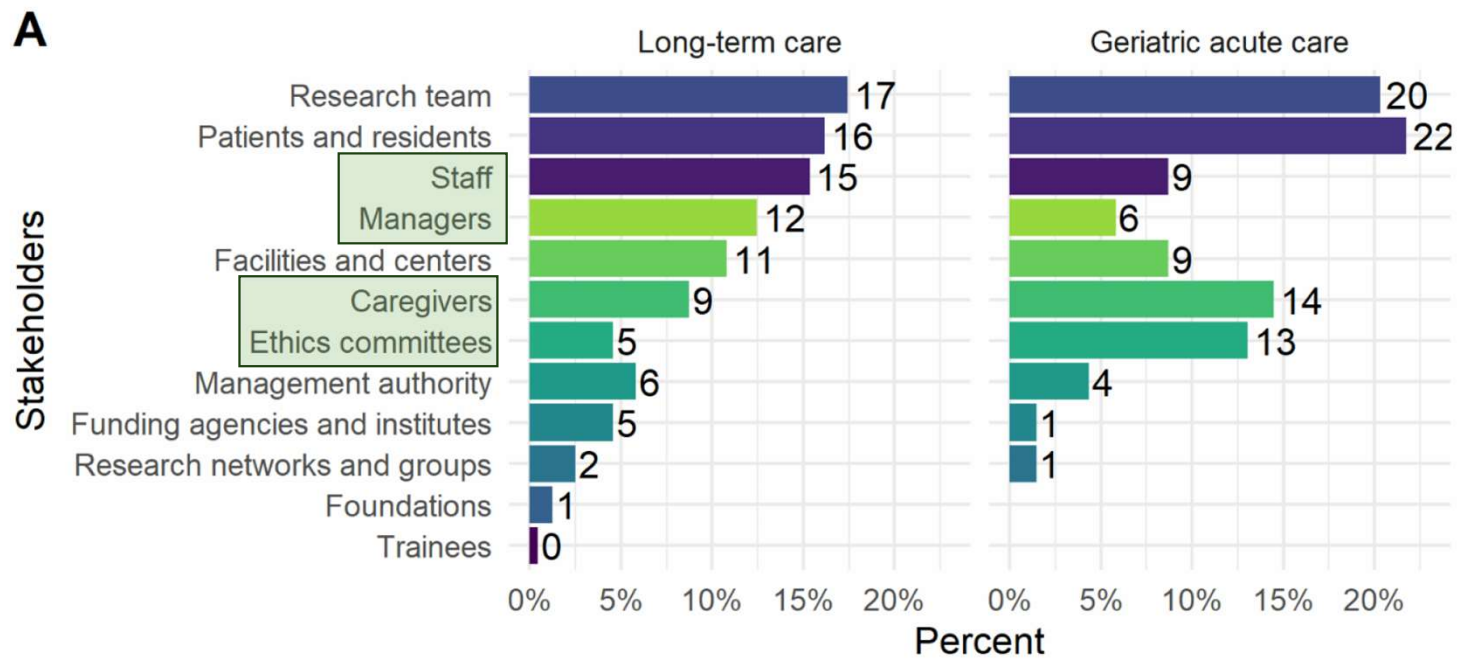
Synthèse – Ce qu'on a trouvé

- Complexité **COMPLEXITÉ**
- Décortiquer et **réduire** cette complexité
 - Par partie prenante
 - Par étape de recherche
 - Par thèmes

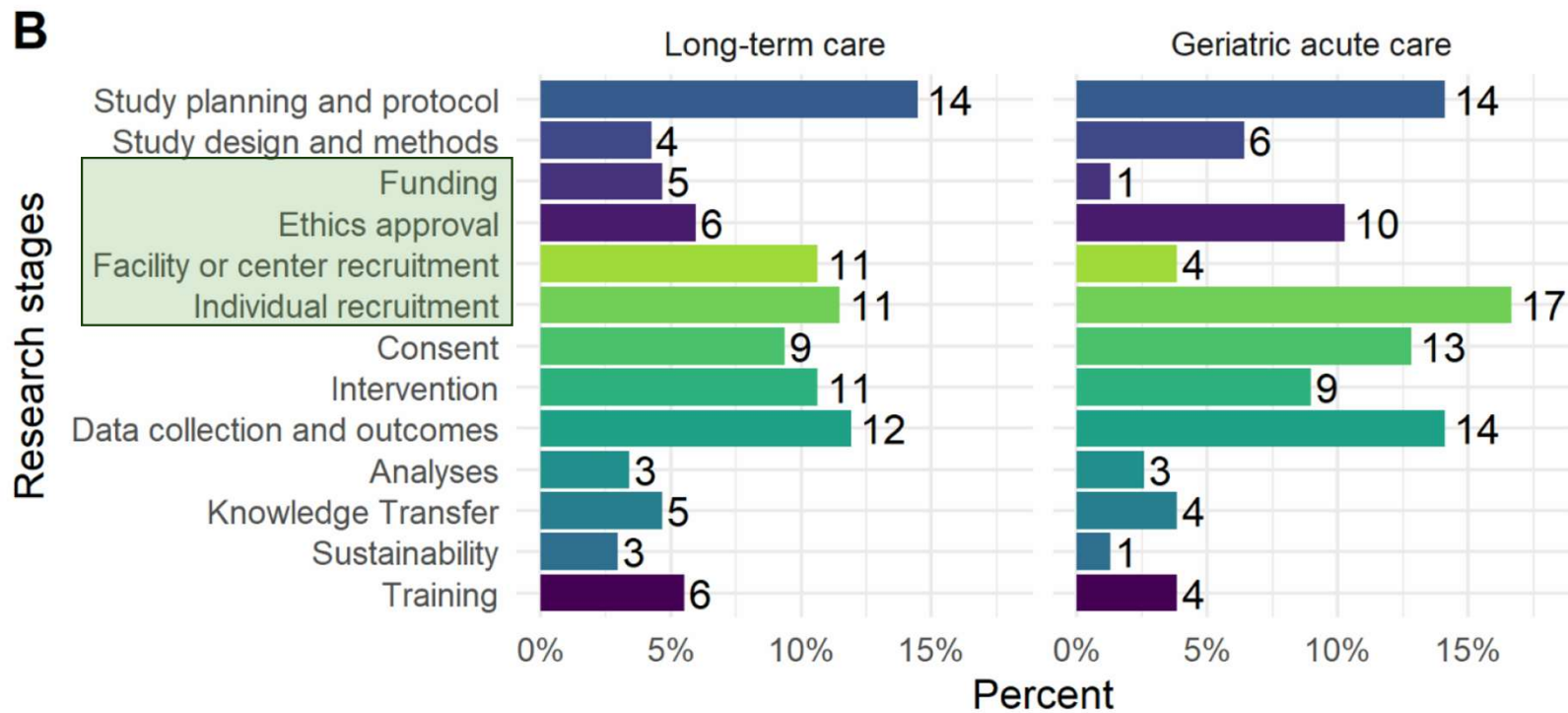


- Méthode **quantitative**
 1. Fréquence des PP, étapes, thèmes
 2. Intersections par unité de contenu codée (concept)
 - Co-occurrences parties prenantes * étapes
 - Co-occurrences parties prenantes * étapes * thèmes
 - Par article
- Résultats distincts UCDG et CHSLD lorsque pertinent

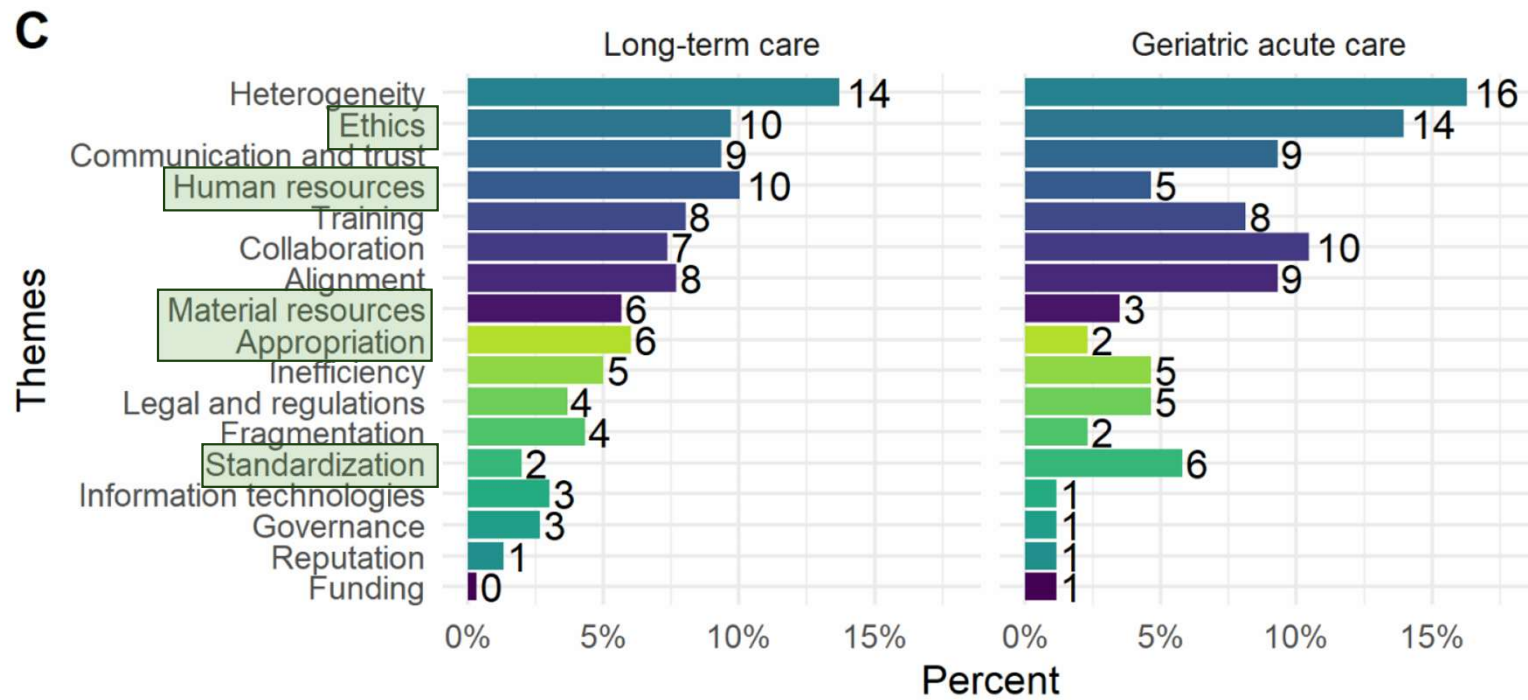
Importance parties prenantes



Importance étapes de recherche

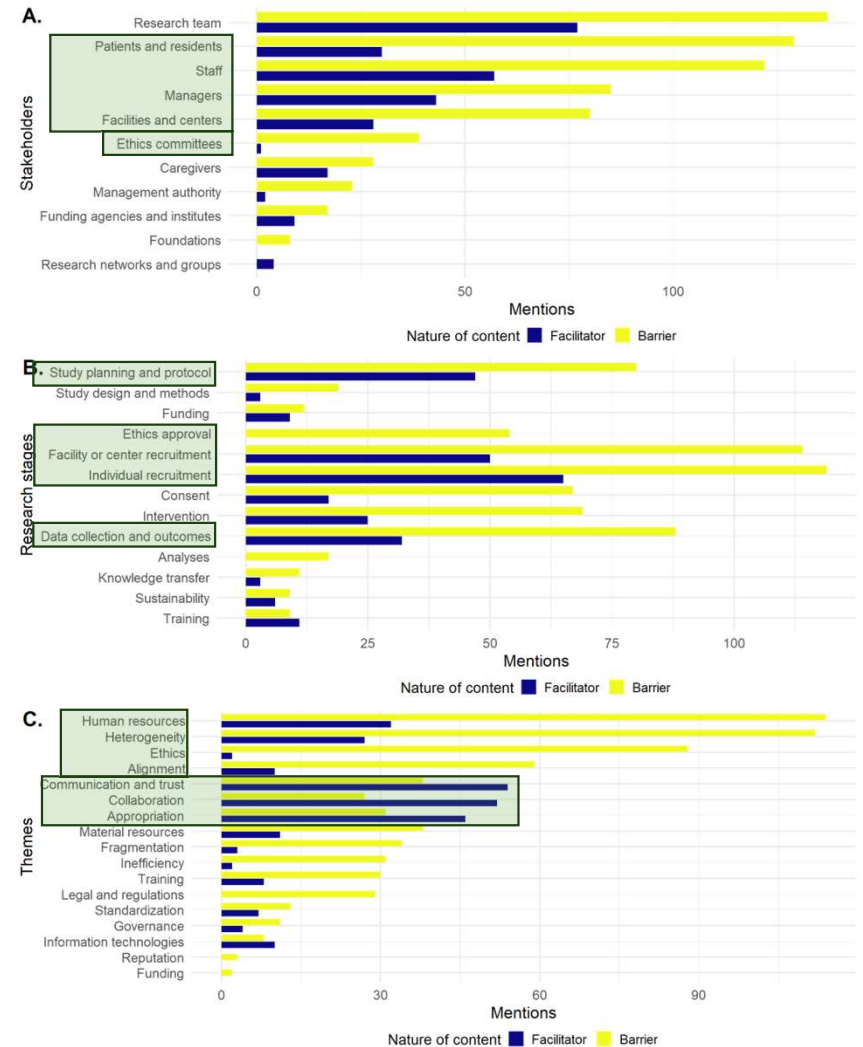


Importance des thèmes



Barrières et facilitateurs

- Regard
 - En absolu
 - En relatif



Intersections des contenus par article

- **1868 intersections**
 - 668 barrières
 - 268 facilitateurs
 - 442 thèmes généraux
 - 490 recommandations/suggestions
- Cartes thermiques – **Canevas pour comprendre et co-construire**
 - De quoi parler, de quoi se préoccuper, de quoi se prémunir?

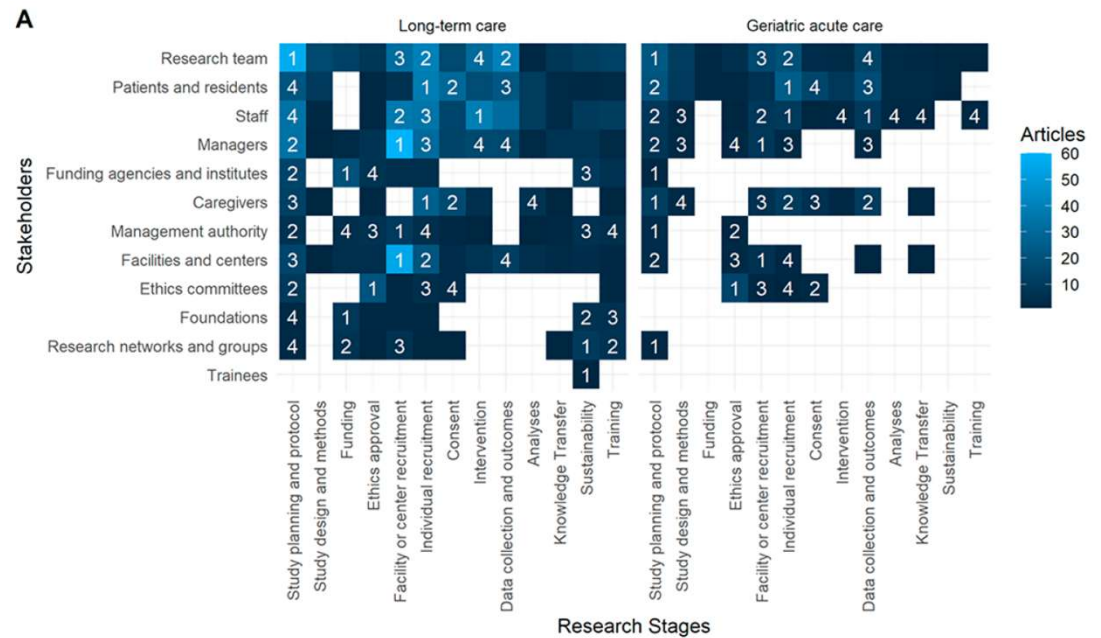
Canevas 1

Étapes par partie prenante

From an individual stakeholder perspective, we suggest using the heatmaps to plan, conduct, and participate in a study, or when building research capacity to:

1. Identify and prioritize the research stages where stakeholders' input and perspective are most relevant.

For example, study planning and protocol involves all stakeholders except trainees, and is centered on the research team (rank 1). At the facility recruitment stage, managers, management authorities, and facilities are main stakeholders (rank 1) whereas staff ranks second, the research networks and the research team in LTC, and research team, caregivers, and ethics committees in GAC rank third, respectively.



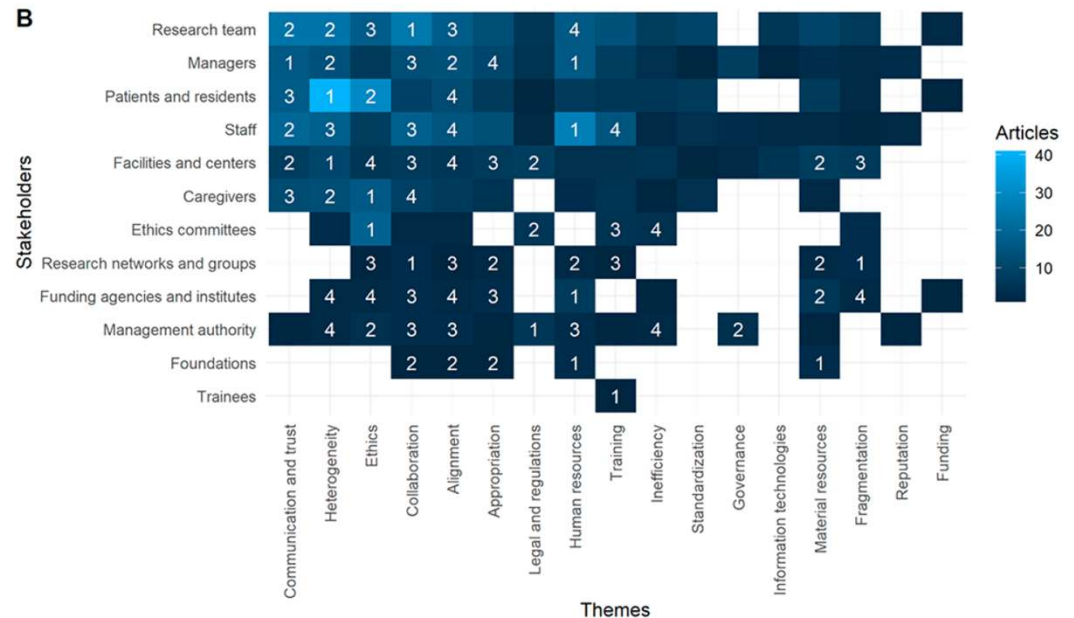
Canevas 2

Thèmes par partie prenante

2. Identify and prioritize the major themes relevant to a stakeholder group.

For example, the most important theme to emphasize for the research theme is collaboration; human resources, communication and trust for managers; heterogeneity for patients and residents as well as facilities; ethics for caregivers and ethics committees.

3. Ensure active participation at the relevant stages and alignment of research considerations and actions with transversal themes.



Canevas 3

Thèmes et partie prenante par étape

Our framework maps stakeholders and transversal themes across research stages. The heatmap identifies and prioritizes the critical interactions between stakeholders and themes at each research stages.

The four most important stakeholders at each stage are shown along with the four most important themes at the intersection. The interaction heatmap suggest the stakeholders who should be solicited in priority at each stage of the research process along with the themes to be discussed to reduce barriers to research and build capacity.

For the overall planning and conduct of a study, we suggest following these steps:

1. At each stage, involve minimally the identified (most critical) stakeholders; if possible, also involve other stakeholders identified in Figure 2.
2. Locate the critical transversal themes, barriers, and facilitators to be discussed among stakeholders to build and mobilize capacity.
3. Prioritize actions to address discussed barriers and facilitators with stakeholders.

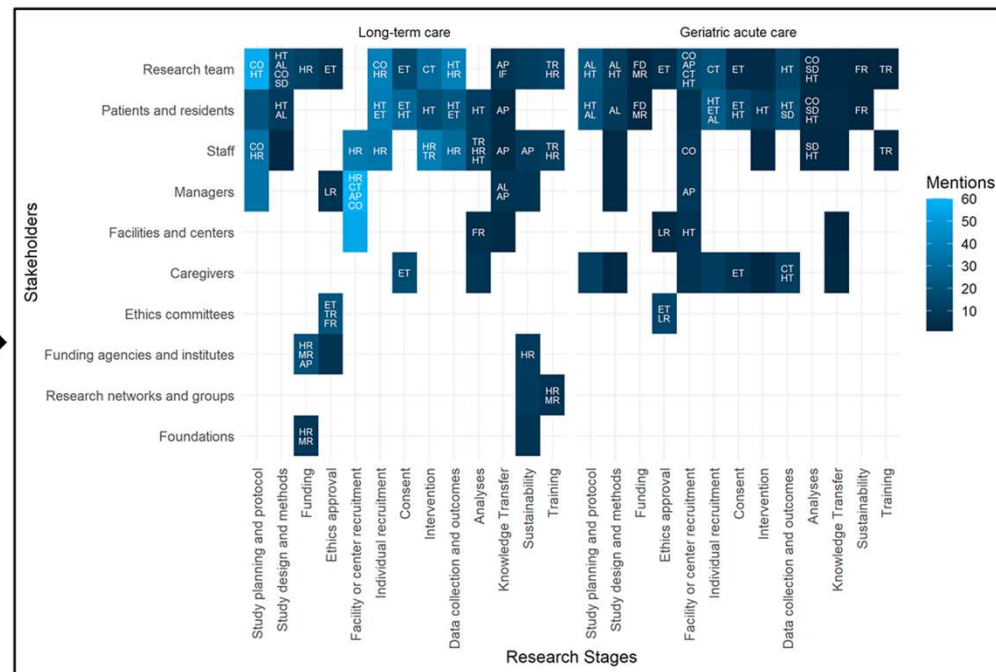


Fig. 3 Final conceptual framework: interaction heatmap of primary stakeholders, research stages, and transversal themes, with steps to build and mobilize research capacity. AL=alignment; AP=appropriation; CT=communication and trust; CO=collaboration; ET=ethical committees; FD=funding; FR=fragmentation; HR=human resources; HT=heterogeneity; LR=legal and regulations; MR=material resources; SD=standardization; TR=training. Ties alter the exact number of themes displayed

Ce qu'on en comprend

COMPLEXITÉ

- Complexité et multiples facettes de la recherche clinique en UCDG et CHSLD
- Reconnaître l'hétérogénéité | personnes âgées ET recherche âgée
 - Différences CHSLD et UCDG
 - Partie prenante, étapes et thèmes pertinents
- CHSLD
 - Personnel, gestionnaires, recrutement installation, RH
 - Rareté de main d'œuvre et priorisation des soins > recherche
- UCDG
 - Proches aidants, éthique, recrutement individuel, standardisation
- **Pas liste unique, mais un canevas/cadre**
 - solutions terrain et spécifiques au contexte
 - Ne pas inclure toutes les parties prenantes à toutes les étapes

Limites

- Cadre initial généré par scan environnemental
 - Perspectives diversifiées
- Variabilité en codification et synthèse
- Quantification de l'importance des intersections par nombre de publications

- Réellement utile? Utilisable?

Ce qu'on compte faire

- Prochaines étapes
 - 2 études sur la communication et les outcomes en CHSLD-CLSC-cliniques CHUM
 - Rappel constant de m'en servir... inertie du changement ++
 - Étude qualitative qui emploie les cartes thermiques pour solliciter des recommandations pour améliorer la recherche clinique

Questions

Face à l'hétérogénéité

1. Théorie ou pratique/praxis?
 - Doit-on simplement se lancer ou doit-on théoriser avant?
2. Est-ce qu'on centralise ou localise?
 - En recherche / en clinique
 - Populations jeune / adulte / âgée

Références

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Merci de votre attention



Fana



Jean-Philippe



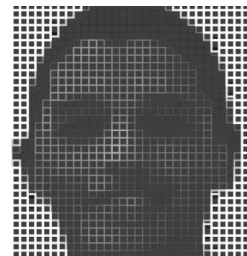
Vincent



Jimna



Myriam



Ariel



Jeremy



Béatrice