



Le projet Milestone

Diane Purper-Ouakil



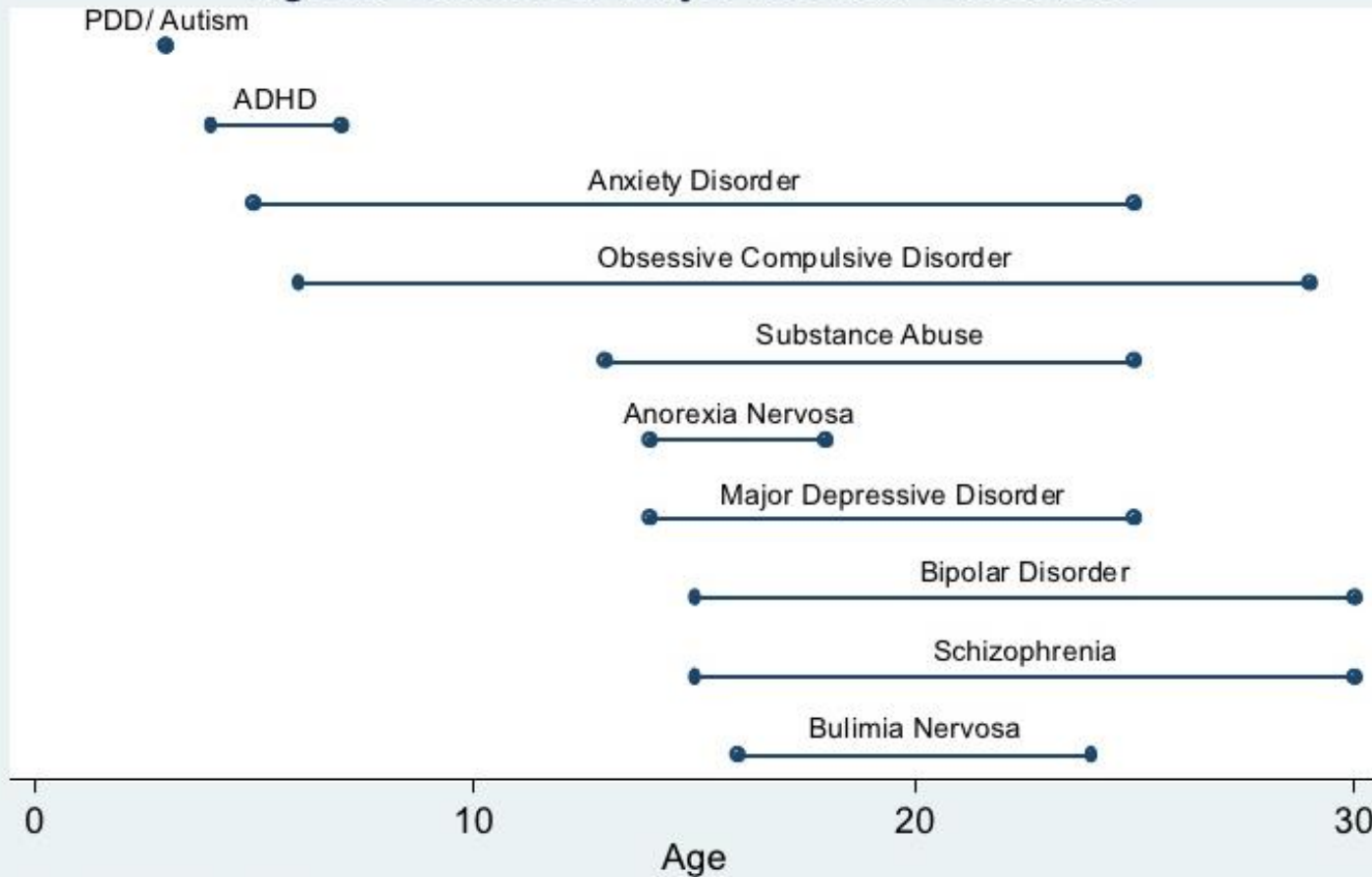


This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442

Contexte général



Age of Onset of Major Mental Disorders

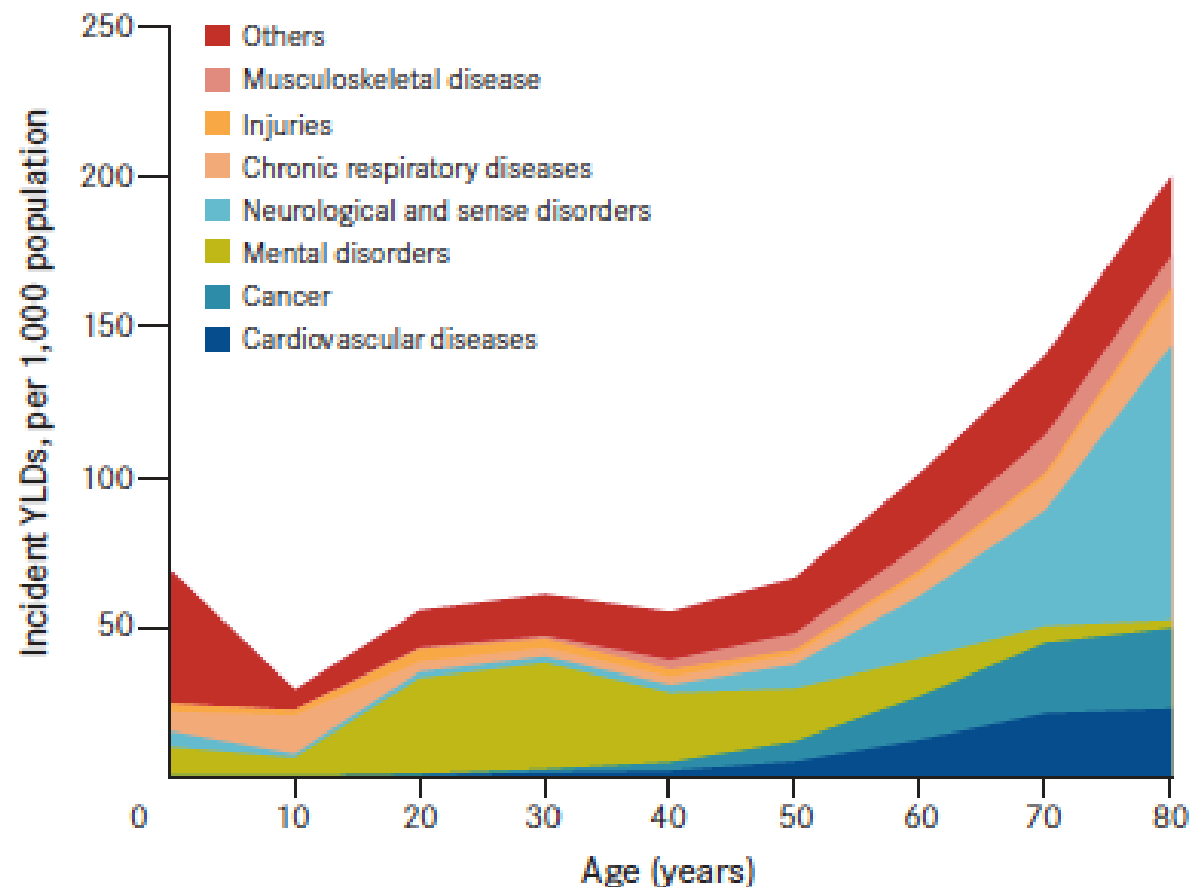


Source: DSM-IV, 2000

Age de
début des
principaux
troubles
mentaux

La santé mentale des 10-30 ans

- Troubles mentaux > autres problèmes de santé
- Victorian Burden of Disease Study, Mortality and morbidity, 2001



Transition dans le contexte des parcours de soin

Passage PEA-PA

Lié à l'âge du patient dans la plupart des services

L'orientation de la jeune personne (JP) est variable : psy d'adultes, médecin traitant..

Objectif de continuité de soins si nécessaire

Différents points de vue –
JP/clinicien/parents

Transfert

Changement
de service

Liée à une modification du
niveau ou du type de soins

Peut avoir lieu au cours
d'un processus de
transition

Transition vs. transfert - Exemple

- Une YP de 17 ans prépare un projet d'admission dans un service de psychiatrie d'adultes
- Au cours de cette période il passer aux urgences pour un episode psychotique aigu et est hospitalisé dans un service d'admission de psychiatrie d'adultes = TRANSFERT
- A sa sortie, il est réadressé à son équipe de PEA et le processus de transition se poursuit.

Investigation into the transition from child and adolescent mental health services to adult mental health services

Independent report by the
Healthcare Safety Investigation Branch

I2017/008

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Health

Mental health: Children failed at vulnerable point

By Nick Triggle
Health correspondent

10 July 2018



Share



The care of young people with mental health problems is suffering when the time comes for them to move to adult services in England, an inquiry says.

The Healthcare Safety Investigation Branch (HSIB) said many young people experienced a difficult transition from child to adult care at exactly the time when they were most vulnerable.

Its report recommended a more flexible approach to moving into adult services instead of having the cut-off at 18.

Every year 25,000 make this transition.

But as adult services often have different thresholds for providing support, delays can happen or young people can lose their support altogether.

Constats

- Peu de planification de la transition
 - Absence de communication entre services
 - Pas de période de suivi conjoint
- Perceptions différentes entre les services de l'âge de la transition
 - Dans certains pays, absence de prise en charge financière de la PEA après 18 ans
- L'équipe de PEA avait des incertitudes sur le service de PA le plus adapté
- Risque non détecté car l'aggravation des symptômes s'est produite pendant la période de transition.



Etude TRACK

- Pour une majorité des JP usagers des services, la transition est mal préparée, exécutée et mal vécue.
- Il y a des représentations mutuelles erronées entre les services
- Il y a un écart entre les protocoles et la pratique
- Les JP avec des troubles neurodéveloppementaux, des troubles de l'humeur et des TP émergents sont le plus souvent concernés par des discontinuités dans les soins



Relais optimal CONTINUE

Singh SP. Transition of care from child to adult mental health services: the great divide. Curr Opin Psychiatry. 2009;22(4):386-90.

Continuité de l'information

- Dossier partagé
- Lettre médicale, bilans

Organisation transfrontalière

- **Planification** de la transition par une réunion impliquant un référent de chaque équipe et le patient et/ou son tuteur légal

Continuité relationnelle

- Période de **soins parallèles** avec un travail conjoint entre les équipes

Continuité du suivi au long cours ou arrêt planifié

- Selon évolution



Suris J-C, Akre C. Key Elements for, and Indicators of, a Successful Transition: An International Delphi Study. *Journal of Adolescent Health* **2015**; 56: 612-18.

Autonomise

- Mettre le jeune au centre du processus
- Prendre en compte ce qui est important pour lui

Informe

- Partager les informations et envisager les différentes possibilités avec le jeune dès le départ
- Partager les informations entre services

Soutient

- L'aider à s'engager vers le nouveau service avec confiance (s'il a besoin de poursuivre les soins) et à poursuivre sa vie vers l'âge adulte



The Milestone Study





Evaluating an innovative transitional care model.

Managing the Link and strengthening transition from Child to Adult Mental Health Care



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442



FACTS & FIGURES

Full project title: THE MILESTONE PROJECT: Managing the Link and Strengthening Transition from Child to Adult Mental Health Care

Start date: 1st February 2014

Duration: 5 years

Project coordinator: University of Warwick, Prof. Swaran Singh (MBBS, MD)

To understand and improve transition of care from Child (CAMHS) to Adult mental health services (AMHS) across different healthcare systems in Europe



- [PROJECT COORDINATOR AND PROJECT MANAGEMENT OFFICE](#) →
- [MEMBERS](#) →
- [SCIENTIFIC CLINICAL AND ETHICAL ADVISORY BOARD \(SCEAB\)](#) →
- [PROJECT SUMMARY](#) →
- [FACTS & FIGURES](#) →

Feb 2014- April 2019



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Principaux objectifs

Identifier les différents systèmes de soin et de formation

- Description des systèmes de soins, des types de structures, des interfaces PEA/PA et des formations des professionnel(e)s

Etudier les trajectoires de transition et comprendre l'évolution des jeunes au sein de ces trajectoires.

- Identifier les processus de transition PE/PA, leurs résultats et les expériences associées, dans divers établissements de soins

Tester un modèle d'intervention innovant en matière de transition

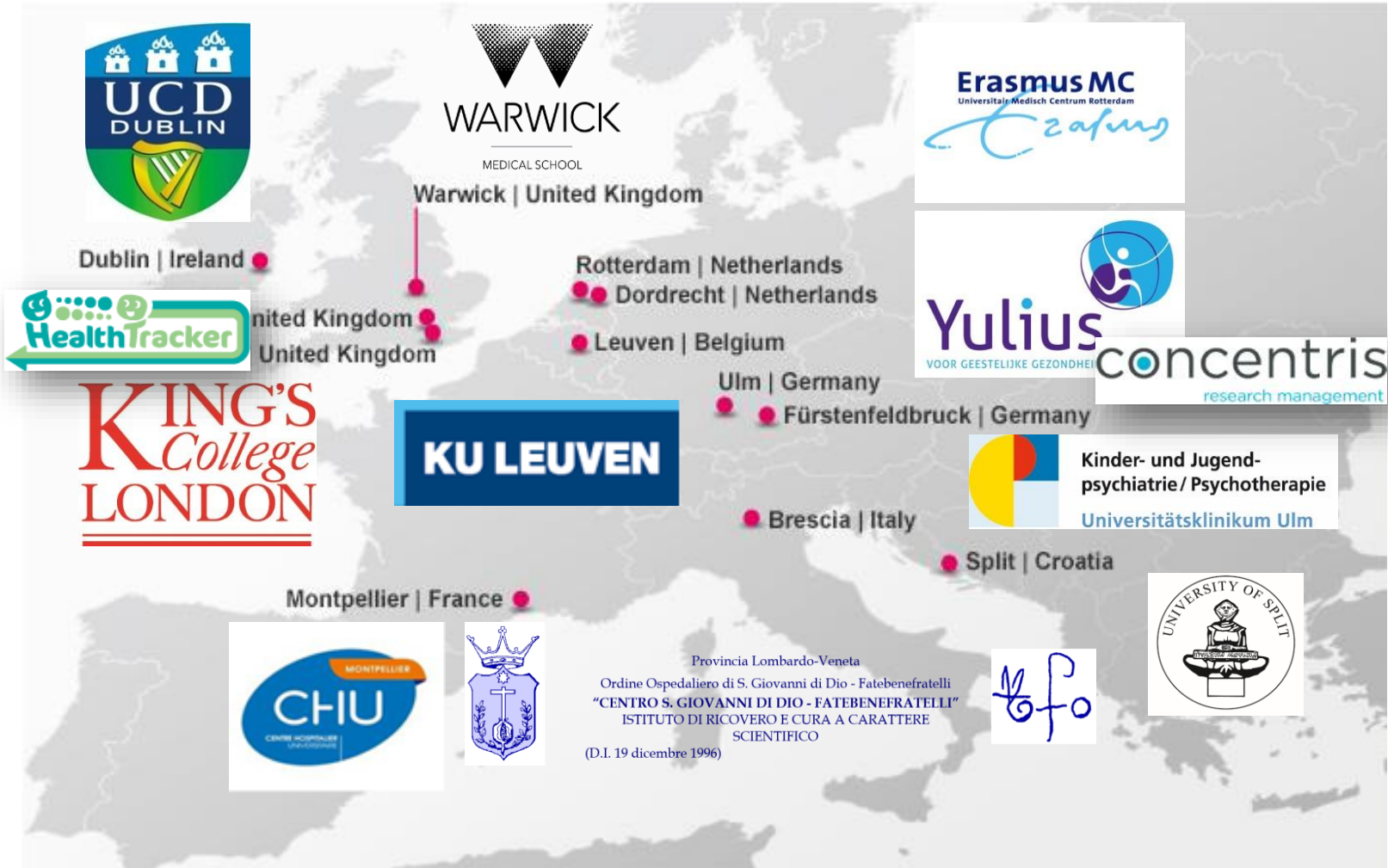
- Outils d'aide à la décision
- Développer un modèle de bonne pratique et un cadre éthique

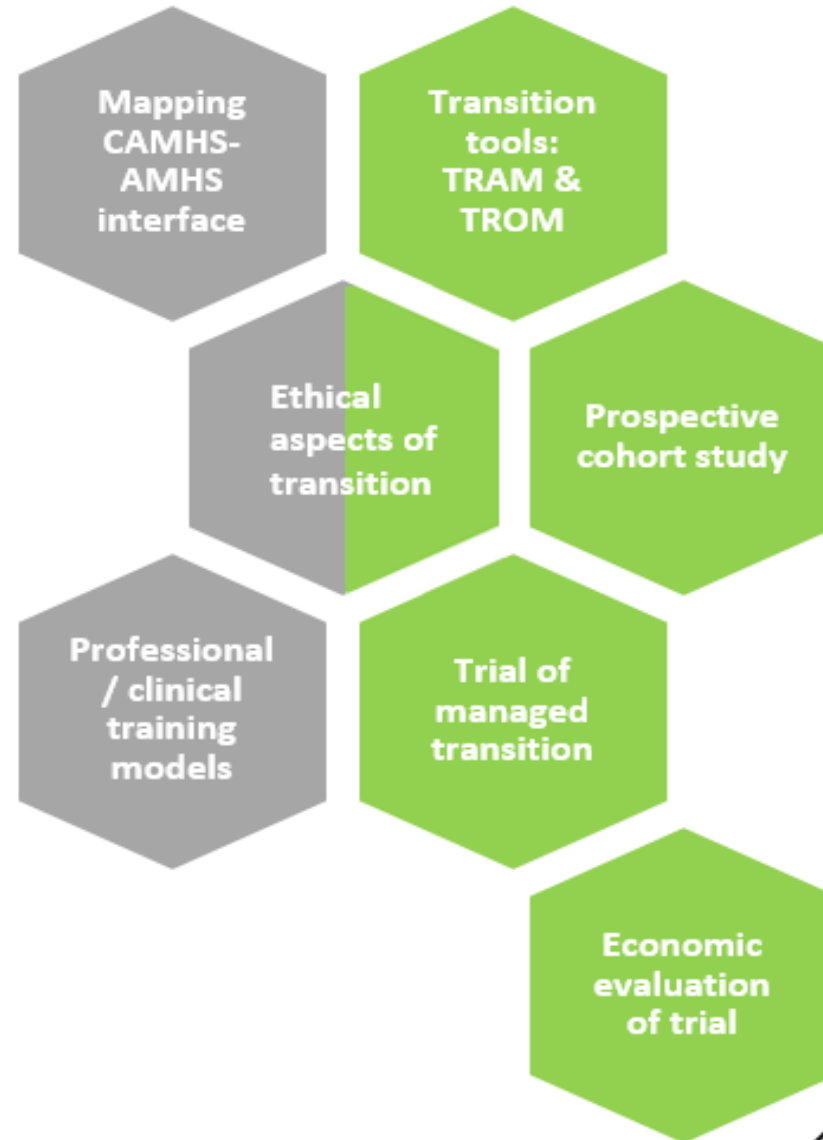


Ce projet a reçu un financement du 7ème programme cadre de l'Union Européenne (réf. No. 602442)



MILESTONE: Managing the Link and strengthening transition from Child to Adult Mental Health Care





BMC Psychiatry

Tuomainen et al. *BMC Psychiatry* (2018) 18:167
<https://doi.org/10.1186/s12888-018-1758-z>

STUDY PROTOCOL

Open Access



Managing the link and strengthening transition from child to adult mental health Care in Europe (MILESTONE): background, rationale and methodology

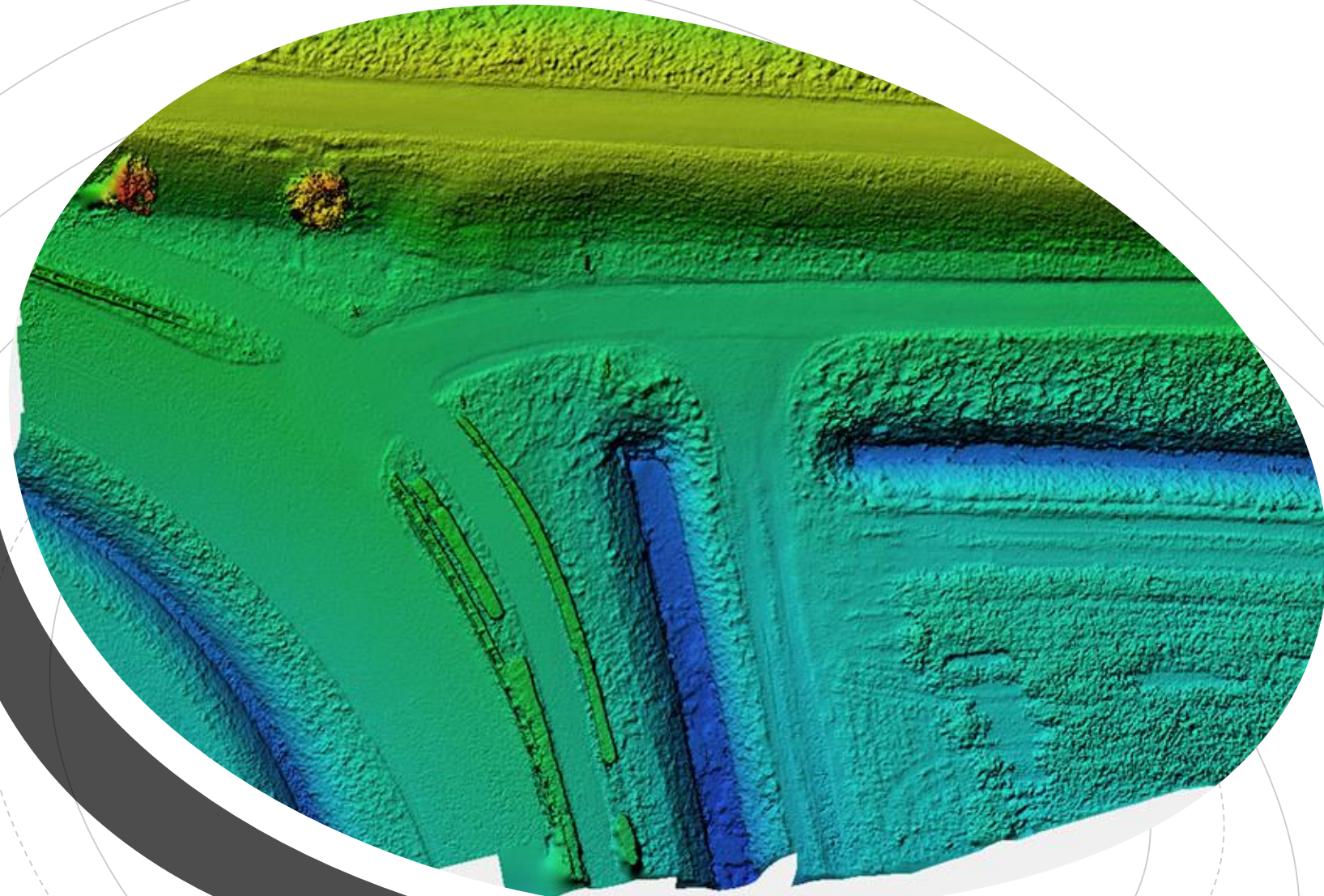
H. Tuomainen^{1†}, U. Schulze^{2†}, J. Warwick³, M. Paul^{1,4}, G.C. Dieleman⁵, T. Franic⁶, J. Madan⁷, A. Maras^{5,8}, F. McNicholas^{9,10,18,19}, D. Purper-Ouakil¹¹, P. Santosh^{12,13,20}, G. Signorini¹⁴, C. Street¹, S. Tremmery^{15,16}, F.C. Verhulst⁵, D. Wolke^{1,17}, S. P. Singh¹ and for the MILESTONE consortium



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Le projet Milestone Principaux Résultats





Interface PEA-
PA en Europe

Architecture and functioning of child and adolescent mental health services: a 28-country survey in Europe

Giulia Signorini, Swaran P Singh, Vlatka Boricevic-Marsanic, Gwen Dieleman, Katarina Dodig-Ćurković, Tomislav Franic, Suzanne E Gerritsen, James Griffin, Athanasios Maras, Fiona McNicholas, Lesley O'Hara, Diane Purper-Ouakil, Moli Paul, Ulrike Schulze, Cathy Street, Sabine Tremmery, Helena Tuomainen, Frank Verhulst, Jane Warwick, Giovanni de Girolamo, for the MILESTONE Consortium

Lancet Psychiatry 2017

Published Online

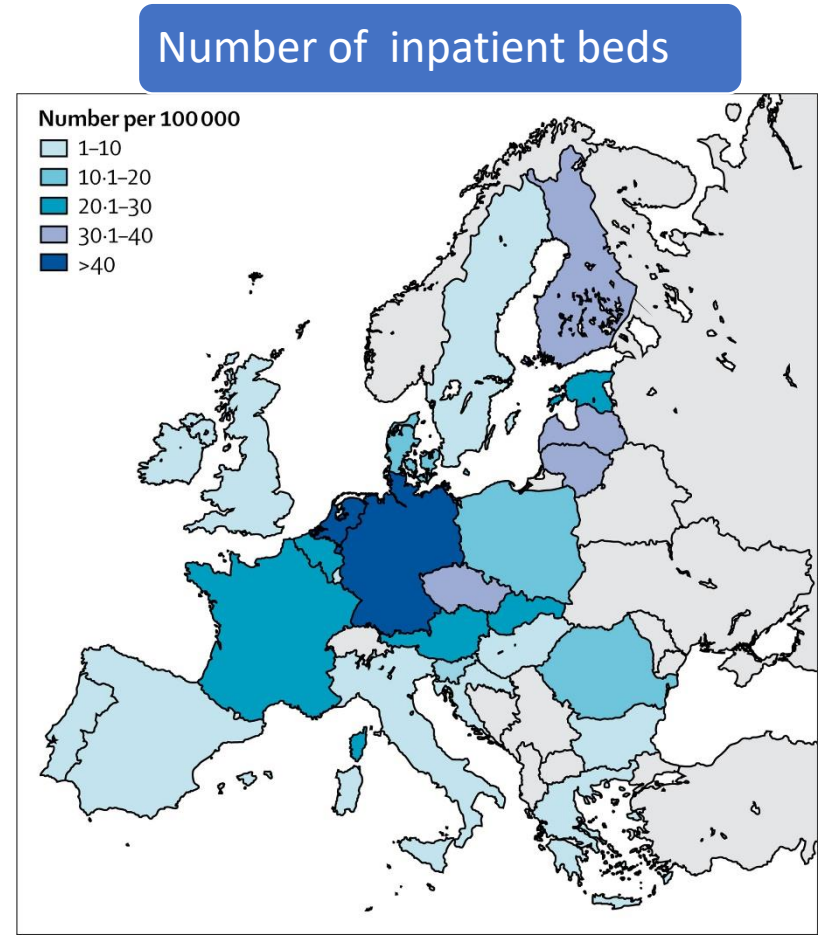
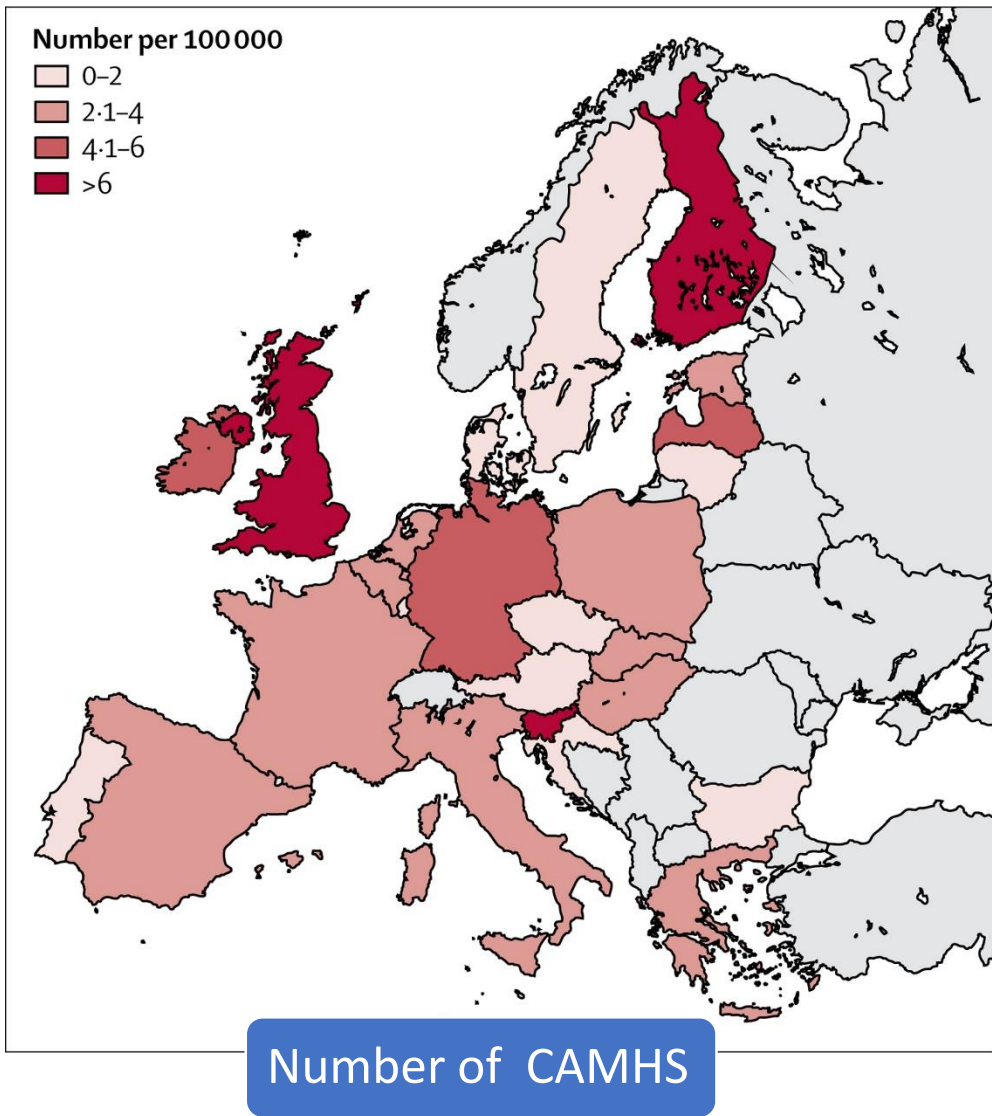
June 5, 2017

[http://dx.doi.org/10.1016/](http://dx.doi.org/10.1016/S2215-0366(17)30127-X)

[S2215-0366\(17\)30127-X](http://dx.doi.org/10.1016/S2215-0366(17)30127-X)

Identifier
les
différents
systèmes
de soin et
de
formation

- Description des systèmes de soins, des types de structures, des interfaces PEA/PA

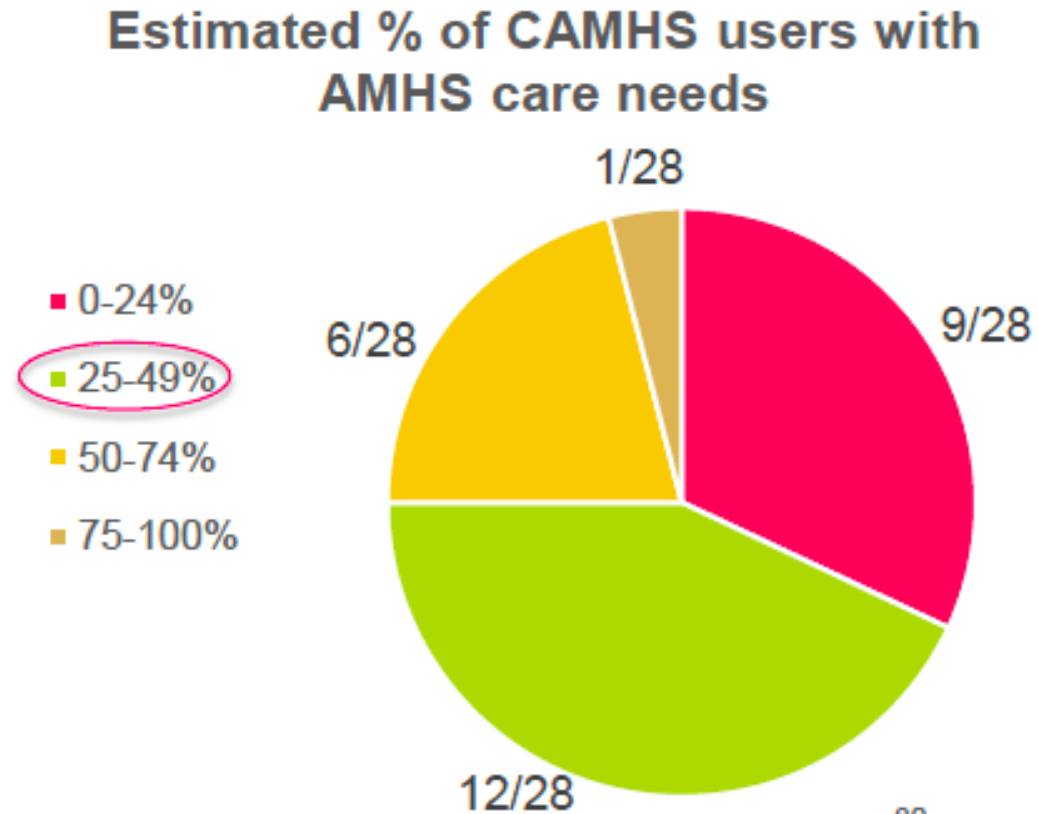


CAMHS – AMHS interface



- **2/28** pays avec des guidelines nationales (Danemark et RU) = recommandations concernant la transition des usagers
 - **4/28** pays (Chypre, Danemark, Espagne, RU) = recommandations nationales ou regionals concernant l'organisation entre les services PEA et PA
 - **17/28** countries (**60%**) = pas de services de preparation de la transition
-
- **3/28** countries (11%) =évaluations standardisées pré-transition
 - **8/28** (29%) = organisaiton spécifique en PA pour l'accueil des usagers veant de PEA.

Proportion de jeunes avec besoins de transition



Aspects éthiques





Résultats du WP éthique

- **Revue systématique** (Paul et al 2018):
 - 6 études, concernant toutes des JP avec besoins complexes.
 - Peu de recherche sur les aspects légaux et éthiques de la transition
- **Focus group inter-culturel** (Ohara et al 2020):
 - Croatie, Irlande et RU
 - 111 participants (age 16-60) jeunes usagers et conseillers
 - Thèmes : Stigmatisation, autonomie et prise de décision
 - Tension entre paternalisme professionnel (et parental) et les désirs d'autonomie des YP



Focus groups
Experiences & ethical
aspects of transition

Ethics of transitioning questionnaire

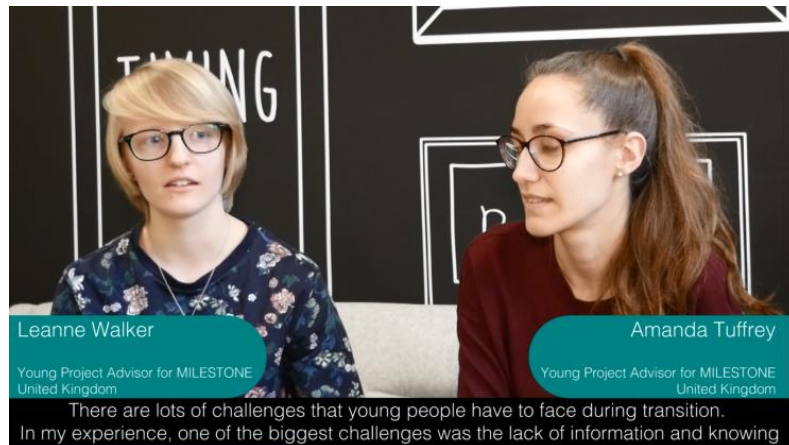


Implication Patient et Public (PPI)

 <http://www.milestone-transitionstudy.eu/>

- 9 jeunes conseillers
- Parents

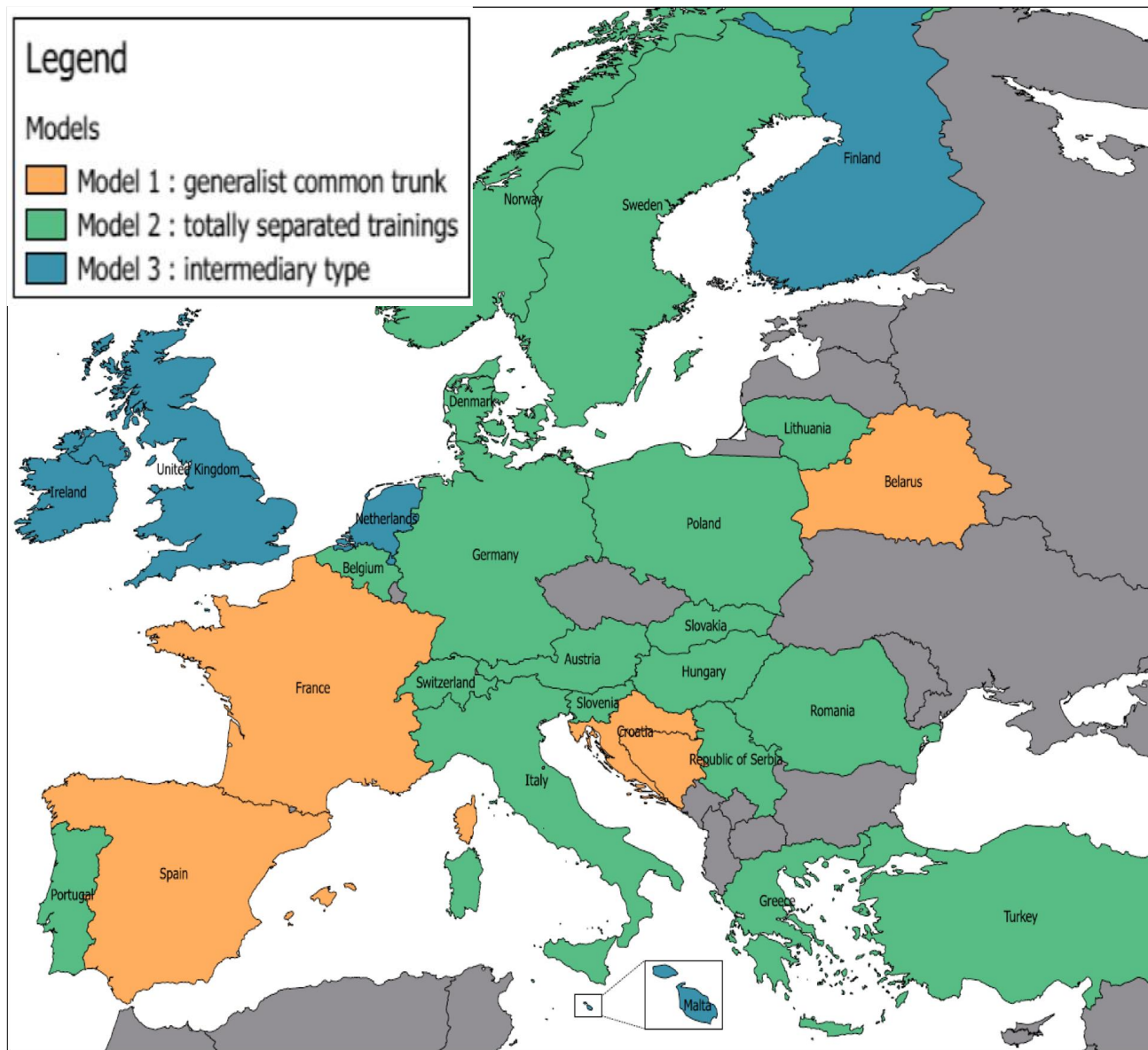
https://www.youtube.com/watch?v=nTs6p_s5Kgs





Formation professionnelle

Résultats WP training



Psychiatry training in Europe

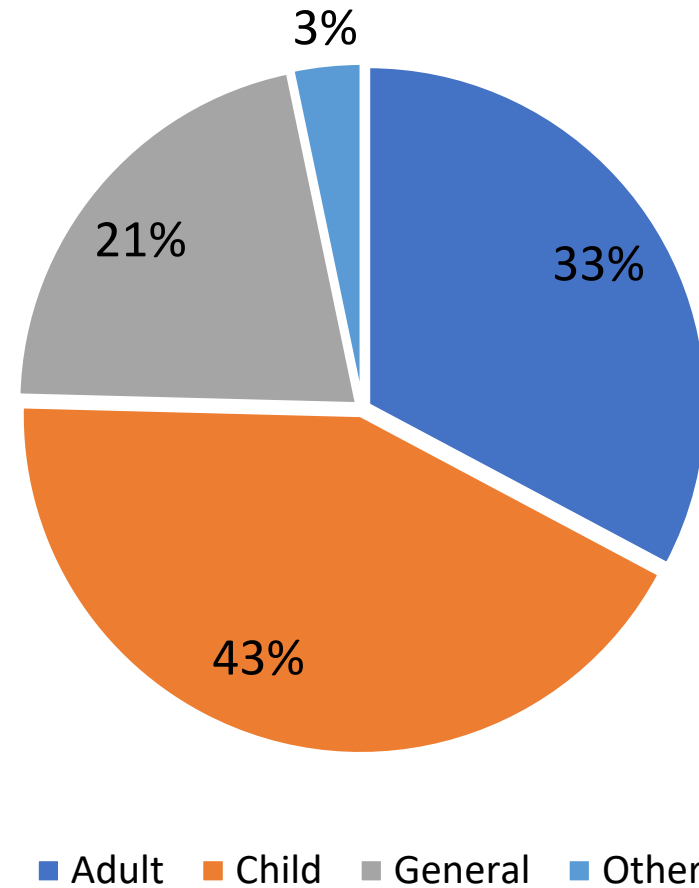
- **Revue systématique** (Russet et al 2019):
 - 3 modèles coexistants de formation des psychiatres en Europe
 - Des proportions différentes de formations communes
 - Un possible écueil à la formation / coopération inter-services
 - Transition formellement enseignée dans deux pays au moment de l'étude.

EFPT study: Federation Européenne des Etudiants en Psychiatrie



Survey trainees 2016-2017 36/40 countries

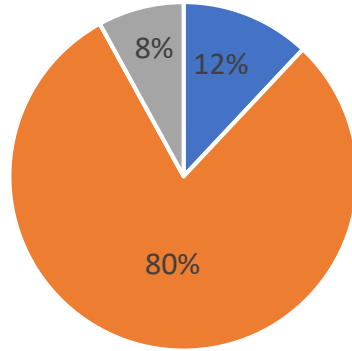
Psychiatry training to become psychiatrist



Hendrickx et al. ECAP 2019

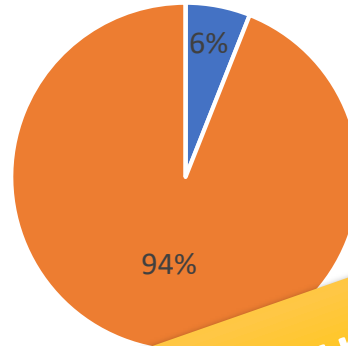
Transition: theoretical training

Adult psychiatrist

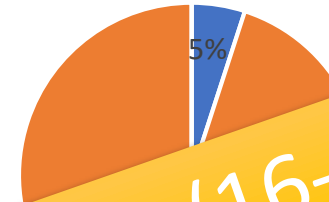


■ Yes ■ No ■ Unknown

Child psychiatrist



General psychiatrist

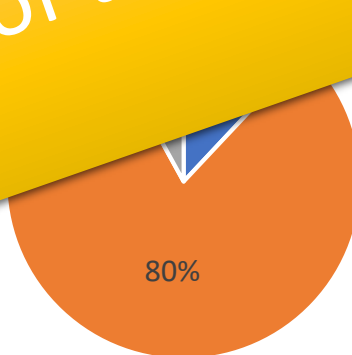


■ Yes ■ No ■ Unknown

Transition: practice

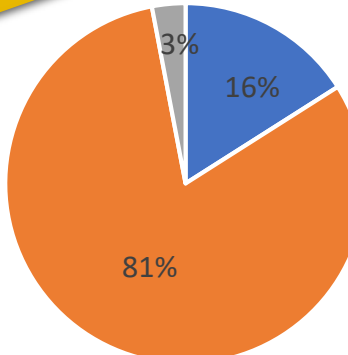
63% of the trainees treat young people (16-26 y) in clinical practice

Adult psychiatrist



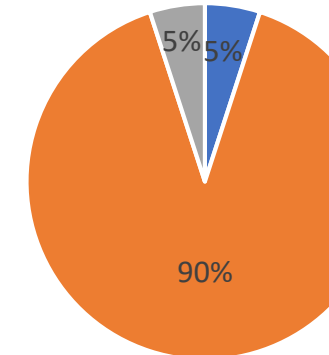
■ Yes ■ No ■ Unknown

Child psychiatrist



■ Yes ■ No ■ Unknown

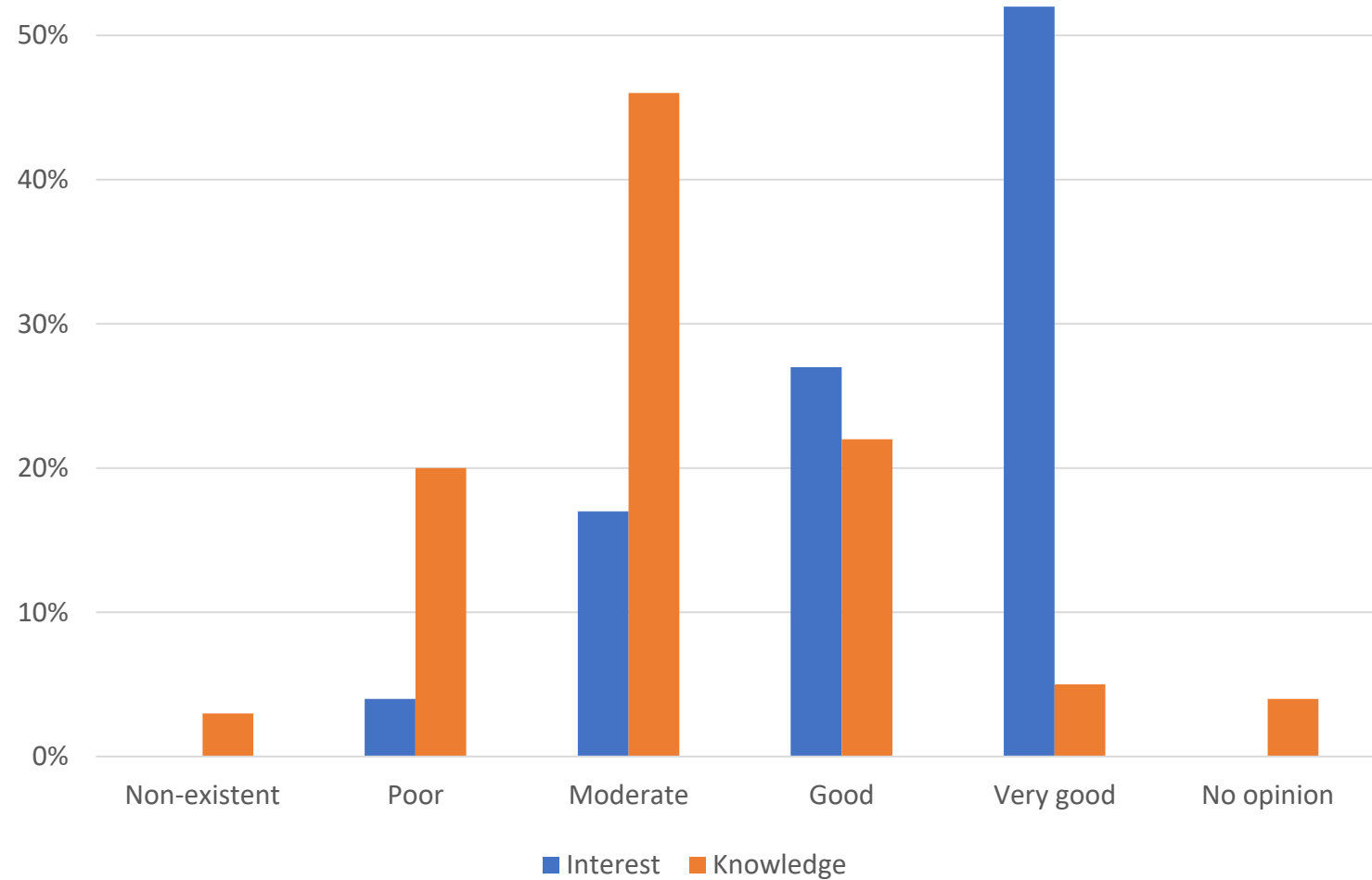
General psychiatrist



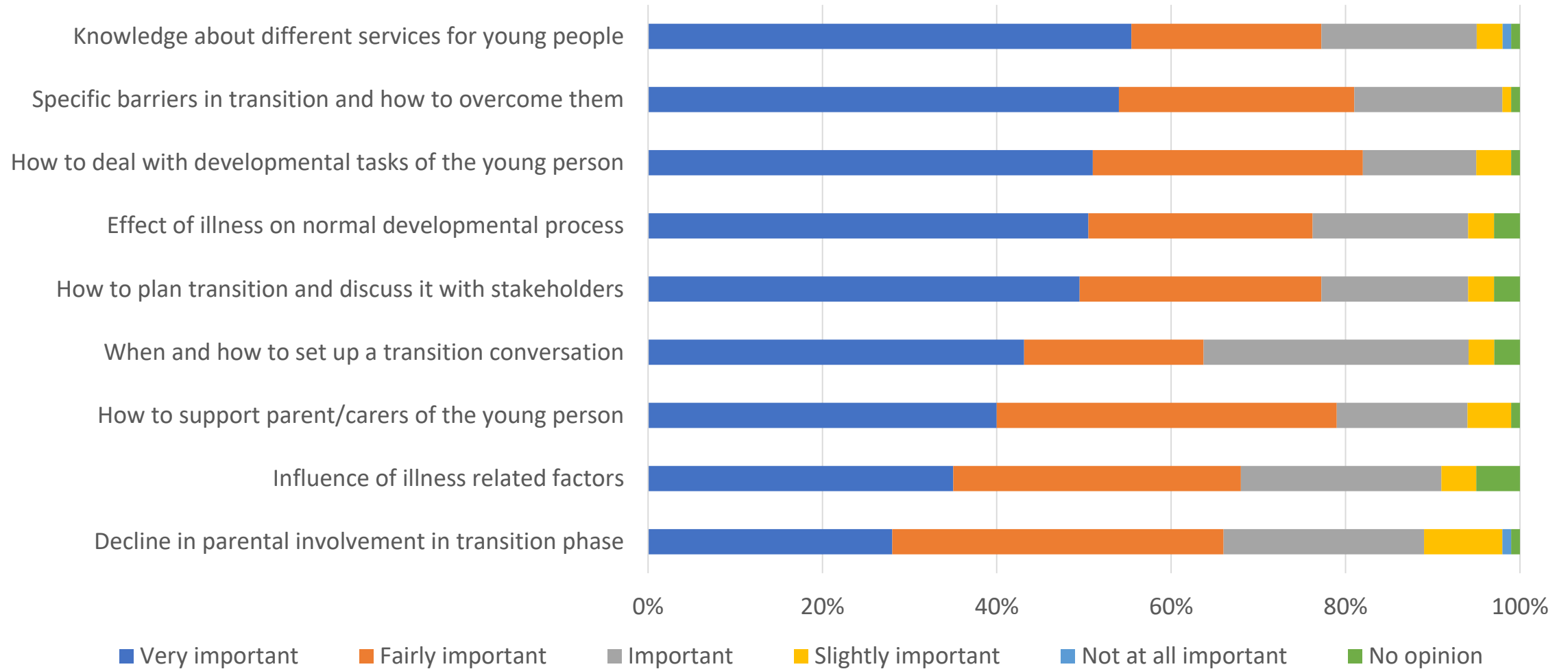
■ Yes ■ No ■ Unknown

60% intéressés par le sujet de la transition
20% déclarent avoir de bonnes connaissances

Intérêt et
connaissances

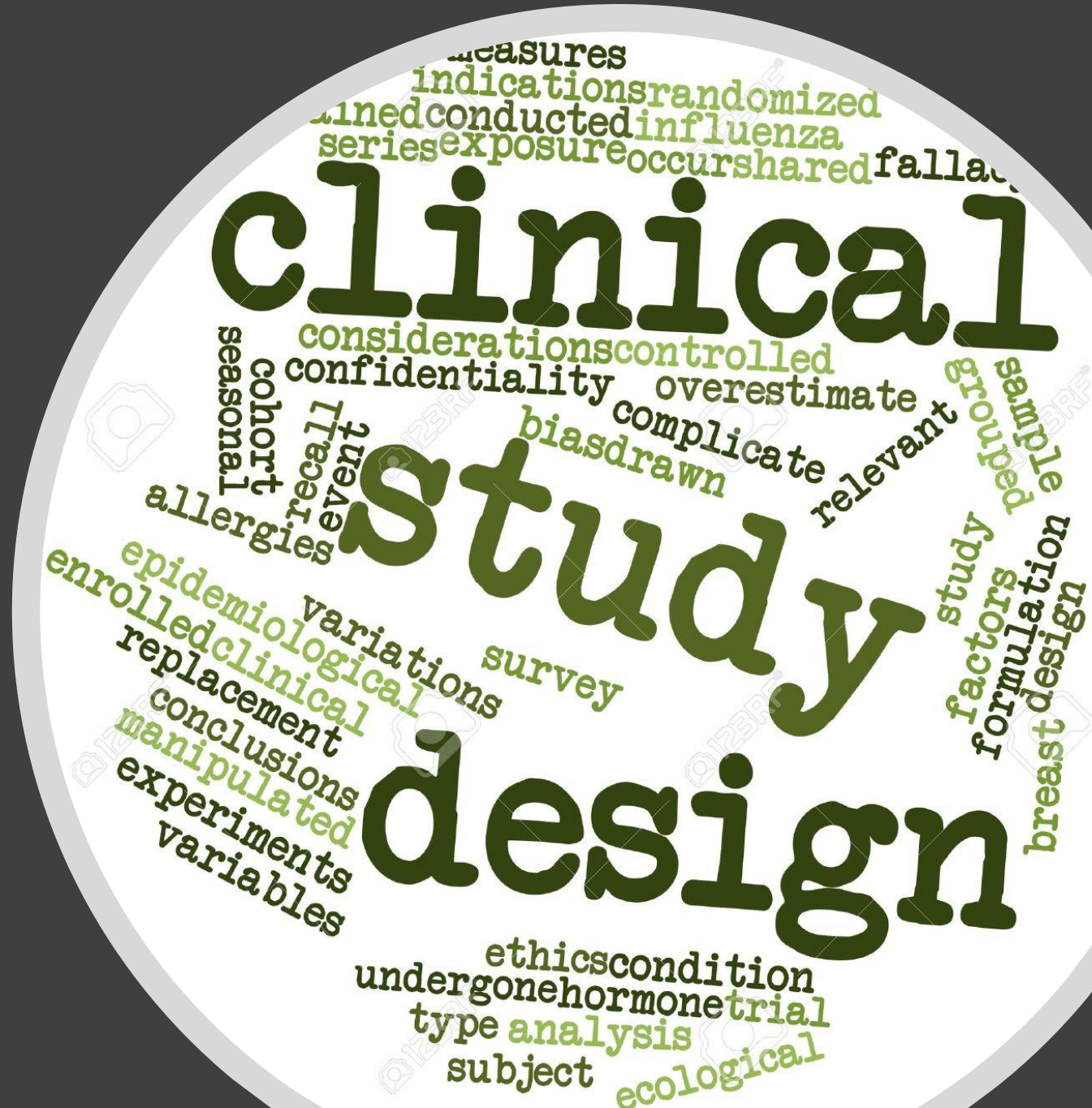


Topics of interest



Etude Milestone

Etudes cliniques



MILESTONE Study

- Suivi de 24 mois de JP suivis en PEA avant la transition de soins
- Devenir & expériences

Etude de
cohorte



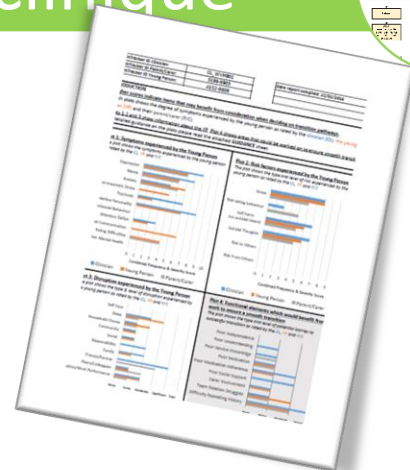
- Essai randomisé “transition managée” (TM) vs. soins usuels
- TM – meilleure évolution clinique et fonctionnelle ?

Essai
clinique

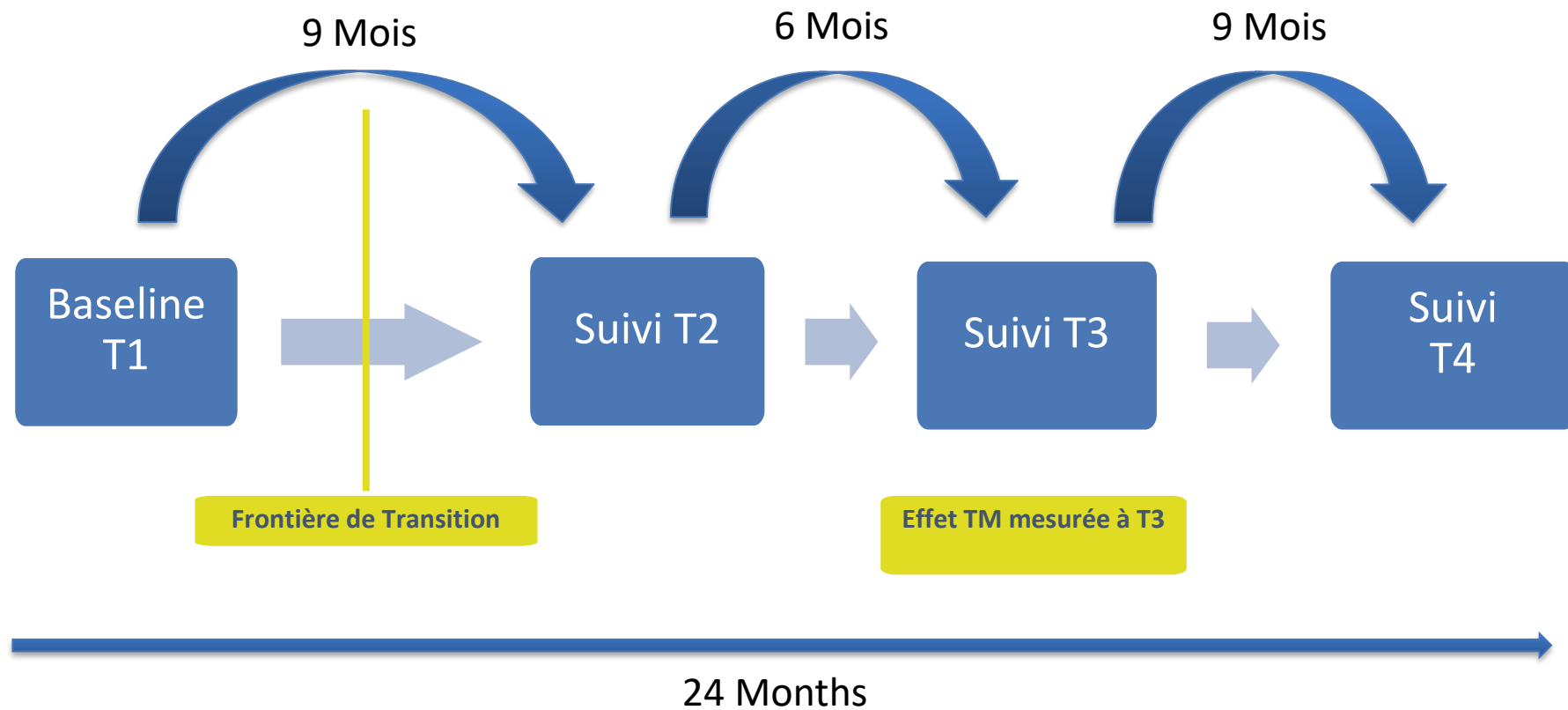


- Evaluation cout-efficacité

Economic
evaluation



MILESTONE Flowchart





Etude de cohorte

Milestone - Resultats

Evaluation initiale



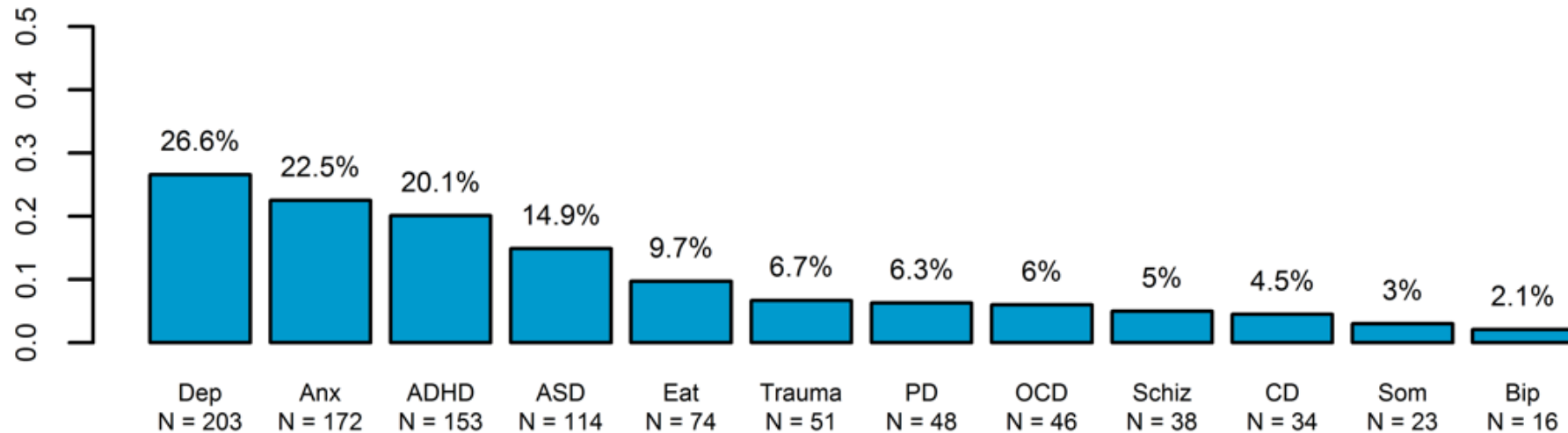
N = 763



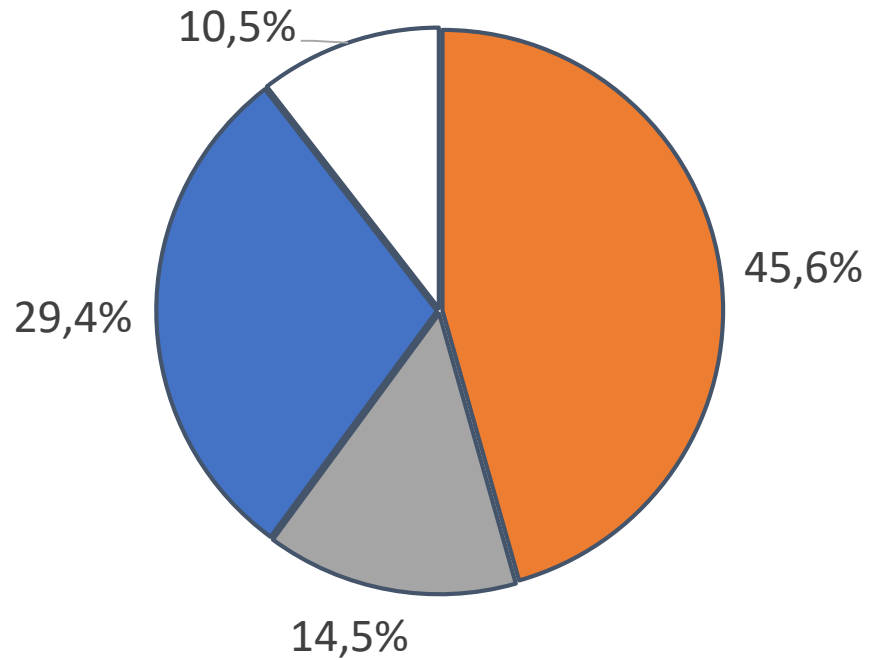
60%



Age moyen = 17.5

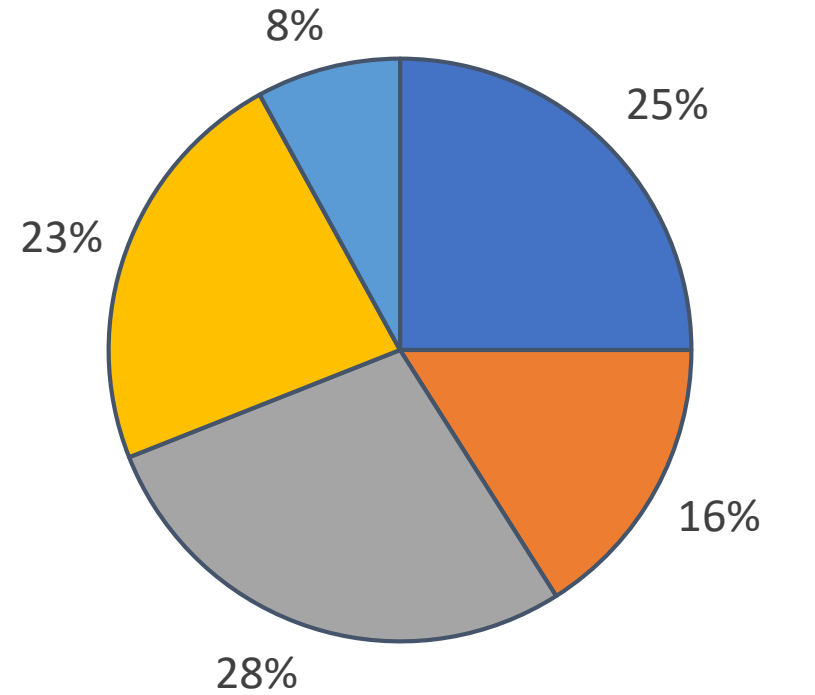


% Patients



- Under clinical threshold
- Subthreshold clinical level
- Clinical level
- Missing

Durée du suivi antérieur



- < 1 jr
- 1-2 jr
- 2-5 jr
- > 5 jr
- Missing

Quelles données influencent la proposition du clinicien en termes de besoin de transition?



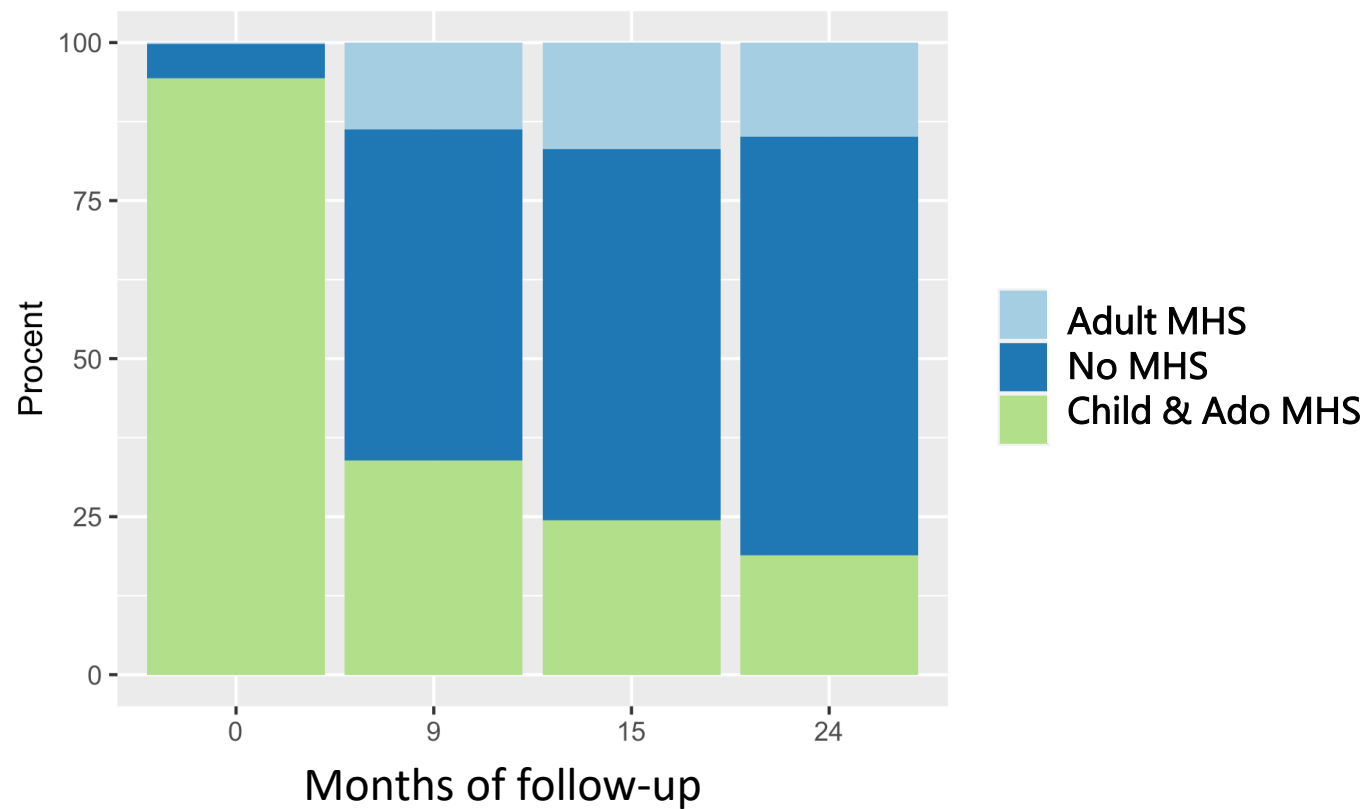
70% des JP avaient besoin d'une continuité des soins

40% avaient besoin d'une transition en PA

Les JP concernées

- Avaient des symptômes plus sévères
- Avaient des parents qui jugeaient la continuité des soins nécessaires

Utilisation des services pendant l'étude



Qui est toujours suivi à 9 mois ?

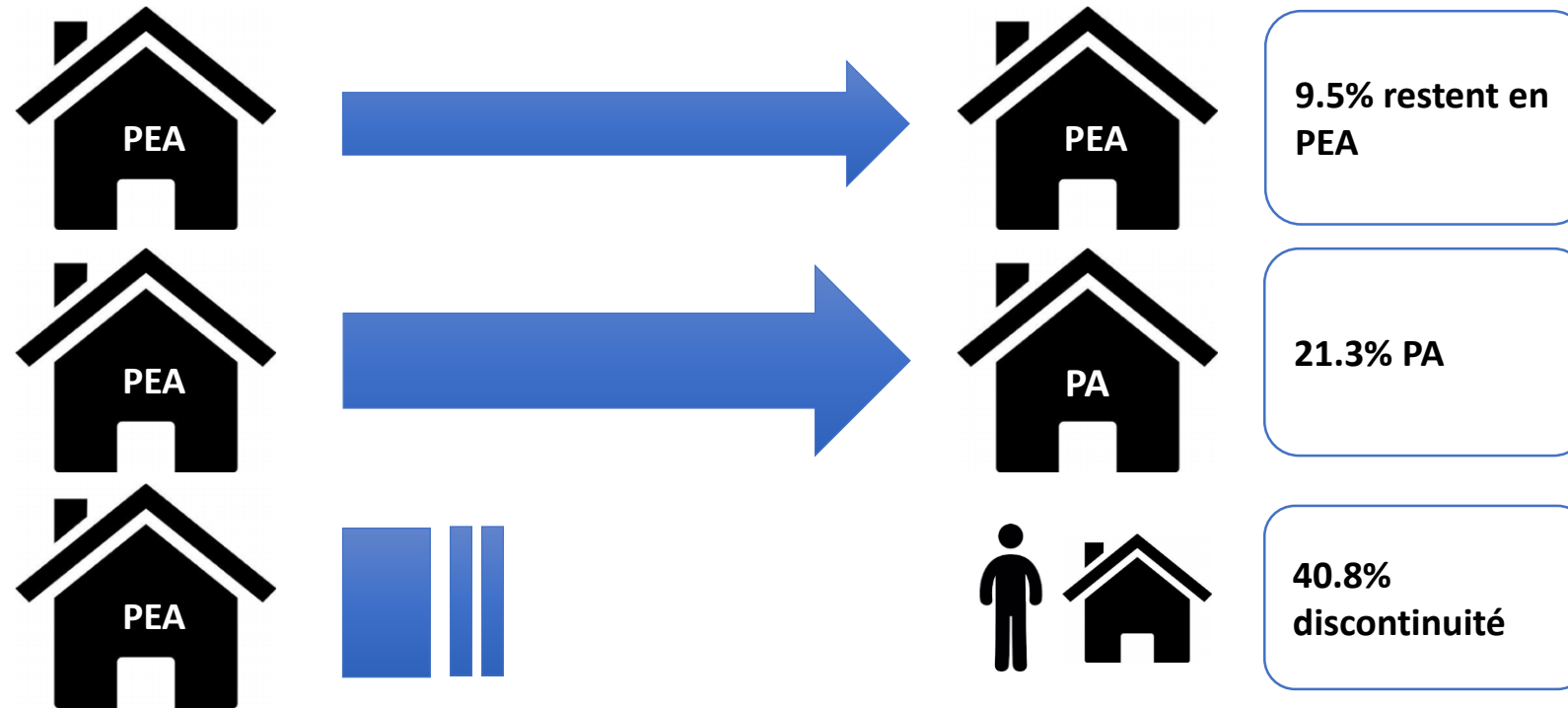
- Les JP avec les troubles les plus sévères selon le clinicien
- JP qui sont d'accord avec la poursuite de soins
- JP avec troubles émotionnels ont la plus grande discontinuité des soins

Seulement 55% des JP dont le clinicien estime qu'ils ont besoin de poursuivre les soins en reçoivent à 9 mois

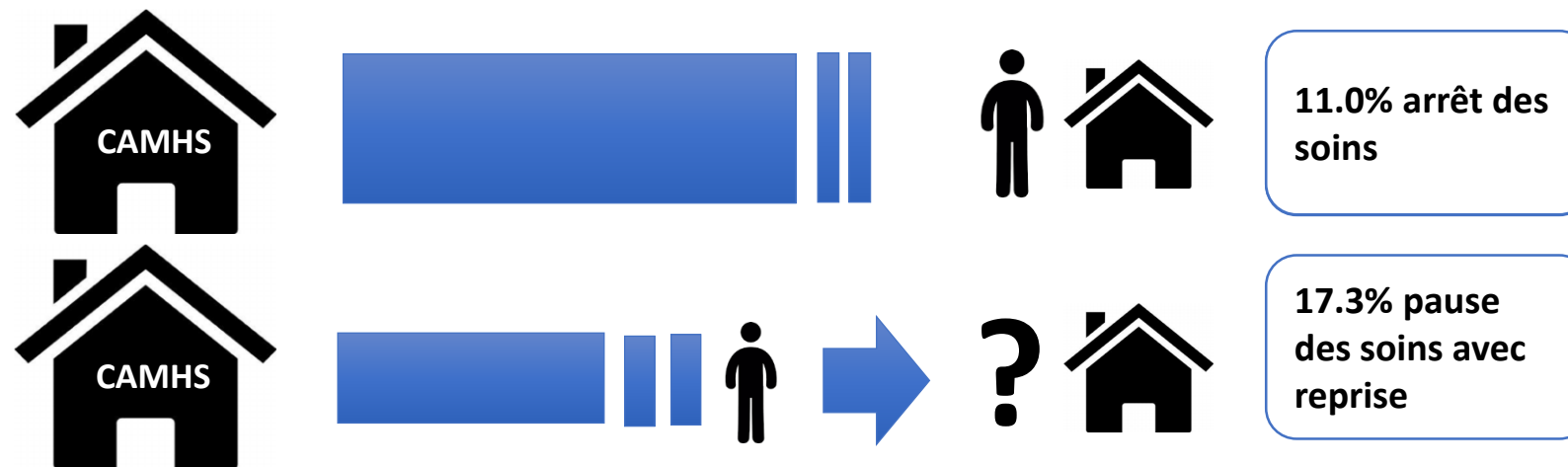
Seulement 26% in AMHS



Trajectoires pendant la transition



Care trajectories during transition period



Variable principale : HoNOSCA (CR)

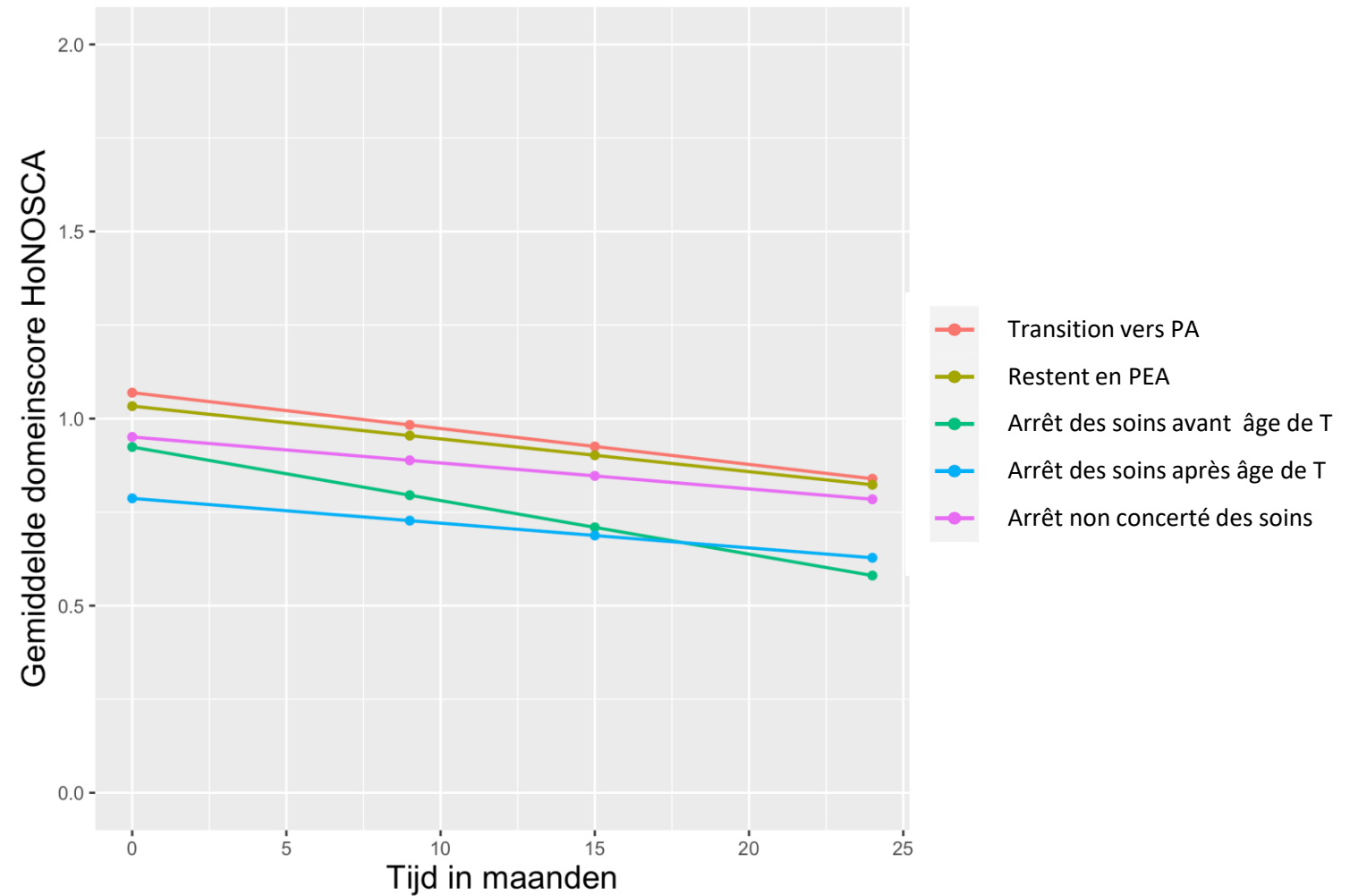


Sévérité biopsychosociale
des symptômes
Besoin de soins

Item Rating	Severity
0	No problem
1	Minor problem
2	Mild problem
3	Moderate
4	Severe to very severe

Honosca – scores cliniques en fonction du temps

HoNOSCA = Health of the Nation Outcome Scale for Children and Adolescents



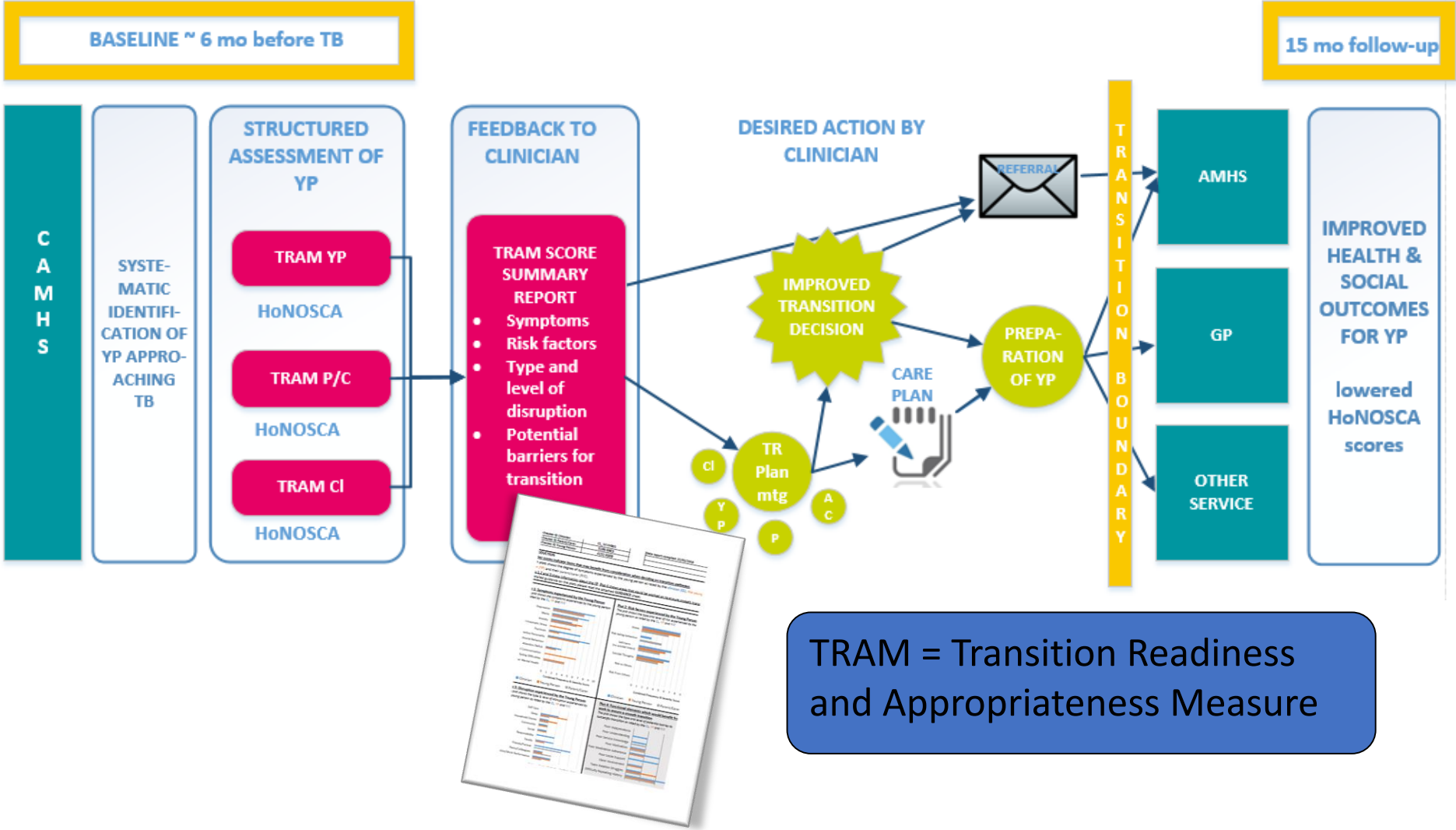


CLINICAL TRIAL

Essai clinique randomisé en
cluster

Milestone - Résultats

Modèle de Transition managée



HoNOSCA = Health of the Nation Outcome Scale for Children and Adolescents

MILESTONE:
specific tools

TRAM (Transition Readiness and Appropriateness Measure)

- Tool to **help decision-making** allowing the identification of young people for whom the transition to adult psychiatry is required and appropriate
- *Need to continue the treatment AND functioning of the young person*

TROM (Transition Outcome Measure)

- **Follow-up** tool for young adults that assesses the quality of the performed transition and the changes in these young adults during this period



TRAM – le passeport de Transition

- Items regroupés en sections
- Questionnaire multi-sources: Adolescent / Parent / Clinicien

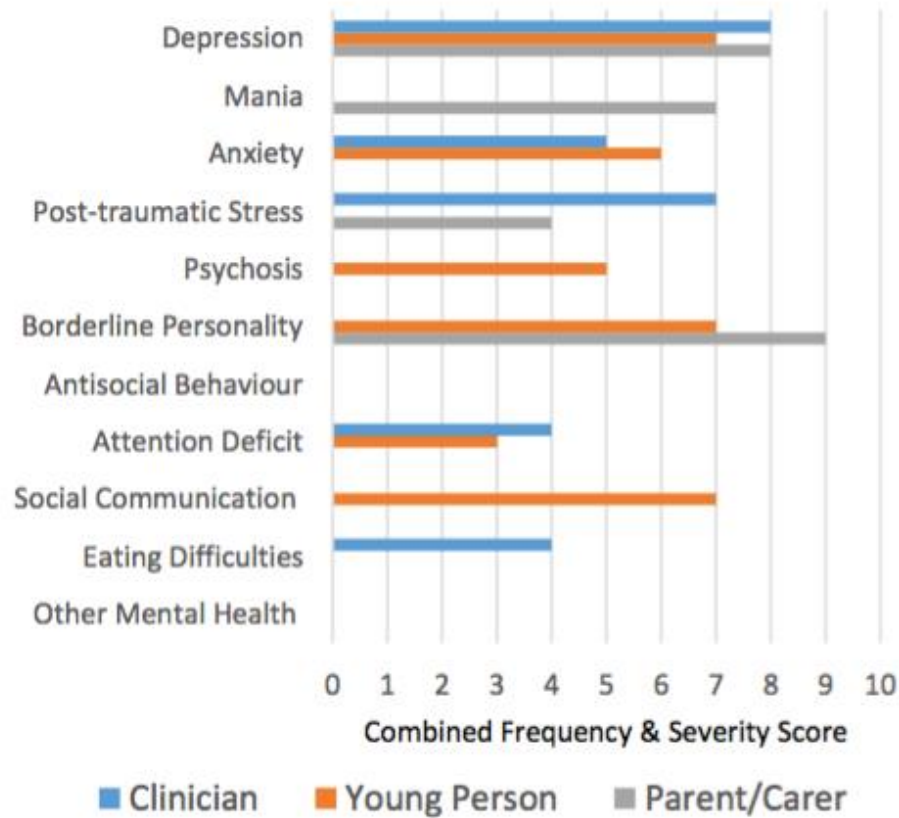
PART A - APPROPRIATENESS FOR TRANSITION						
1. SYMPTOMS		Clinician	Young Person	Parent/Carer		
<small>Freq = Frequency, D=Not experienced, 1 = Rarely, 2 = Sometimes, 3 = Often, 4 = Most of time, 5 = All of time Sev = Severity, 1 = Very mild, 2 = Mild, 3 = Moderate, 4 = Severe, 5 = Very Severe</small>						
Depression	Freq	Sev	Freq	Sev	Freq	Sev
Mood	0	0	0	0	0	0
Anxiety	0	0	0	0	0	0
Psychosomatic stress	0	0	0	0	0	0
Dephobic	0	0	0	0	0	0
Borderline personality	0	0	0	0	0	0
Autistic behaviour	0	0	0	0	0	0
Attention deficit	0	0	0	0	0	0
Social communication difficulties	0	0	0	0	0	0
Eating difficulties	0	0	0	0	0	0
Other mental health conditions	0	0	0	0	0	0
2. CURRENT ILLNESS		Clinician	Young Person	Parent/Carer		
<small>D = Disordered, no treatment needed, 1 = Resolving, still on treatment, 2 = Mildly ill, 3 = Moderately ill, 4 = Severely ill, 5 = Very severely ill</small>						
Overall illness	0	0	0	0	0	0
3. ONE-BUILD DISRUPTION		Clinician	Young Person	Parent/Carer		
<small>Total number of areas affected</small>						
0 = No disruption, 1 = Some disruption, 2 = Moderate disruption, 3 = Significant disruption, 4 = Total disruption	0	0	0	0	0	0
Self care	0	0	0	0	0	0
Sleep	0	0	0	0	0	0
Household chores	0	0	0	0	0	0
Comm unity	0	0	0	0	0	0
Social	0	0	0	0	0	0
Academic ability	0	0	0	0	0	0
Relationships with family	0	0	0	0	0	0
Relationships with friends/peers	0	0	0	0	0	0
Relationships with peers/colleagues	0	0	0	0	0	0
Educational/work performance	0	0	0	0	0	0
PART B - READINESS FOR TRANSITION						
7. BARRIERS TO FUNCTIONING		Clinician	Young Person	Parent/Carer		
<small>Number of moderate or severe barriers</small>						
<small>Provide response options differ for each question. Roughly: 0 = No barrier, 1 = Minor barrier, 2 = Moderate barrier, 3 = Severe barrier</small>						
Ability to do independent living	0	0	0	0	0	0
Decision making/understanding	0	0	0	0	0	0
Plans and/or access to needed services	0	0	0	0	0	0
Plan of action	0	0	0	0	0	0
Plan of action and timeline	0	0	0	0	0	0
Plan of social support	0	0	0	0	0	0
Not wanting care/involved	0	0	0	0	0	0
Difficulty to manage health related issues	0	0	0	0	0	0
Difficulty to manage living history	0	0	0	0	0	0
8. OTHER LIFE CHANGES		Young Person	Parent/Carer			
<small>Number of positive life changes</small>						
<small>Number of negative life changes</small>						
<small>0 = No change or change with no impact, -1 = Positive change, -2 = Negative change</small>						
Family relationships	0	0	0	0	0	0
Relationships with friends and partner	0	0	0	0	0	0
Major life events	0	0	0	0	0	0
School/college years	0	0	0	0	0	0
Illness/death	0	0	0	0	0	0
Police involvement	0	0	0	0	0	0
Fire/abuse	0	0	0	0	0	0
Other	0	0	0	0	0	0

TRAM in the MILESTONE

Completions	Adolescent	Parent	Clinician
	932	752	849

Plot 1: Symptoms experienced by the Young Person

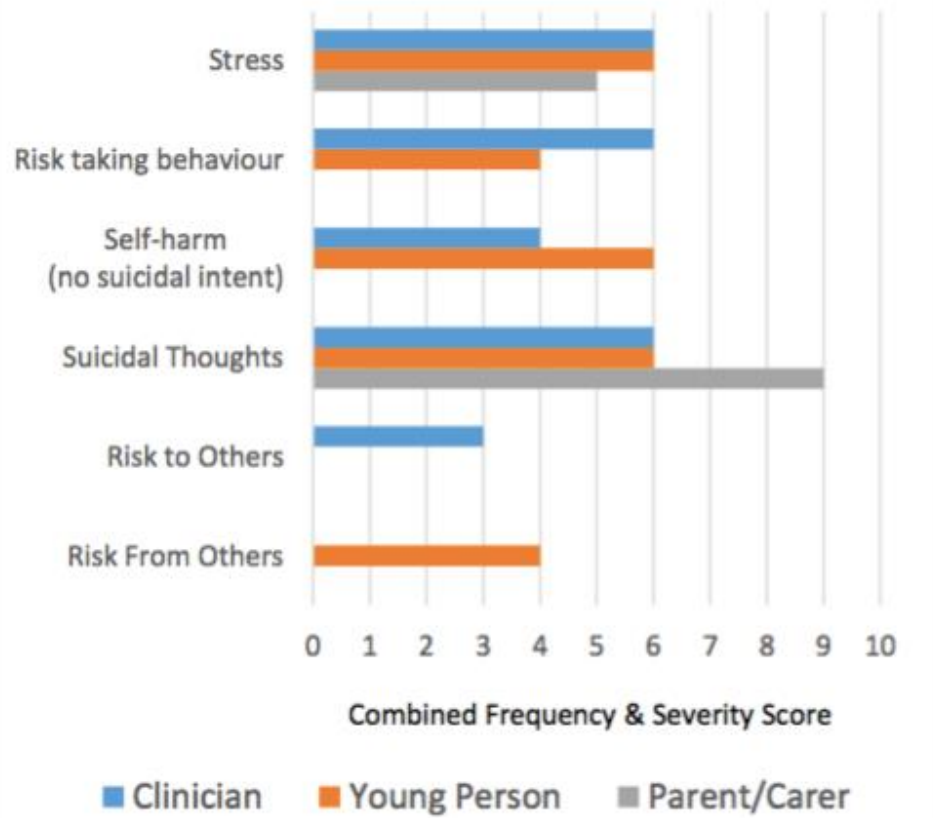
The plot shows the symptoms experienced by the young person as rated by the CL, YP and P/C



TRAM Présentation
résumée
Symptômes

Plot 2: Risk factors experienced by the Young Person

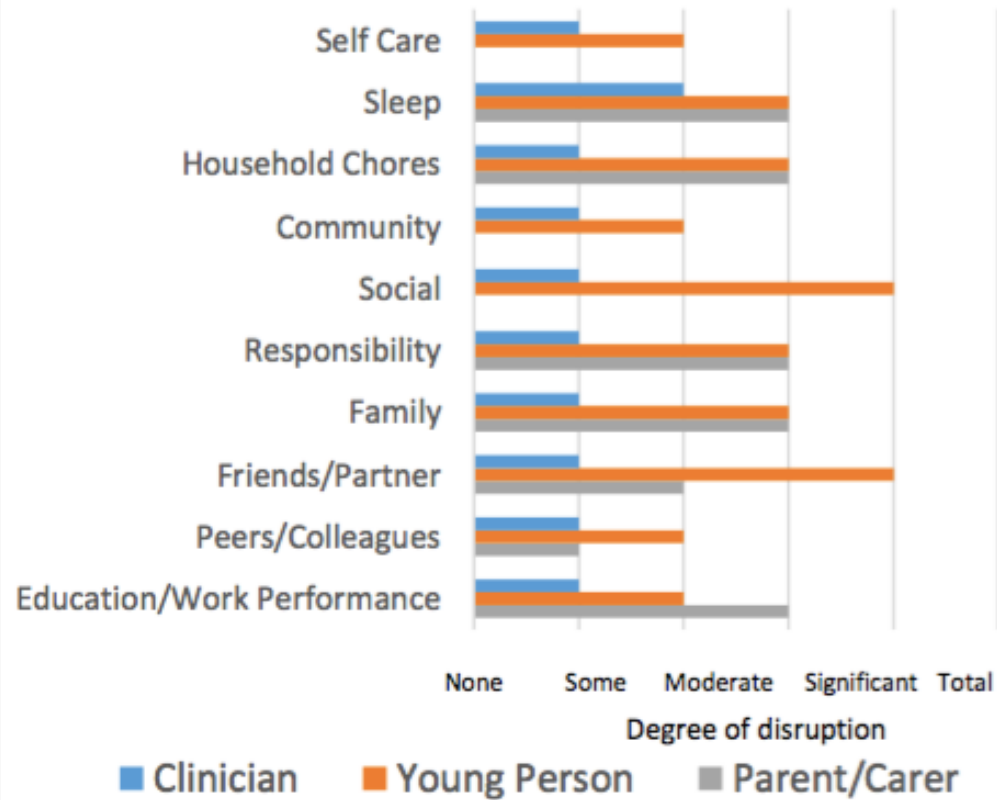
The plot shows the type and level of risk experienced by the young person as rated by the CL, YP and P/C



**TRAM Présentation
résumée
Facteurs de risque**

Plot 3: Disruption experienced by the Young Person

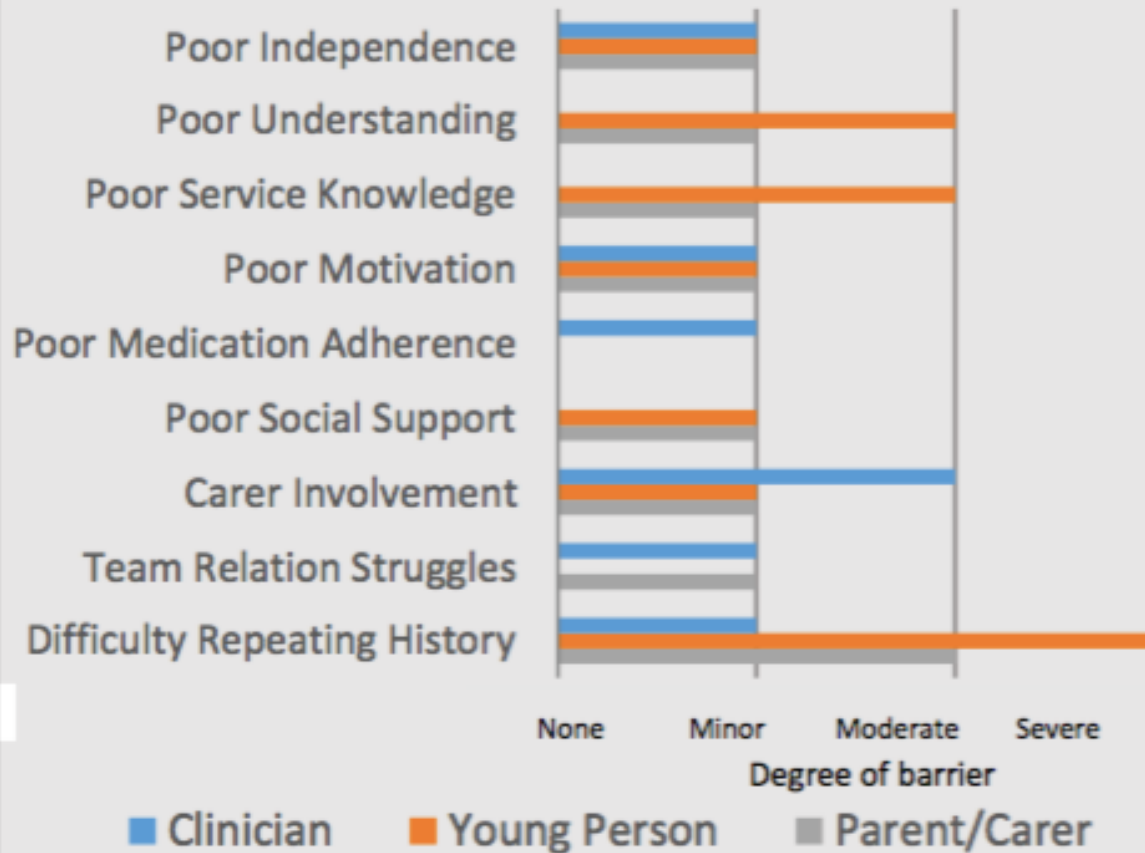
The plot shows the type & level of disruption experienced by the young person as rated by the CL, YP and P/C



**TRAM Présentation
résumée
Gêne ressentie**

Plot 4: Functional elements which would benefit from work to ensure a smooth transition

The plot shows the type and level of potential barriers to successful transition as rated by the CL, YP and P/C



**TRAM Présentation
résumée**
**Dimensions d'intérêt pour
preparer la transition**

Résultats principaux

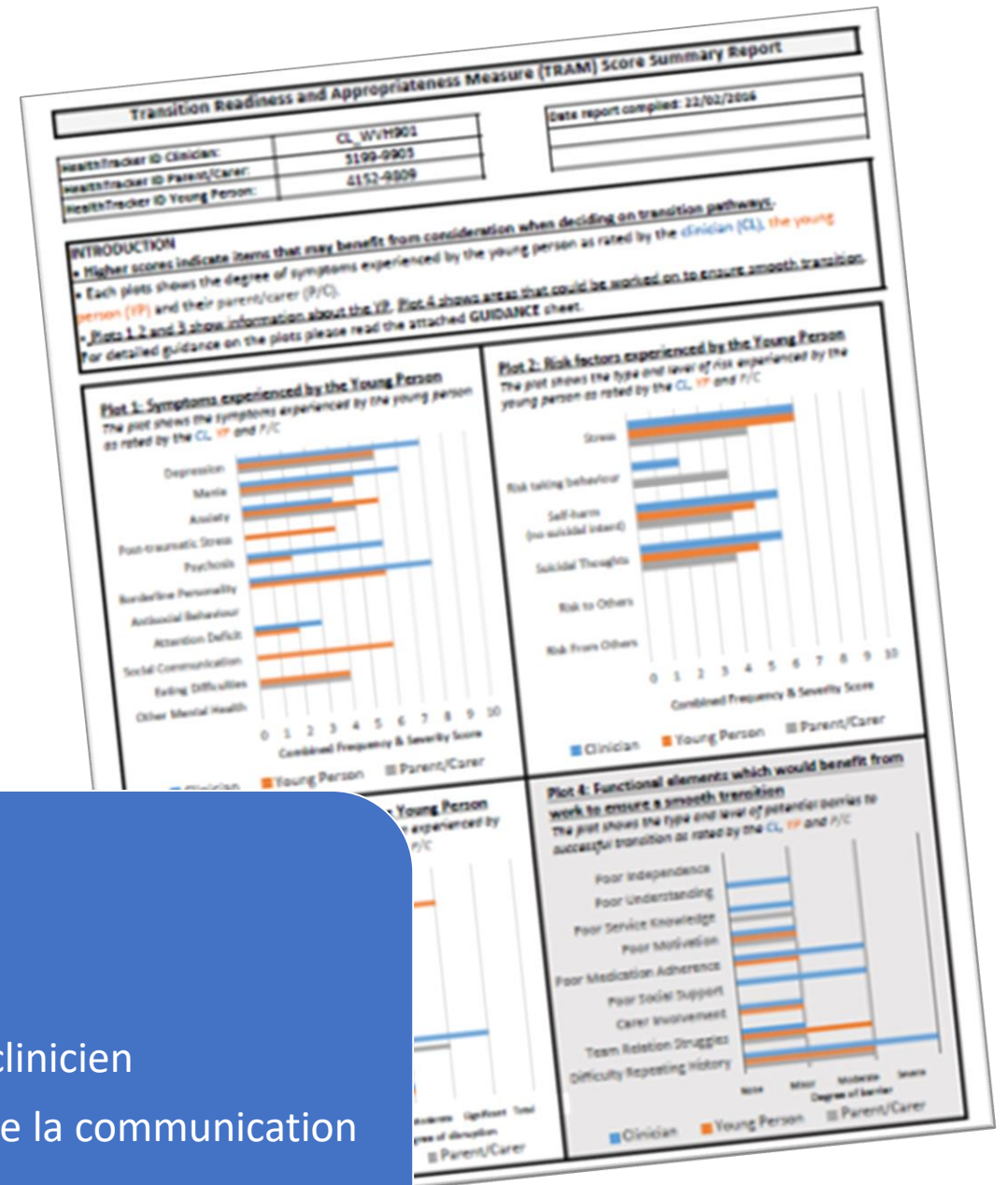
MILESTONE

- En cours de publication

- **Etude medico-économique:**
- **Faible cout de l'intervention** (entre €23-€111 par YP)
- **Conclusion:**
- Le modèle de transition managée est une intervention facile, bien acceptée et généralisable qui peut contribuer à améliorer l'évolution des JP en transition.
- Le résumé de TRAM peut être généré par une plateforme en ligne et incorporé dans le dossier medical. bn

Managed Transition points principaux

- Evaluation structurée
- En amont de l'âge de transition
- Avec participation de tous JP/parents/clinicien
- Le résumé graphique TRAM – améliore la communication entre services



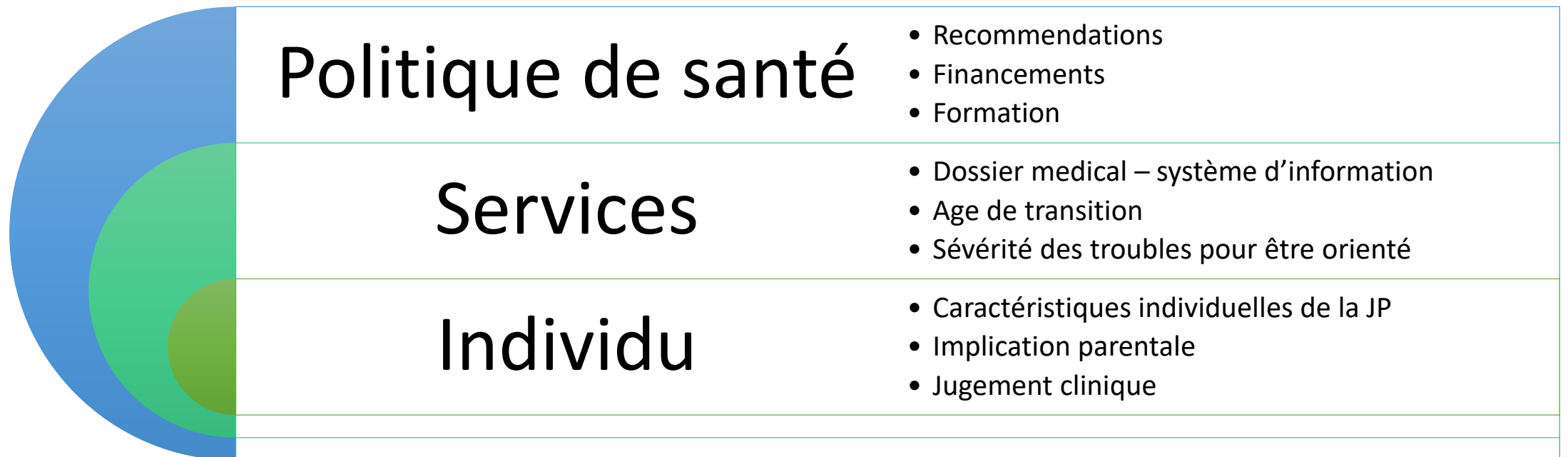


This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442

Conclusion



Enjeux de la transition entre services en santé mentale





The MILESTONE team

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Références

- Appleton, R., Connell, C., Fairclough, E., Tuomainen, H., and Singh, S. P. 2019. 'Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review', *Eur Child Adolesc Psychiatry*, 28: 1431-46.
- Hendrickx G, De Roeck V, Russet F, Dieleman G, Franic T, Maras A, McNicholas F, Paul M, Santosh P, Schulze U, Signorini G, Singh SP, Street C, Tuomainen H, Verhulst F, Wolke D, Purper-Ouakil D, Tremmery S; MILESTONE Consortium. Transition as a topic in psychiatry training throughout Europe: trainees' perspectives. *Eur Child Adolesc Psychiatry*. 2020 Jan;29(1):41-49
- Hendrickx G, De Roeck V, Maras A, et al. Challenges during the transition from child and adolescent mental health services to adult mental health services. *BJPsych Bull*. 2020;44(4):163-168.
- O'Hara L, Holme I, Tah P, Franic T, Vrljičak Davidović N, Paul M, Singh SP, Street C, Tuomainen H, Schulze U, McNicholas F; MILESTONE Consortium. A cross-cultural qualitative study of the ethical aspects in the transition from child mental health services to adult mental health services. *Child Adolesc Ment Health*. 2020 Sep;25(3):143-149.
- Paul, M., O'Hara, L., Tah, P., et al. 2018. 'A systematic review of the literature on ethical aspects of transitional care between child- and adult-orientated health services', *BMC Med Ethics*, 19: 73.
- Paul, M., Street, C., Wheeler, N., and Singh, S. P. 2015. 'Transition to adult services for young people with mental health needs: A systematic review', *Clin Child Psychol Psychiatry*, 20: 436-57.
- Russet, F., Humbertclaude, V., Dieleman, G., et al. 2019. 'Training of adult psychiatrists and child and adolescent psychiatrists in Europe: a systematic review of training characteristics and transition from child/adolescent to adult mental health services', *BMC Med Educ*, 19: 204.
- Santosh, P., Adams, L., Fiori, F., et al. 2020. 'Protocol for the development and validation procedure of the managing the link and strengthening transition from child to adult mental health care (MILESTONE) suite of measures', *BMC Pediatr*, 20: 167.
- Santosh P, Singh J, Adams L, Mastroianni M, Heaney N, Lievesley K, Sagar- Ouriaghli I, Allibrio G, Appleton R, Davidović N, de Girolamo G, Dieleman G, Dodig-Ćurković K, Franić T, Gatherer C, Gerritsen S, Gheza E, Madan J, Manenti L, Maras A, Margari F, McNicholas F, Pastore A, Paul M, Purper-Ouakil D, Rinaldi F, Sakar V, Schulze U, Signorini G, Street C, Tah P, Tremmery S, Tuffrey A, Tuomainen H, Verhulst F, Warwick J, Wilson A, Wolke D, Fiori F, Singh S; MILESTONE Consortium. Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study. *BMJ Open*
- Signorini, A, Singh, SP, Boričević, V, et al. 2017. 'Architecture and functioning of child and adolescent mental health services: a 28-country survey in Europe', *Lancet Psychiatry*, 4: 715-24.
- Signorini, G, Singh, SP., Marsanic, V, et al. 2018. 'The interface between child/adolescent and adult mental health services: results from a European 28-country survey', *Eur Child Adolesc Psychiatry*, 27: 501-11.
- Singh, SP, Tuomainen, H, Girolamo, G de, et al. 2017. 'Protocol for a cohort study of adolescent mental health service users with a nested cluster randomised controlled trial to assess the clinical and cost-effectiveness of managed transition in improving transitions from child to adult mental health services (the MILESTONE study)', *BMJ Open*, 7.
- Tuomainen, H., Schulze, U., Warwick, J., et al. 2018. 'Managing the link and strengthening transition from child to adult mental health Care in Europe (MILESTONE): background, rationale and methodology', *BMC Psychiatry*, 18: 167.