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Giulia Signorini<sup>1\*</sup>, Swaran P. Singh<sup>2</sup>, Gwen Dieleman<sup>3</sup>, Tomislav Franic<sup>4</sup>, Suzanne E. Gerritsen<sup>3</sup>, James Griffin<sup>5</sup>, Athanasios Maras<sup>3</sup>, Fiona McNicholas<sup>6, 7, 8, 9</sup>, Lesley O'Hara<sup>6</sup>, Diane Ouakil<sup>10</sup>, Moli Paul<sup>2</sup>, Paramala Santosh<sup>11,12,13</sup>, Ulrike Schulze<sup>14</sup>, Cathy Street<sup>2</sup>, Sabine Tremmery<sup>15,16</sup>, Helena Tuomainen<sup>2</sup>, Frank Verhulst<sup>17</sup>, Jane Warwick<sup>5</sup>, Giovanni de Girolamo<sup>1</sup>, for the MILESTONE Consortium

# ARCHITECTURE, FUNCTIONING AND TRANSITIONAL CARE INTERFACES OF CHILD AND ADOLESCENT MENTAL HEALTH SERVICES: A EUROPEAN 28-COUNTRY SURVEY

- <sup>1</sup> Saint John of God Clinical Research Center, Brescia, Italy
- <sup>2</sup> Mental Health and Wellbeing, Warwick Medical School, University of Warwick, Coventry, UK
- <sup>3</sup> Child and Adolescent Psychiatrist, Yulius Academy
- <sup>4</sup> Department of psychiatry, Clinical Hospital Center Split, Split, Croatia
- <sup>5</sup> Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, Coventry, UK
- <sup>6</sup> Department of Child and Adolescent Psychiatry, SMMS UCD, Belfield, Dublin 4
- <sup>7</sup> Geary Institute, University College Dublin, Belfield, Dublin 4.
- <sup>8</sup> Department of Child Psychiatry, Our Lady's Hospital for Sick Children, Crumlin, Dublin 12,
- <sup>9</sup> Lucena Clinic SJOG, Rathgar, Dublin 6
- <sup>10</sup> CHRU Montpellier-St Eloi hospital, Child and Adolescent psychiatry unit (MPEA1), France
- <sup>11</sup> Department of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK
- <sup>12</sup> Centre for Interventional Paediatric Psychopharmacology and Rare Diseases (CIPPRD), National and Specialist Child and Adolescent Mental Health Services, Maudsley Hospital, London, UK
- <sup>13</sup> HealthTracker Ltd, Gillingham, UK
- <sup>14</sup> Department of Child and Adolescent Psychiatry/Psychotherapy, University of Ulm
- <sup>15</sup> University of Leuven, Department of Neurosciences, Child & Adolescent Psychiatry
- <sup>16</sup> University Hospitals Leuven, Department of Child & Adolescent Psychiatry, Leuven, Belgium
- <sup>17</sup> Department of Child and Adolescent Psychiatry and Psychology, Erasmus University Medical Center, Rotterdam, The Netherlands

For the MILESTONE Consortium\*

### \*Corresponding Author:

Dr. Giulia Signorini, Saint John of God Clinical Research Centre

Via Pilastroni 4, Brescia (Italy) Ph 0039-0303501590 E-mail: gsignorini@fatebenefratelli.eu

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### **Abstract**

Introduction: Seventy-five percent of all mental health disorders manifest before the age of 25 and persist into later adulthood. Current service configuration with distinct Child and Adolescent Mental Health (CAMHS) and Adult Mental Health (AMHS) Services leads to a discontinuity of care at this high-risk time. Objectives: To gather detailed information about CAMHS characteristics and interface with AMHS at national and regional levels across Europe, including legal aspects of adolescent care. Methods: An on-line mapping survey of all 28 EU countries using the European CAMHS Mapping Questionnaire (ECM-Q) and the Standardized Assessment Tool for Mental Health Transition (SATMEHT). The survey was aimed at expert(s) in each country. **Results:** The response rate was 100%. The characteristics and activities of CAMHS varied considerably between the 28 EU member states, with significant information missing at national level. Up to 50% of CAMHS users were considered in need of transition to AMHS; yet, in the majority of countries, only up to 30% of young AMHS service users had previous contact with CAMHS; written policies for managing the interface were available in only four countries; and half (14/28) indicated that no transition support services were available. Conclusion: EU countries vary widely in the structure and functioning of CAMHS, as well as in transition policies and practices. Resource allocation seems not to match epidemiological estimates, and policymaking on transitional care is deemed. A marked improvement in the planning, monitoring and delivery of transitional mental health services is urgently needed.

**Key words**: child and adolescent mental health services, transition, survey, adult mental health services, youth mental health, Europe

### 1. INTRODUCTION

Transition to adulthood is the period of onset of most serious mental disorders that disable or kill in adult life. There is increasing evidence that early intervention may reduce the severity and persistency of many disorders and leads to more favourable outcomes. Initiation of treatment is, however, often delayed until several years after onset [1, 2], resulting in potentially avoidable disease burden. Eight out of ten main causes of disability in young people aged 10–24 years are psychiatric and behavioral in nature [3]. Three quarters of adult mental disorders have an onset before the age of 25 years, and up to 50% before the age of 16 [4].

Despite the burden and the worldwide recognized importance of prevention and health promotion in young people, access to Child and Adolescent Mental Health Services (CAMHS) remains difficult owing to a large discrepancy between the number of young people needing help, and availability of resources, particularly in low and middle income countries [5]. The availability of CAMHS is patchy worldwide and the care provided sometimes not sufficient [6-9]. Comparable to somatic care there is a clear distinction between care for children and adolescents and adults, with distinct CAMHS and Adult Mental Health Services (AMHS) with a transition boundary (TB) ranging from 16-21 years. There are profound conceptual, clinical, and ideological differences between CAMHS and AMHS [10,11], which impede continuity of care for young people, especially those who make a transition from one to the other [12]. McGorry et al [13] have noted that the interface is "the weakest link in a system where it should be most robust".

The MILESTONE project aims to improve transitions for young people from CAMHS to AMHS across Europe (more details at: <a href="http://www.milestone-transitionstudy.eu/">http://www.milestone-transitionstudy.eu/</a>). The survey presented here arises from the MILESTONE set of actions toward "Mapping the CAMHS-AMHS Interface across European Mental Health Services". It aimed to systematically compare CAMHS in all European Union (EU) countries in terms of differences and similarities in service configuration, characteristics and activity, as well as transition policies and practice; transition is in fact a longitudinal dimension of service delivery, and a comprehensive understanding of this pathway cannot exclude the knowledge of quantitative and qualitative characteristics of CAMHS.

### 2. METHODS

The term 'CAMHS' refers to a specialist, community based, multidisciplinary, mental health service delivering medical and psycho-social interventions for children and adolescents with mental health problems and disorders, as recognized by international classification manuals (ICD or DSM). 'Transition', on the other hand, refers to young people moving on to AMHS if they still require care or treatment; good quality transition is characterized by joint working, information transfer and therapeutic continuity.

### 2.1 Assessment instruments

We carried out the survey with two specific instruments. The European CAMHS Mapping Questionnaire (ECM-Q) is an adaptation of the European Service Mapping Schedule (ESMS) [14], which was developed to aid description and classification of mental health services and to allow the measurement of service use, and also integrates many of the domains used in the WHO CAMHS Atlas [15].

The Standardized Assessment Tool for Mental Health Transition (SATMEHT) was developed from an instrument used in the TRACK study [12], and from other questionnaires found in the literature, at national and international level [16-19]. The SATMEHT assesses characteristics and policies of CAMHS regarding transition. Both survey instruments (available as Supplementary Material 2) were finalized after multiple revisions following internal review within the MILESTONE team, as well as taking into account the advice of external experts.

The English language questionnaires were designed for online completion by country experts, and a dedicated web domain was developed in collaboration with an Italian software service (Kema SNC).

## 2.2 Identification and selection of country experts

We identified and approached individual experts within each of the 28 EU member states. Experts were identified with the help of WHO Regional Office in Copenhagen and the coordinator of the WHO Child Atlas project [15]. In eight countries, the survey was completed by the MILESTONE Principal Investigator or by a member of his/her team.

## 2.3 Data collection & quality control

Each respondent was sent login credentials to complete the online questionnaires. Missing or potentially ambiguous responses were identified, and each respondent was sent a detailed list of country specific queries. Respondents were sent up to three email

reminders and if we were still unable to obtain a response (21%, N=6) data originally submitted were used.

### 2.4 Data analysis

Data were collated in Microsoft Excel 2013, imported into Stata13 (StataCorp. 2013. *Stata Statistical Software: Release 13*. College Station, TX: StataCorp LP) for cleaning and analysis, and analyzed and presented using appropriate descriptive methods.

### 3. RESULTS

Data collection occurred between October 2014 and March 2015, followed by quality control (from May 2015 to September 2015). We obtained responses from experts in all 28 EU countries. Over 95% of survey items were completed.

The specific sources of information used by country experts were official national statistics or service reports (61% of countries, N=17), but also consultation with colleagues or experts, personal knowledge of the field (36%, N=10) and web searches (3%, N=1).

Twenty-two countries out of 28 (79%) were able to provide national references (e.g., publications, websites, national reports) containing information about the organization of CAMHS or tackling the epidemiology of child and adolescent mental health disorders in their country.

## 3.1 The organization of CAMHS in Europe: similarities and differences

Table 1 shows the cross-sectional demographic characteristics of the participating countries and the number and capacity of CAMHS services in all 28 EU countries as well as the number of child and adolescent psychiatrists and clinical psychologists specialized in the area of child/adolescent mental health available nationally. Data were not available for each country. Total population and the percentage of young people under the age of majority were derived from Eurostat databases [20]. Young people comprise about a fifth (average: 19%) of the general European population: Bulgaria, Germany and Malta have the smallest proportion of young people (16%) and the Republic of Ireland has the largest (25%).

### Table 1

The absolute number of CAMHS varies considerably across countries, and is partially linked to the geography and demographic profile of the country population (see also a map graphically showing differences in numbers, Supplementary material 3). For

example, Malta and Luxembourg each have two CAMHS, whereas Italy and Germany have 210 and 537 CAMHS, respectively. The number of CAMHS may be related to how it is delineated, as a service may be made up of many teams. However, there is no consistent pattern. For example, UK and France have 939 and 383 CAMHS, respectively, despite a similar population size; and although Denmark is as populated as Finland and has a higher population density, there are only 13 CAMHS compared to 140 in Finland. In terms of relative numbers, the range is from 12.9 (Finland) to 0.5 (Bulgaria) CAMHS per 100.000 young patients (YP) (26:1 ratio).

There is also a marked heterogeneity in terms of inpatient beds and noticeable differences in availability between large, highly populated countries (such as UK, France, Italy) and small, less populated ones (such as Luxembourg, Malta or Cyprus) (see also a map graphically showing differences in number of beds per target population, Supplementary material 4).

The number of clinicians working in CAMHS per 100,000 target population varies also considerably irrespective of population density, ranging from 1.9 to 36 child psychiatrists (4.5 in the UK and 8 in Germany vs 36 in Finland). The number of child and adolescent psychologists also varies, and in many countries prevalence is higher than that of psychiatrists (with the exception of Croatia, Czech Republic, Ireland, Portugal and Slovakia), but with considerable variety in this ratio (from 5:1 in Sweden to 1:1 in Finland and 2:1 in Croatia).

The majority of countries (25/28) report having a juvenile justice system that in 64% (N=16) of cases enables connections with specialized/dedicated forensic child and adolescent mental health services. A variety of specialized educational services for young people are available in most areas: specialized services for mental retardation in 89% (N=24) of countries, for learning disabilities in 86% (N=24), for physical and mental disabilities in 82% (N=23), for language and speech delay in 75% (N=21), and for behavioral problems in 64% (N=18) of countries. Specialized educational services for deaf/blind children are available only in 57% (N=16) of the countries.

Regarding the availability of specific facilities providing community outpatient child/adolescent mental health care, over 60% of experts (61-79%, N=17-22) thought that the number of public, or state-funded, group homes, respite care placements, day patients' programmes, outpatient clinics and health/primary health clinics were insufficient in their

respective countries. Specialized private specialists services and foster care placements (of different types) are available in only half of the responding countries. In Croatia, the Netherlands and Poland outpatient care is also provided by non-governmental organizations (NGOs), by specialized 'centers for youth and family' (offering parenting support), or through community services (delivering 'assertive' community treatment).

Roughly half of the responding countries reported that CAMHS offer language interpreters for patients unable to speak the national language, either for diagnostic assessment (50%, N=14) or for care delivery (43%, N=12). More than a third of countries (40%, N=11) reported having such services available only in limited geographical areas, while four countries (14%) reported having none for diagnostic assessment and five (18%) none for care delivery.

CAMHS opening hours vary considerably across EU, ranging between two (Estonia) to 12 hours (Romania) per day, from Monday to Friday, with an average of 8 hours/day. Mobile emergency (24 hours a day) CAMHS teams are limitedly available (43% of countries, N=12) or active only in limited areas (36% of countries, N=10).

## 3.2 Training of CAMHS professionals

Overall, for both medical (89%, N=25) and psychological (56%; N=14/25 replies) professions, national training programmes are in place, with an average duration of five years, leading to a certificate of specialization as "child psychiatrist" and "child/adolescent psychologist", respectively. Continuing Education programmes for child psychiatrists and child/adolescent psychologists are compulsory only in 64% (N=18) and 36% (N=9/25 replies) of countries, respectively. Other professionals working with young people with mental disorders are social workers (93%, N=26, of responding countries), speech and language therapists (89%, N=25, of countries), psychiatric nurses (86%, N=24, of countries), and other professionals (79%, N=22) such as occupational therapists, psychotherapists, physiotherapists, nutritionists, music therapists, and art therapists.

### 3.3 Collaboration with other services

Less than half (43%, N=12) of the countries reported having a national protocol or agreement between schools and health services for facilitating appropriate and timely referrals to CAMHS for children with suspected learning disabilities. In many parts of the EU (46%, N=13, of countries) there were no protocols in place at all and in one country

(Belgium, 4%) coverage was extremely patchy (limited to a few communities or areas). The majority of countries (63%, N=18) confirmed the availability, in most or all areas, of specific protocols for the referral of severe cases of abuse/neglect to mental health care providers by other community services (e.g., schools, social services, other public and private agencies). Similarly, 70% of responding countries (N=19/27) stated that there are regular relationships between CAMHS and child safeguarding services in most/all areas. In terms of referral procedures, 16/28 countries (57%) reported the existence of official guidelines for referring patients from primary to secondary/tertiary care.

Respondents from most countries indicated that there is at least one service user association (86%, N=24) and one family/caregivers' association (96%, N=27) operating (or in existence). The degree of involvement of such organizations in the last two years in the formulation or implementation of mental health policies at national level (i.e. participation in meetings dedicated to this purpose) differed considerably across countries, ranging from "rarely" (18-11% respectively for users and family associations, N=3-5) and "not routinely" (39-46%, N=11-13), to "frequently" (29%, N=8). In 14% of cases (N=4) the question did not apply, either because of the absence of national associations or due to the lack of specific national policies.

## 3.4 CAMHS activity data on Young people

A periodic activity report of CAMHS is obligatory in 86% (N=24) of countries (only Croatia, Germany, Luxembourg and Spain reported having no such requirement). Activity data weren't available for 32% (N=9) of the responding countries, mainly due to the lack of national registries (presently available in 18 countries), or lack of access to such sources of information.

### Figure 1

The range of ages of young people treated in CAMHS varied greatly between countries, the proportion of males being slightly higher (58%) than that of females. Figure 1 shows the percentages of young people treated in CAMHS in the past 12 months for 19 countries. Seven reported that 3-6% of the young population had contact with CAMHS during the last year; the proportion was 1-3% in 11 countries, and less than 1% in one country (Slovakia).

The number of recorded new cases, for the last year available, was provided by 13/28 (46%) countries, and generally ranged between 0.2% to 2% of the young population.

Less than half the countries (46%, N=13) were able to provide complete data for every diagnostic category and one (Czech Republic) could provide no breakdown of ICD-10 categories F80-F98. In all the countries, neurodevelopmental disorders are the most frequent diagnostic group (for both DSM-5 or F80-98 for ICD-10) for those in care at CAMHS. Information was not provided in sufficient detail to allow comparison between countries regarding specific developmental disorders. More details can be found in Supplementary Materials 5 and 6, where data are presented as proportions of reported total numbers of cases.

## 3.5 Policy and legislation in the area of child mental health and child rights

Sixty-eight percent (N=19) of the 28 EU countries reported having an official national child and adolescent mental health policy, covering young people until their transition boundary (TB) age. The age ranges mentioned in the policies for each country are listed in Supplementary Material 7. In two countries, the policy had been adapted in order to extend its coverage to a few years after the official TB age (Finland: 23 years; Germany: 21 years). The key components of the policies include regulations on the types of health care provided and on the competency of care providers (covered by 63% of countries, N=17/27 replies), guidelines regarding access to services (59%, N=16/27), specific written standards of service provision (48%, N=13/27) and other matters, such as rights regarding consent and privacy (7%, N=2/27). Many sectors were reported to be involved in the development of policies about child/adolescent mental health, including mental health (64%, N=18), primary care (54%, N=15), child protection (50%, N=14), health and social welfare (36%, N=10), human rights (29%, N=8) and other social services (7%, N=2).

All 28 EU countries have specific laws to protect children from abuse and exploitation. Majority of countries reported having formal procedures for informed consent (96%, N=27), confidentiality of health care services and records (N= 93%, N=26) and prescriptions of medications (n= 82%, N=23). Specific laws pertaining to the participation of children in experimental trials were available in 89% of the countries (N=25).

National expected minimal standards of care for mental health professionals working in CAMHS were reported by at least two thirds of surveyed countries; 86% (N=24) reported that such standards exist for psychiatrists, 75% (N=21) for psychologists,

and 68% (N=19) for nurses). Standards of care include professional certification and maintenance of competency, in-service training, clinical supervision and clinical practice guidelines. Standardized evaluation of mental health services occurs in 68% (N=19) of the surveyed countries: areas evaluated include patients' satisfaction (43% of countries, N=12), clinical outcomes (36%, N=10), families' satisfaction (32%, N=9) and other national requirements (32%, N=9), such as national accreditation of service providers, sentinel reporting systems, standards set by health insurance (i.e. minimum number of staff, minimum staff qualifications).

## 3.6 Health financing

CAMHS across EU receive funding through different channels. The most common source is from government taxes (25/28 countries, 89%): in ten countries, this accounts for the majority (80-100%) of funding. Two other important sources of funding come from service user families and social insurance, 68% (N=19) and 61% (N=17) of countries, respectively. In almost half of the countries private insurance (57%, N=16) and Non-Governmental Organizations (NGOs) (46%, N=13) play an important role in funding; international grants fund services in 6/28 (21%) countries. In Croatia additional sources of funding for CAMHS are provided by local communities. In all countries, families with a child or an adolescent with a disabling mental disorder receive subsidies or free government ancillary benefits in the form of exemption of all medical care costs. Other such subsidies or benefits include: access to specialized education programs (96% of countries, N=27); provision of a disability pension (82%, N=23); access to institutional care (89%, N=25); provision of respite/practical help for caregivers (71%, N=20) and provision of parental training or education (61%, N=17). In a few countries (reported for 14% of countries, N=4), benefits include domiciliary care, rehabilitation courses for individuals and families, and parent/caregiver financial help. Additional information are shown in Supplementary Material 8.

## 3.7 Data collection and quality assurance

Systems for collecting epidemiological data on child and adolescent mental health disorders are in place in at least half of the surveyed countries, but only 10/28 (36%) were able to provide references for English language publications reporting detailed national data (for example, prevalence and incidence studies, service utilization studies, suicide rate studies, psychotropic drug utilization studies, etc). Sixty-seven percent (N=18) of

European countries reported the existence of a national data collection system for child and adolescent mental health disorders, but only 3% of countries (N=6) indicated that there is regular monitoring of treatment outcomes.

## 3.8 Care for special populations

Specific subgroups of children and adolescents have poor access to specific mental health services dedicated to them in several countries: for example, only 37% (N=10/27 replies) provide access for refugees, 26% (N=7/27) for orphans or victims of natural or man-made disasters, 22% (N=6/27) for seriously emotionally disturbed children, and 15% (N=4/27) for minority groups, runaway/homeless children (11%, N=3/27), and indigenous people (7%, N=2/27). A third (33%, N=9/27) of countries have no special services designed to meet the specific needs of these subgroups and only 26%, (N=7/27) indicated having highly specialized services for fostered, forensic, disabled, autistic or substance abusing children.

## 3.9 Medication and psychosocial treatments

Most countries reported that all psychotropic medications most commonly used in CAMHS are available within their primary health care system (data from Malta and Estonia were missing). Psychostimulants are available in primary care in 88% (N=23/26 replies) of responding countries. In 24 countries (92%), primary care can access also second-generation antidepressants, antipsychotics and anxiolytics/sedatives.

First-generation antipsychotics are available in 88% of responding countries (N=23/26 replies), and mood stabilizers (e.g., sodium valproate, lithium, carbamazepine, lamotrigine, and oxcarbazepine) in 85% (N=22/26 replies) of countries, although in Denmark these medications are not available in primary care settings (prescriptions are authorized only if made by a child/adolescent psychiatrist).

### Figure 2

Figure 2 shows the availability of psychosocial treatments in CAMHS (data missing for Malta and Estonia). The most commonly available are family psycho-education (88%, N=23/26 replies), cognitive-behavioral therapy, learning assistance/educational support and speech/language training (81%, N=21/26 replies). Parental training/guidance is available in 77% (N=20/26 replies) of the countries.

## 3.10 A focus on transition

The majority of country experts (48%, N=12/25 replies) estimated that 25% to 49% of CAMHS service users will need transition to AMHS. Table 2 shows the percentages of CAMHS service users anticipated to need adult mental health care by the percentages of AHMS patients under 30 years of age who have had previous contact with CAMHS, which is estimated to be 20%(N=9/23 replies) to 30%(N=5/23 replies) of AMHS service users. There is little evidence of a clear pattern in these data. These estimates are based mostly on expert opinion (75%, N=21), not actual statistics.

### Table 2

In the majority of countries (89%, N=25), CAMHS and AMHS are a separate organization, and in many instances (68%, N=19) there are regional differences in their configuration. In the majority of cases, transition age in health care is set at 18 years old, with exceptions in France and Malta (16 years), Cyprus (15-19 years), Czech Republic (18-19 years), Denmark (17 years), Estonia (19 years), Finland (18-23) and UK (16-18) (see also Supplementary Material 7). The use of broad transition age ranges can be explained by differences in service configurations.

Sixty-one percent of countries (N=17) reported that there was no specialized transition planning available in their country. In the minority of countries where such planning is available, transition generally occurs between the ages of 16 and 20 years, with the sole exception of Denmark, which offers transition planning for patients with eating disorders aged 13 years and over. Professionals involved in specialized transition planning are psychiatrists (36%, N=9/11 replies), social workers (64%, N=7/11), psychologists (55%, N=6/11), nurses (36%, N=4/11) and other professionals (9%, N=1/11).

Only two countries (Denmark and the UK) have written national or regional policies or guidelines for the management of individual patient transition from CAMHS to AMHS, and the interface between these two services is regulated by official agreements or guidelines in only four of the 28 countries (Cyprus, Denmark, Spain and the UK).

Where provided, transition support services often are helped financially by a separate funding system accessible to CAMHS and AMHS (38%, N=10/26 replies) and also by the general availability of flexible funding (19%, N=5/26 replies). Private or public individual insurance (23%; N=6/26 replies) and different funding levels (15%, N=4/26 replies) are also important factors affecting budgets for transition support services. Finally, financial agreements with private services are in place in only 8% (N=2/26) of responding

countries. More than half (57%, N=16) have no CAMHS case managers. In 21.5% of countries (N=6), a CAMHS case manager has the right to follow-up the young patient once he or she has moved from the child/adolescent to the adult service. Elsewhere, case managers are not entitled to do this.

### 3.11 Involvement of different stakeholders in the transition process

In almost half the countries (46%, N=13) parents are involved in the transition pathway although sometimes or often only to the extent of being informed about the procedures and characteristics of the transition. In other countries (14%, N=4), the degree of involvement is determined by agreements reached between the young patient and his/her parents; in 18% of countries (N=5) parents can also choose the service they would like their young person to be referred to or even the treating clinician (11%, N=3). In 11% of the countries (N=3), parents have no or only limited involvement in transition decisions (i.e. they are involved only when requested by patients).

In case a service user's parent is considered by the CAMHS professional as suffering from a severe mental disorder affecting his capacity to best decide for the child/adolescence, the other partner or spouse is deemed the first point of contact regarding the transition discussion according to the majority (6/28 countries), followed by the general practitioner as a second choice (6/25 countries). When a parent is suffering from any mental disorder, their role in their child's transition planning is generally limited to receiving information about the process (63%, N=17/27 replies) rather than playing an active role (26%, N=7/27 replies) or being left alone to manage by themselves (4%, N=1/27 replies).

Our respondents deemed that the difficulties experienced by young people facing CAMHS-AMHS transition arise from a lack of connection between the two services (82% of countries, N=23), a lack of specific adolescent competencies in AMHS (64%, N=18), cultural differences (46%, N=13), a lack of capacity in AMHS and use of different eligibility criteria (both 36%, N=10), a lack of specific service to refer patients on to (21%, N=6), ignorance of other systems (14%, N=4), catchment areas issues (11%, N=3) and other conditions (i.e. still attending school) (4%, N=1).

When CAMHS patients have a comorbid physical illness, transition is usually managed by communicating or referring to the appropriate specialist (71%, N=20), followed by the options of leaving the CAMHS professional to decide what to do (32%,

N=9), extending the medical treatment in CAMHS (18%, N=5), or anticipating the transfer to AMHS (4%, N=1).

In three countries (11%) a standardized assessment of the needs of young people approaching the transition boundary has been conducted. In two cases, Lithuania and Sweden, this was carried out at the local level, and in one country (Ireland) as a state-wide initiative. In terms of efforts made by AMHS to address the transition needs of incoming CAMHS service users, only 29% (N=8) replied with a positive answer: these efforts included the formalization of transition policies, strengthening cooperation with CAMHS, and improving the diagnosis and treatment of selected disorders (such as ADHD and Autism spectrum disorders).

Most countries have no or limited support from transition teams (indicated in the 89% of cases, N=25) and no community support groups (86%, N=24) to help young people as they move into the less structured adult environment). Initiatives such as joint working with adult service providers are reported as not available in 79% of countries (N=22), partnership approaches involving the young person in planning their own transfer to adult services are unavailable or have very limitedly availability in 64% of countries (N=18). In contrast, shared documentation and record keeping systems are available in 50% of countries (N=14). France reported having specific facilities to ease access of adolescents to health services with centres available in most areas. In the UK, a limited supply of transition support workers was reported. Countries may also offer additional initiatives such as "houses of adolescents" (France) and educational and pedagogical psychological services (Lithuania).

## 3.12 Transition programmes and actions

No countries reported having any professional transition specialists available, and 50% of them (N=14) reported having no transition support services at all. Only three countries (Poland, Slovak Republic and Spain) could provide hard data about the functioning of the specific programs described above. More details are provided in Supplementary Material 9.

A third of countries (37%, N=10/27) have no requirement to document on transition planning, and in the other two thirds this goal is included in their policies only sometimes or always. Service users are never involved in care plan and decision-making in 31% of countries (N=8/26 replies), yet always involved in 38% (N=9/26 replies).

Marked differences between countries were found also regarding the intention to organize joint meetings with adult services, occurring always in only 7% (N=2/26), sometimes in 50% (N=13/26) and never in 42% (N=11/26) of countries. There is no system that ensures accountability (i.e. with a single clinician identified from one of the services to coordinate the transition) in half the countries.

Other aspects of transition include efforts to ensure the involvement of parents/caregivers in care plan and decision making (sometimes in 42%, N=11/26; always in 35%, N=9/26 of countries), preparing the young person for ending a therapeutic relationship and starting a new one (sometimes in 44%, N=11/25; always in 36%, N=9/25 of countries). Other goals were reported, such as the establishment of phone contacts between teams in addition to the exchange of medical documentation (France) and provision of care at the same mental health centre (Lithuania).

### 4. DISCUSSION

This is the first survey of CAMHS facilities, activity data and transition policies and practices carried out at European level more than 10 years after the publication of the WHO Child and Adolescent Mental Health Atlas [15, 21].

### 4.1 Country differences

Although heterogeneity in CAMHS quantity might be related to the way in which services are constructed in each country and the number of separate CAMHS teams, this might not necessarily indicate their availability. However, this variety is also mirrored in the numbers of available clinicians. Professional availability is in fact heterogeneous, and differences between countries do not seem to match neither the target population nor service distribution. Between-country differences in service availability appear to be more marked than those in prevalence rates of child/adolescent mental disorders, suggesting that resources distribution does not match epidemiological prevalence estimates of child/adolescent mental disorders [22-23]. Such differences are likely to be dependent on policy issues, financial resources, social, cultural and ethical attitudes, and the general architecture of mental health care in each country. For instance, the very limited number of inpatient beds in a country like Italy reflects the very limited number of psychiatric beds in general [24,25], after the law leading to the closing of all mental hospitals and to a radical decrease in the provision of inpatient and residential care. On the other hand, other

countries, such as Germany, have a high number of inpatient beds cutting across all types of psychiatric care (child/adolescent care, adult psychiatric care, psychogeriatric care and forensic care) [26]. Moreover, according to the variations in the way services are nationally and regionally configured, several countries might have other services such as intensive home treatment teams, psychotherapeutic facilities, or Flexible Assertive Community Teams (FACT) [27], delivering almost comparable care in an outreached fashion.

Several experts involved in this survey noticed that the provision of specific types of community child/adolescent mental health care in their own countries is insufficient to meet the needs of the specific clinical groups requiring this type of care (i.e. public group homes, respite care placements, day patients' programmes, outpatient clinics and health/primary health clinics). This is an area that needs strengthening in the future.

## 4.2 Current and future needs of care for neurodevelopmental disorders

Our data show that the bulk of child/adolescent mental health care is targeted to children and adolescents with neurodevelopmental disorders; in countries where a specification of subcategories was made, autistic spectrum disorders accounted largely for this diagnostic category. A consequent, important clinical implication is that in many countries adult mental health services do not treat these patients and often adult psychiatrists lack specific training in this field. Such individuals, as they become adults, may not find any suitable mental health service for their care needs [28]; the exception being those who also present comorbidities.

## 4.3 European figures on CAMHS activities: problems and perspectives

The percentage of the target population assisted by CAMHS varies substantially between different countries: although the high Italian proportion of CAMHS users can be explained by the combination of areas of assessment and treatment offered in CAMHS (child and adolescent neurological diseases + child and adolescent mental disorders ), the high proportion of CAMHS users in Lithuania, the Netherlands and Slovenia does not seem to be justified neither by target population density, nor by CAMHS availability, nor by differences in transition age (18 years for all three countries).

The poor interface between CAMHS and AMHS is the major cause of transition gap: the percentages of CAMHS users in need of continuity of care are not mirrored by percentages of young AMHS users with previous contact with CAMHS. For example, in the Netherlands at least 75 % of CAMHS users are estimated to need further care once

they reach transition age, while only 20% of young AHMS users seem to come from CAMHS services. Consequentially, 80% of new AMHS users have not previously been treated in the CAMHS system. This conflicts with actual epidemiological estimates of the age of onset of mental disorders [4]. The discrepancy between 'perceived' need of CAMHS users for AMHS and 'actual' referrals need further exploration in order to better understand their impact on transition and will be addressed in the MILESTONE project. Despite such perceived need it seems to be reluctance, by CAMHS clinicians, to refer on and, by families and youth, to be referred to AMHS [29]; at the same time it seems to be present concerns from AMHS as to their level of competency in dealing with childhood onset disorders, such as ADHD, autism and conduct disorder. Yet, few of those youth who transition experience optimal transition [12]. Lack of optimal care is also noticeable when referring to special populations (e.g., minorities, refugees, orphans), as one third of interviewed countries report no special services designed to meet the specific needs of these subgroups.

Finally, governments support families with children affected by mental health disorders, mostly through financial channels (e.g. exemption of medical care costs; disability pension); although access to specialized educational programs is overall guaranteed, parental training or practical support (i.e. caregiver respite, rehabilitation courses, domiciliary care) are not considered a universal benefit for these families. Parent training is not available in about a fourth of surveyed countries (23%; N=6).

This discrepancy between 'needed' care and 'available' care raises crucial implications for the development and the implementation of evidence-based transition policies, protocols and care pathways for young people. The organization of services and the distribution of resources should be based on users' perspectives and needs [30]; transition should not be considered an individual life event, but rather a process that involves multidisciplinary teams of actors, services and stakeholders [31].

### 4.4 Limitations

Caution is necessary in interpreting these data, since experts may sometimes provide information which does not match official sources, but is based on professional experience or reflects local data, and which may be inconsistent if compared to national profiles. Moreover, it is important to note that the lack of standardized and valid data

sometimes makes it difficult to interpret between country differences or overall estimates (especially regarding activity data). Another complicating factor might be represented by the fact that in a number of countries (as in the UK or the Netherlands) - as a result of the challenging economic conditions - many services have been going through largescale reorganization, resulting, for instance, in a reduction of clinical beds both in CAMHS and AMHS and in the implementation of FACT.

### 5. CONCLUSION

This paper provides important information for the evaluation and planning of European CAMHS undergoing change: visible differences should be overcome in order to arrive at a unified, appropriate and timely configuration of services for children and adolescents in the 28 European countries. The survey points out areas of concern: (i) a poor service planning, discrepancies in equipment across countries and lack of any kinds of standardized outcome assessments, underlining an urgent need for clearer national/regional policies of service delivery and structure, and for measures of treatment delivered and taken up, and of its effectiveness; (ii) a limited or variable involvement of service users, stressing the importance of a better identification, or assessment, of young people's needs and satisfaction with services; (iii) CAMHS/AMHS professional training needed to bridge the gap between medical and service-related cultures.

All these considerations highlight the need of testing the actual availability of services through standardized national data collection systems, as well as European actions specifically focused toward the collection of comparable international figures [32], under a clearly identified and shared terminology, in order to form a holistic view of children's and adolescents' health and wellbeing and mental health services.

Addressing youth mental health needs in the most efficient and cost-effective way is part of the essential ongoing investment in adolescent health and wellbeing [33]. This challenge implies an unprecedented reconfiguration of current service provision, as well as a harmonization of data collection systems.

## **Author contributions**

GS and GdG wrote the manuscript; JW and JG supervised data quality control and analysis; SS, GD, TF, SG, AM, FMN, LOH, DPO, MP, PS, US, CS, ST, HT and FV provided substantial contribution to the conception of the work, revising it critically for important intellectual content, approved the final version and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### **Conflict of interest**

The Authors declare that there is no conflict of interest in the submitted work.

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Table 1

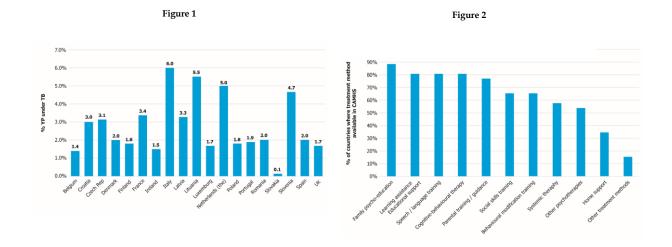
Demographics and the capacity of CAMHS per 100,000 young people under the age of 18, or legal transition boundary (TB)

COUNTRY	Population density (persons per km²) <sup>a</sup>	Total Population (100,000) <sup>a</sup>	% of population under the age of TB (18) <sup>a</sup>	No. public CAMHS	Total beds in child/adolescent psychiatric units	No. CAMHS per 100,000 YP	No. inpatient beds per 100,000 YP	No. child and adolescent psychiatrists per 100,000 YP	No. child and adolescent psychologists per 100,000 YP
Austria	103,6	84.0	18	11	317	0.7	21.0	6.0	*
Belgium	370,3	110.0	20	53	650	2.4	29.0	11.1	*
Bulgaria	66,3	73.6	16	6	48	0.5	4.0	1.9	1.7
Croatia	74,9	42.8	19	10	70	1.3	8.8	6.3	3.1
Cyprus†	92,5	8.4	19	8	8	5.1	5.1	8.3	32.0
Czech Rep	136,3	104.4	17	14	628	0.8	34.6	6.8	4.4
Denmark	131,5	55.6	22	13	224	1.1	18.5	10.3	22.4
Estonia	30,3	12.9	18	5	50	2.1	21.0	16.8	25.2
Finland	18	53.8	20	140	350	12.9	32.3	36.0	36.9
France <sup>‡</sup>	104,5	649.3	20	383	2107	3.0	16.4	9.1	*
Germany	226,6	802.2	16	537	8400	4.1	64.0	8.0	32.9
Greece	83,3	108.2	17	45	60	2.4	3.2	16.3	*
Hungary	106,1	99.4	18	55	139	3.1	7.7	3.4	8.4
Ireland	67,5	45.7	25	60	60	5.2	5.2	5.2	5.1
Italy	201,2	594.3	17	210	324	2.1	3.2	20.0	*
Latvia	32	20.7	17	19	140	5.3	39.0	11.2	*
Lituania	46,8	30.4	19	5	180	0.9	31.5	14.0	21.0
Luxemburg	215,1	5.1	21	2	35	1.9	32.6	21.4	65.3
Malta <sup>‡</sup>	1352,4	4.2	16	2	12	3.0	18.0	3.0	*
Netherlands	500,7	166.6	21	113	1981	3.2	56.6	10.7	*
Poland	124,1	380.4	19	178	1300	2.5	18.2	3.5	*
Portugal	112,8	105.6	18	34	24	1.8	1.3	5.4	4.7
Romania	86,5	201.2	19	*	688	*	17.9	3.1	*
Slovakia	110,5	54.0	19	37	220	3.6	21.5	3.6	2.7
Slovenia	102,4	20.5	17	34	46	9.7	13.1	6.0	15.4
Spain	92,5	468.2	18	201	204	2.4	2.4	*	*
Sweden	23,8	94.8	20	20	157	1.0	1.2	23.4	104.2
UK	266,4	631.8	21	939	1264	7.0	9.4	4.5	*

<sup>&</sup>lt;sup>a</sup> EUROSTAT data \* denotes data missing from ECM-Q survey † Legal TB at 17 years ‡Legal TB at 16 years

Table 2
Estimated % of CAMHS users anticipated to need transition to AMHS care by estimated % of AMHS users who have had previous contact with CAMHS (under 30 years of age)

	Estimated % of CAMHS users with AMHS care needs as they age											
		0-24%	25-49%	50-74%	75-100%							
Estimated % of AMHS users under 30 years of age with previous history of CAMHS service use	10%	Greece, Poland	Portugal			3						
	20%	Cyprus, Italy, Slovenia,	Austria, Ireland, Romania	Malta	Netherlands	8						
	30%		Bulgaria, Croatia, Germany, Latvia, Luxembourg			5						
	40%	Hungary	Sweden			2						
	50%	Denmark	Finland	France, Lithuania		4						
	60%	Estonia		Spain		2						
	70%	Slovakia				1						
	NA		Czech Republic	UK								
		9	12	5	1							



## FIGURES CAPTIONS

**Figure 1** Percentages of all young people (YP) below the transition boundary age treated in CAMHS in the past 12 months

**Figure 2** Availability of treatment methods to CAMHS in EU countries\* *Footnote: \*Data excludes Malta and Estonia*