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COST 4133/10

MEMORANDUM OF UNDERSTANDING

Subject :	Memorandum of Understanding for the implementation of a European Concerted Research Action designated as COST Action BM1004: Enhancing the scientific study of early autism: A network to improve research, services and outcomes

Delegations will find attached the Memorandum of Understanding for COST Action BM1004 as approved by the COST Committee of Senior Officials (CSO) at its 178th meeting on 25 May 2010

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MEMORANDUM OF UNDERSTANDING
For the implementation of a European Concerted Research Action designated as

COST Action BM1004
ENHANCING THE SCIENTIFIC STUDY OF EARLY AUTISM: A NETWORK TO IMPROVE RESEARCH, SERVICES AND OUTCOMES

The Parties to this Memorandum of Understanding, declaring their common intention to participate in the concerted Action referred to above and described in the technical Annex to the Memorandum, have reached the following understanding:

1. The Action will be carried out in accordance with the provisions of document COST 4159/10 "Rules and Procedures for Implementing COST Actions", or in any new document amending or replacing it, the contents of which the Parties are fully aware of.
2. The aim of the Action is to establish an interdisciplinary scientific network to advance the pace of discovery about the earliest signs of autism; to combine techniques from cognitive neuroscience with those from the clinical sciences; and to establish European practice guidelines on early identification and intervention.
3. The economic dimension of the activities carried out under the Action has been estimated, on the basis of information available during the planning of the Action, at EUR 72 million in 2010 prices.
4. The Memorandum of Understanding will take effect on being accepted by at least five Parties.
5. The Memorandum of Understanding will remain in force for a period of 4 years, calculated from the date of the first meeting of the Management Committee, unless the duration of the Action is modified according to the provisions of Chapter V of the document referred to in Point 1 above.

A. ABSTRACT AND KEYWORDS

Autism is a lifelong neurodevelopmental condition with high morbidity and cost for the individual, their family and society. A wide number of scientific methodologies and disciplines are relevant to the study of early autism, including studying genetically 'at risk' siblings; the development of novel neuroimaging techniques; and developing and testing screening instruments and interventions. The lack of a forum to enhance the scientific synergies between these strands of basic and applied research has hindered progress. This COST Action will establish an interdisciplinary scientific network to advance the pace of discovery about the earliest signs of autism; to combine techniques from cognitive neuroscience with those from the clinical sciences; and to establish European practice guidelines on early identification and intervention. Increased and earlier recognition has impacted across Europe in terms of demand for diagnostic services and interventions. Current health care systems across Europe are very variable in terms of their expertise and capacity to support families with young children with autism, often leading to marginalisation. This Action will enable developments in clinical practice and policy to be informed by cutting edge science and a rigorous evidence-base, significantly improving quality of life for individuals with autism, their families and broader European society.

Keywords: autism, 'at risk' studies, cognitive neuroscience, early identification, intervention

B. BACKGROUND

B.1 General background

It is now recognised that autism, characterised by impairments in social reciprocity, language and communication and rigid and repetitive behaviour, affects around 1% of the population (Baird et al., 2006), meaning that approximately 8 million individuals in Europe are affected. Autism affects 4 times as many males as females but the reasons for this are not well understood; the possibility also remains that autism is under-recognised in girls, perhaps especially at a young age. The increase in diagnosed prevalence is likely due to broadening of the diagnostic concept and greater public and professional awareness, although other factors including possible (as yet unknown) environmental and socio-genetic factors cannot be ruled out (Fombonne, 2009). Increased and earlier recognition

has impacted across Europe in terms of demand for diagnostic services and treatments (McConachie & Robinson, 2006).

It is well-established that autism has high morbidity and cost for the individual, their family and wider society. A recent health economic analysis estimated the cost of services for people with autism in the UK to be €30 billion per annum (£27.5 billion; Knapp et al., 2009) which translates to €400 billion per annum for European countries, were service costs to be equivalent. The public health and societal consequences of early identification and treatment of autism are a priority for Europe. Current health care systems across Europe are very variable in terms of their expertise and capacity to support families with young children with autism, often leading to marginalisation. Scientifically, there is an increasing international focus on studying the emergence of autism in infancy and toddlerhood (Yirmiya & Charman, in press) and in many areas European scientists are leading figures in the field. Several interlinked approaches are being deployed in a number of European countries. These include the study of genetically 'at risk' younger siblings of an older child with a diagnosis; application of novel neuroimaging techniques to infants and toddlers; testing how well screening instruments work in prospectively identifying cases; and designing and evaluating early intervention programmes. Reflecting the fact that autism is a complex neurodevelopmental disorder, different branches of science across a wide range of disciplines are required to understand and treat autism, spanning across both basic (e.g. genetics, cognitive neuroscience) and clinical sciences (e.g. epidemiology, surveillance, randomised controlled trials). There are many European scientists studying autism. However, until recently different disciplines have not interacted sufficiently to maximise the rate of scientific progress that will result in societal benefits. Most research studies have been conducted within single European countries. Currently there is a critical mass of clinical and basic scientists funded by their own government agencies engaged in similar studies on all of the above topics across Europe. To date, there has not been a mechanism for exchange of information and collaboration across these sites, making the establishment of the COST Action Enhancing the Scientific Study of Early Autism (ESSEA) timely, with a high likelihood of significant advances and potential to build future capacity.

B.2 Current state of knowledge

Whereas 10 years ago autism was seen as a rare disorder and was commonly not diagnosed before the age of 5 years and often considerably later; now it is recognised to affect around 1 in a 100 individuals and diagnosis from age 2 years, or even earlier, is possible in some cases.
Several basic and applied scientific lines of investigation have contributed to this progress in understanding and practice. In each of these areas European scientists have been at the forefront of international developments.

(i) The study of genetically 'at risk' younger siblings of an older child with a diagnosis.
Over the past decade a number of groups in Europe, Israel and North America have begun to exploit the relatively high recurrence rate of autism in families (Rogers, 2009; Yirmiya & Charman, in press; Zwaigenbaum et al., 2009). Between 5% and 10% of children subsequently born to an older child with a diagnosis of autism will develop the disorder and more recent studies suggest even higher rates. This allows the prospective study of infants at genetically 'at risk' of developing autism to be studied from the first few months of life. These studies have found a number of differences, mostly in early social communication behaviours and mostly emerging around the younger siblings' first birthday.
The ESSEA COST Action will allow European laboratories conducting these 'at risk' studies to collaborate and share measures. Such coordination and collaboration is essential since the design is predicated on perhaps 10% of the younger siblings developing autism. Thus, even with large numbers of families participating in any one centre, the power to detect early predictors of later autism will require collaborative efforts. The important study of at-risk infant siblings necessarily requires large sample sizes that can only be provided within the context of the Europe-wide collaboration.

(ii) The application of novel methods for studying young children and infants.
Building on the work of ongoing studies of 'at risk' siblings (subsection (i) above) and experimental work conducted with toddlers (two and three year olds) with autism identified via screening studies (subsection (iii) below), a number of European groups have been conducting neuroimaging studies

with both groups. Several groups are using electrophysiological measures (evoked response potentials (ERP); electroencephalographs (EEG)) and others are beginning to use structural magnetic resonance imaging (MRI) and new technologies such as Near Infra Red Spectroscopy (NIRS). In work with 'at risk' siblings emerging findings have suggested that there may be atypical neural processing (as evidenced by abnormal ERP responses) of both social and non-social stimuli (Elsabbagh et al, 2009; McCleery et al, 2007, 2009). Structural MRI (Zeegers et al., 2009) and EEG (Orekhova et al., 2008) studies have recently been conducted with toddlers and preschool children with autism and suggest that there may be a brain basis for some of the little understood sensory and motor symptoms that are commonly seen in autism. However, the majority of research on infant perception and cognition in Europe is dissociated from the study of clinical conditions such as autism.

The ESSEA COST Action will enable scientists engaged in this cutting edge work to collaborate and further develop these new technologies. Europe has many leading infant experimental scientists who are currently not engaged in autism research and the Action will enable them to forge collaborations with autism researchers for the first time.

(iii) Testing how well screening instruments work in prospectively identifying autism.

The first ever prospective screening study of autism was undertaken just over 10 years ago in the UK (Baird et al., 2000; Baron-Cohen et al., 1996). The Checklist for Autism in Toddlers (CHAT) study found that it was possible to prospectively identify cases from the general population using a screen at 18 months of age. Since this time several other European scientists have developed novel screening instruments and tested their ability to identify cases at 14 months of age (Dietz et al., 2006; Oosterling et al., 2009). Other groups in several European countries are engaged in studies testing the efficiency of screens to identify cases in nursery and preschool (Belgium, Israel) and clinical services (Italy, UK); as well in large population studies (Italy, Norway, The Netherlands). The ESSEA COST Action will allow clinical scientists to compare and pool datasets to identify whether screens work differently in different communities. Exchange of information on screening studies and the emerging population estimates for the prevalence of autism that such studies also produce might identify real differences in prevalence or presentation that would raise fundamental questions regarding the epidemiology and clinical course of the disorder; for example whether girls are under-identified by clinical services at a young age but are identified at a higher rate by the application of systematic screening instruments. The COST Action will lead to the production of

harmonised clinical guidelines on early identification of autism. This will be of especial import to Eastern European countries where service development and organisation is undergoing a rapid pace of change.

(iv) Testing early intervention approaches through rigorous controlled trials.

In many European countries the growing number of young, diagnosed children exceeds the capacity of available services. This increase in service utilisation challenges both researchers and service providers to develop effective dissemination strategies for intervention approaches for which there is sound empirical evidence. The research evidence-base supports the use of behavioural, developmental and social-communication approaches for preschool children with autism (Howlin et al., 2009; Rogers & Vismara, 2008). In recent years a number of leading European clinical scientists (Belgium, The Netherlands, UK) in the autism field have been undertaking 'first phase' controlled (randomised) intervention trials that focus on promoting and enhancing social communication and language skills. These have used a variety of social-communication and behavioural strategies, including the promotion of joint attention, imitation and social engagement skills. These pilot studies have shown that intervention, both directly delivered by therapists and parents trained in these methods, can improve language, developmental and social outcomes.

The ESSEA COST Action will enable clinical scientists to identify common and unique aspects of intervention approaches that have delivered a promising evidence-base. This will lead in future FP7 applications to comparable trials of the same intervention programmes to be conducted across different European countries. This will help inform the clinical evidence base about 'what works for toddlers and preschool children with autism'. This evidence can be widely disseminated across European countries; especially in countries where early autism clinical services are only just emerging.

Such screening and intervention approaches (subsections (iii) and (iv)) will also benefit in the long run from links to basic science conducted with infant siblings (subsections (i) and (ii)). As potential improvements in laboratory methods begin to provide reliable sources of information for clinical purposes, those can become integrated into clinical programmes. For example, the UK is currently testing whether early and subtle differences at the level of brain functioning, as measured in the laboratory, may be modified by changing early environmental characteristics, through parent-

mediated intervention programmes. Such developmentally based approaches are likely to inform not only the efficacy of the intervention, but also explain why and how the intervention has led to improvements or otherwise.

B.3 Reasons for the Action

The ESSEA COST Action will significantly enhance scientific capacity in Europe to study autism. The interdisciplinary nature of the Action is particularly important in that it brings together basic and clinical scientists from a wide number of disciplines. Whilst great progress has been made in our understanding of autism over the past decade, many fundamental questions remain unanswered, including for most individual cases the aetiology and the most effective interventions. Answers to these questions are required to improve outcomes for individuals and their families and to reduce societal cost and inequality across Europe. The Action will build on and enhance a number of existing bilateral cross-country collaborations and ensure that the European science field on early autism continues to be at the forefront internationally. The inclusion of clinical scientists, who in each of their own countries contribute strongly to policy and clinical practice recommendations, means that co-ordinated European-wide policy and practice recommendations will emerge.
The ESSEA COST Action will enhance European scientific capacity, knowledge-transfer and impact. The Action will deliver clinical practice guidelines setting clear European standards for services in early identification, screening, diagnosis and early intervention. The latter is of critical importance because current knowledge, capacity and provision is very variable and only just becoming established in more recent EU member states and non-EU COST countries.

B.4 Complementarity with other research programmes

The ESSEA COST Action with its focus on scientific and clinical discoveries about early autism complements well existing and recent European research and policy initiatives.
An FP7 funded project *PSYCH-CNVs Copy number variations conferring risk of psychiatric disorders in children* is investigating recently discovered ‘copy number variations’ (genetic mutations) in a number of psychiatric disorders, including autism (plus schizophrenia and bipolar disorder). Several of the investigators from PSYCH-CNVs will be involved in the ESSEA COST

Action. Discoveries from the PSYCH-CNVs study relevant to autism could be applied to the family genetic 'at risk' study of siblings for which the combined sample size of several European sibling studies would be required.

A European Association for Communication in Health Care (EAHC) project 2006-2009 has been *European Network of Surveillance on risk factors for Autism and Cerebral Palsy (ENSCAP)*funded to identify pre- and peri-natal risk factors and biomarkers for autism and cerebral palsy by pooling existing population medical databases.

An FP6 molecular genetic study (*MOLGEN Using European and international populations to identify autism susceptibility loci* 2005-2008) was recently completed. Several of the clinical scientists involved in the ESSEA COST Action were collaborators on the MOLGEN project and the present COST Action will benefit from this previous collaboration.

A DG-SANCO (European Public Health Alliance) policy initiative was published in 2008. The *European Autism Information System (EAIS)* reported on variation in measured prevalence and in early surveillance mechanisms across the Europe. The ESSEA COST Action will provide the novel and innovative basic scientific discoveries (for example, on the most reliable early signs of autism; the efficiency of different early screening tools; the effectiveness of different interventions) on which decisions regarding how to take the EAIS report forward in terms of public health policy across Europe can be made. Several of the participants in the Action were collaborators on the EAIS project.

The ESSEA COST Action uniquely involves a large multidisciplinary network of basic and clinical scientists with expertise in infancy and early autism that will provide answers to basic developmental questions about autism onset, identification and treatment. The Action will enhance synergy between basic and clinical science to inform public health policy and practice in Europe over the coming decade.

C. OBJECTIVES AND BENEFITS

C.1 Main/primary objectives

The main objective of the Action is to establish an interdisciplinary scientific network to advance the pace of discovery about the earliest signs of autism; to combine techniques from cognitive neuroscience with those from the clinical sciences; and to establish European practice guidelines on early identification and intervention.

C.2 Secondary objectives

The ESSEA COST Action will enable scientists engaged in basic science and clinical autism research to exchange information and develop interdisciplinary collaborations across Europe. It will co-ordinate and defragment the innovative work being conducted in Europe and bridge the multi-disciplinary basic and clinical science relevant to the understanding of early autism, thus significantly accelerating the pace of new scientific discovery. The network will have an international impact as the COST Action will create the largest collaborating group of scientists studying early autism internationally, including the USA. Furthermore, several European groups have ongoing collaborations with USA and Canadian groups studying early autism and the ESSEA COST Action will enable productive exchange of information with North American networks such as the Baby Siblings Research Consortium and the Autism Treatment Network.

The secondary objectives of the Action, in furthering the main aim, will be:

(i) Methods and measures sharing across European sites. In a number of areas critical to the scientific study of early autism a large number of European groups are using similar (or 'almost comparable') measures in comparable samples. Examples include: behavioural and electrophysiological experimental studies of 'at risk' younger siblings examining their cognitive and brain responses to social and non-social stimuli; and screening questionnaires completed by parents and kindergarten staff to identify cases of autism. The Action will enable scientists to develop common (or 'exactly comparable') measures across sites. This will allow comparison of

findings across different laboratories and eventually the possibility of pooling data from different studies that will increase the power, for example in ‘at risk’ sibling and intervention studies that require sample sizes of hundreds of participating families.

(ii) Understanding discrepancies between the utility of clinical screening instruments and emerging prevalence statistics in different countries. By enabling scientists to exchange information from ongoing studies the Action will help identify which screening instruments work more, or less, efficiently. However, exchange of information on screening studies and the emerging population estimates for the prevalence of autism that such studies also produce might identify real differences in prevalence or presentation that would raise fundamental questions regarding the epidemiology and clinical course of the disorder. For example, whether girls are under-identified by clinical services at a young age but are identified at a higher rate by the application of systematic screening instruments. The translation and validation of screening and diagnostic instruments in a wide number of European languages will help harmonise research and clinical practice across Europe. The timing of the Action means that these outcomes will have a particular impact on Eastern European countries where service provision and organisation is undergoing rapid development.

(iii) There are a number of novel features the Action that mark it out as particularly innovative. It brings together for the first time internationally leading infant experimental scientists who are currently not engaged in autism research to enable them to forge collaborations with autism researchers. The important study of at-risk infant siblings necessarily requires large sample sizes that can only be provided within the context of the Europe-wide collaboration. Finally, the need to test the efficiency of screening instruments and the effectiveness of interventions is enhanced by pooling and comparison of datasets; both to identify more or less efficient approaches but also to utilise discrepancies between the findings of studies conducted in different European countries.

(iv) The ESSEA COST Action will lead to the publication of evidence-based European-wide clinical practice guidelines for the early identification and diagnosis of autism and for evidence-based approaches to early intervention. The Action and Work Group activities will help build an

evidence-based practice consensus view, based on novel data analysis that will take place as part of the Action, which will inform European and national government policy initiatives to determine that future direction of publicly funded healthcare and education services in the autism field.

C.3 How will the objectives be achieved?

Aside from the biannual Management Committee (MC) and Working Group (WGs 1 to 4) meetings, the Action will be achieved by appropriate Short Term Scientific Missions (STSMs), principally involving exchanges of Early Stage Researchers (ESRs); an Action Think Tank of ESRs which will report to the MC and 4 WGs; two summer schools for ESRs; co-supervision of doctoral (PhD) students; and in Year 4 a European conference on 'early autism'. To ensure that the primary and secondary objectives of the ESSEA COST Action remain related to the priorities that individuals with autism, their families and autism advocates identify; the MC and WGs will consult with lay national autism organisations in participating countries as well as European organisations such as Autism Europe.

C.4 Benefits of the Action

The ESSEA COST Action will enhance European scientific capacity in the study of early autism. It will bring together for the first time world leading scientists who study typically developing infants and toddlers with clinical scientists with expertise in early autism. The participants in the Action will be the leading and largest group of scientists internationally collaborating in the study of early autism and they will be drawn from a wide number of different disciplines and European countries. The Action will help defragment European research on early autism and advance the pace of scientific discovery and the translation of these findings into meaningful and implementable clinical advances. A likely outcome will be future FP7 applications for a large-scale European-wide project to combine behavioural, clinical, neuroscientific and genetic approaches to the study of early autism and for cross-national early intervention trials.

Furthermore, it will lead to knowledge-transfer so that in future the basic science findings will inform and be integrated with clinical practice developments. At the end of the Action there will be new European practice guidelines for services in terms of early identification, screening, diagnosis and early intervention. These practice guidelines are of critical importance because current knowledge, capacity and provision is very variable and only just becoming established in more recent EU member states and non-EU COST countries.

The integration of basic and clinical science approaches exemplified by the Action is critical to ensure that cutting-edge knowledge, methods and an empirical evidence base about what works (in terms of efficient screening and identification, as well as effective interventions) are the basis on which harmonised practice guidelines are developed. To date, there has been insufficient exchange of information across European countries to underpin such much-needed developments and the COST Action will allow this to happen for the first time. The Action will ensure that any future activities of the DG-SANCO sponsored EAIS initiative will be informed by a sound, empirical evidence-base (see Section B.4) and state-of-the-art methods. The ESSEA COST Action represents a cost-effective mechanism to provide significant uplift to European science in this much-needed medical field.

C.5 Target groups/end users

The outcomes of the Action will benefit children with autism, their families, carers, health professionals and educators. The childhood prevalence of ~1% and the fact that autism is a lifelong condition for which there is no 'cure' means that approximately 8 million individuals in Europe are affected by autism.

Children with autism and their families will benefit from early identification followed by early intervention. Although there are examples of good practice in isolated pockets of Europe, practice and available services are very variable and in some areas poor and insufficient. The results of the Action will enable those services that emerge over the coming decade to be based on the most scientific and proven evidence-base. Early intervention has the potential to ameliorate the severity of the course of autism, perhaps even preventing debilitating 'secondary handicaps' and social exclusions that can develop when untreated. This will have significant positive impact on costs and

burden to European societies, promoting wellbeing and quality of life for individuals with autism and their family members, as well as decreasing inequality in societies.

Healthcare professionals and educators will benefit in terms of an improved knowledge-base about how autism emerges in infancy and how it can be treated that in future will underpin practitioner training and education about the early signs of autism; how instruments such as screening tools can aid in early detection; and an improved evidence-base for interventions.

National and European policy makers who commission and direct healthcare and education policy will benefit from an improved European evidence-base about efficient and effective autism services for young children. If efficacious interventions were able to reduce service costs by 10% across the lifespan the saving to Europe would be €40 billion per annum (Knapp et al., 2009).

The scientific community will benefit from the Action by enabling the largest international interdisciplinary network of scientists studying early autism to be gathered together. The Workshops, STSMs, ESR exchanges and co-supervision of doctoral students will speed information exchange and methodological progress across a large number of basic and clinical science laboratories and build future capacity.

The lay autism community, advocacy groups and the general public will benefit by a European wide increase in knowledge and understanding of this complex neurodevelopmental condition.

D. SCIENTIFIC PROGRAMME

D.1 Scientific focus

The ESSEA COST Action will bring together participating scientists to identify where (i) collaboration; (ii) the use of common measures, (iii) adoption of scientific techniques and methods from other countries; and (iv) data pooling and novel analytic techniques will add scientific value to the study of early autism in Europe. It is envisaged that over the first two years of the Action several novel techniques and applications of different methods and statistical analyses, relevant to the study of early autism, will emerge that can be deployed in the later years of the Action. The focus on 'early autism' recognises that autism is a developmental disorder whose course and outcome can be changed by early identification and intervention (often called 'prevention') to the benefit of individuals, their families and European society.

In Year 1 of the Action, the primary task will be the exchange of scientific information about current and planned studies. This will be co-ordinated by the MC but the focus of each of the 4 WGs will be to provide a comprehensive picture of current and planned activities across Europe within their domain of activity. In Years 2 to 4 of the Action, the WGs will exploit the potential to use the above four methods in the 4 WG areas of activity; namely (a) WG1: The study of genetically 'high risk' younger siblings; (b) WG2: The application of novel methods for studying young children and infants; (c) WG3: Testing how well screening instruments work in prospectively identifying cases; and (d) WG4: Testing early intervention approaches through rigorous controlled trials.

The key scientific questions that the Action will help answer are:

WG1: What are the earliest behavioural signs of autism? Are the first abnormalities seen in the social (e.g. face processing) or in the non-social (e.g. attentional mechanisms) cognitive domains?

WG2: Do brain/neural responses indicate abnormality in processing social and non-social stimuli before or after early emerging behavioural signs? What does this tell us about neurodevelopmental models of the emerging autistic deficit?

WG3: Can clinical screening instruments help prospectively identify cases of autism? What is the optimal age to conduct autism screening? Which of the available instruments (or combinations of items from different instruments) works best to identify cases? How well do screening instruments translate to different languages and communities?

WG4: What elements of early intervention programmes are effective in promoting positive social and communication outcomes for preschool children with autism? What are the most appropriate outcome measures in early intervention trials and how reliable are they?

The overarching focus of the Action will be to utilise and develop expertise and capacity amongst the community of European scientists engaged in research on early autism. The Action will bring together for the first time experts in studying infant cognition and behaviour in with experts in the early clinical manifestations of autism. This will provide world-leading research into the earliest clinical signs of autism and how these can be detected using novel experimental methods and existing and new clinical instruments. The Action will focus on interdisciplinary approaches, where possible combining data from behavioural and developmental cognitive neuroscience approaches.

The Action will also prioritise the clinical application of new discoveries; so that findings can be translated in the short-to-medium term into clinical practice guidance. The ultimate aim of the scientific programme will be identify new methods for the early detection and treatment of young children with autism in order to improve outcomes for (and reduce costs to) individuals, their families and European society. The Action will enable a European network of scientists to develop innovative collaborations leading to the identification of early and reliable signs of autism by the age of 2 years and testing the effects of interventions from this young age.

D.2 Scientific work plan methods and means

The work plan and goals of each of the 4 WGs will be described first; and then specific activities to enhance the synergy of the work and outcomes across the 4 WGs will be described.

(a) WG1: The study of genetically 'at risk' younger siblings of an older child with a diagnosis.
Europe has a number of outstanding basic science labs studying cognition and behaviour in infants (see below). Recently, some of these labs have begun to link to autism groups in the study of 'at risk' younger siblings of a child with a diagnosis, reflecting the elevated recurrence rate in families. These have two primary aims: First, to identify the earliest detectable signs in those siblings who go on to have autism (tentatively diagnosable at 3 years of age). Second, to use the genetic design to study features of the 'broader autism phenotype' (BAP). The BAP might indicate endophenotypic characteristics that, whilst not predictive of an autism outcome, are scientifically informative in relation to studying the emergence, and potentially the causes, of autism (see Elsabbagh & Johnson, 2007; Rogers, 2009; Yirmiya & Charman, in press; Zwaigenbaum et al., 2009).
While the study of infant siblings has traditionally focused on the subgroup of babies who end up with a diagnosis in the third year, recent models (Elsabbagh & Johnson, in press) have highlighted that studying the BAP group (including those siblings who do not go on to develop autism) may prove an effective model for understanding early gene-environment interactions leading to variable developmental pathways. Current scientific work is hence focused on understanding how early and subtle manifestations of risk across multiple developing brain systems become compounded leading to autism in some toddlers or canalised leading to subclinical expression in others. The idea is that understanding such dynamic processes early on will provide valuable implications for early

detection and intervention programs aimed at minimising the impact of severe symptoms and may even have broader implications for other childhood developmental conditions.
The ESSEA COST Action will allow a number of European laboratories conducting these 'at risk' studies to collaborate and share measures. Such collaboration is essential since the design is predicated on perhaps 10% of the younger siblings developing autism so that even with large numbers of families participating in any one centre the power to detect early predictors of later autism will require European-wide collaborative efforts. Current European sibling studies have a number of features that make collaboration through the Action desirable. Several groups internationally have expertise in behavioural experimental studies with infants as young as 6 to 12 months of age but a number of specialised European laboratories are recruiting mothers during pregnancy and seeing children in the first few months of life (UK) and even soon after birth in the neonatal period (Italy). Some laboratories are experts in infant experimentation and/or early autism but a number of groups are also studying dyadic or interactional developmental processes (for example siblings at risk and their mother interacting together). As yet we know neither what the earliest signs of autism will be nor at what age they will be detectable. The Action will allow translation of these novel methodological features into other European laboratories.
Summary: The important study of high-risk infant siblings necessarily requires large sample sizes that can only be provided within the context of the Europe-wide collaboration.

(b) WG2: The application of novel methods for studying young children and infants.
It is essential for the scientific study of early autism that expertise in advanced methods for studying infant perception, cognition, and brain function are further developed and broadened. Many studies are combing behavioural experimental studies of infants 'at risk' from 6 months of age (and increasingly even earlier) and studies with toddlers (two and three year olds) identified via early screening studies with a variety of brain imaging techniques. These methods include automatic eye tracking, electrophysiological measures (event related potentials (ERP) and electroencephalographs (EEG), functional and structural magnetic resonance imaging (MRI), and Near Infra Red Spectroscopy (NIRS). This work group will discuss the most recent advances in these methods, exchange information, and spread expertise between different labs. Specifically, particular protocols will be developed that can be run a multiple sites and the data pooled at a later date. Plans will be developed to ensure compatibility of data across different sites, and for a central repository of data

storage allied with common analyses. Finally, the Action will advance new analysis methods to relate data across different methods (e.g. eye-tracking, NIRS and functional MRI). Combining these methods in the context of studies of infants at-risk will be an international first. Although multiple international laboratories (primarily in North America) are conducting sibling programmes, Europe (Italy, Sweden, UK) has emerged as having a clear strength in neuroscience and laboratory methods with this population.

Emerging findings suggest that detecting autism early on may require multiple brain and behavioural measures combined within each infant. Collaborative efforts to improve data acquisition and analytic techniques will be essential for the success of this approach. This ambitious perspective will rely heavily on the integration of multiple scientific and technical expertise, to enable the development of sensitive and reliable infancy laboratory measures to quantify risk and outcome in infant siblings. For example, two laboratory techniques, eye tracking and EEG, have been used extensively across different centers with complementary expertise. Pooling such expertise to enable substantive improvements in data acquisition and analytic techniques is likely to lead to rapid developments and discoveries in this emerging field.

Summary: Europe currently has strength in the science of infancy, but this is currently dissociated from the study of autism which has held back the rate of discoveries.

(c) WG3: Testing how well screening instruments work in prospectively identifying cases.

The only three general population screening studies for autism internationally have been conducted in Europe (The Netherlands, Norway, UK). A number of other population screening studies are underway (Belgium, France, Italy, Portugal, Spain). The methods of these studies in part overlap and in part differ, in terms of the specific instruments used, the age the screening takes place, the respondent who completes the screen (parent, healthcare professional, educator) and the length of the follow-up outcome assessments. These differences (and the similarities) will be useful for identifying the key scientific and clinical questions to take into the next phase of development of screening instruments for autism. The public healthcare systems in many European countries are ideally placed to conduct such studies and mean that the results will likely be generalisable across European countries.

The ESSEA Action will enable clinical scientists to do comparative analysis of how the same screen worked when used in different languages in different countries. Differences will inform us

about language and cultural factors that need to be taken into account when translating such instruments. Specialised statistical analysis will be possible on pooled datasets drawn from a number of studies conducted in different countries; for example Item Response Theory techniques to test which clusters of items are most efficient in identifying cases (and not identifying non-cases). Finally, screening studies act as a cumulative estimate over time of prevalence. That is, the screen initially identifies some cases early, whilst others will come to light later on as having been 'missed' (screen false negatives) by the screen. Examination of patterns of early and later detected cases will allow for the first cross-European country prevalence estimates where the method of sampling is invariant. Aside from the issues to do with language and translation highlighted above, this presents the potential to identify and subsequently to investigate any variability in prevalence across countries that is not possible by comparison of rates from existing prevalence studies where sampling methods differ from study-to-study. Collaborative studies and data pooling might identify real differences in prevalence or presentation that would raise fundamental questions regarding the epidemiology and clinical course of the disorder. For example, whether girls are under-identified by clinical services at a young age but are identified at a higher rate by the application of systematic screening instruments. Current prevalence estimates suggest that autism is 4 or more times more commonly identified in boys than in girls but it is unknown whether this gender discrepancy is lower in prospectively identified cases picked up in screening studies. European-wide collaboration is required to have sufficient numbers of identified female cases to test this hypothesis. The members of WG3 will draft the clinical guidelines on early identification, screening and diagnosis of autism.

Summary: European scientists have conducted the first and most rigorous studies of early screening and identification internationally. Establishing common measures and pooling datasets will test with more power than previously which items and which screening instruments are most efficient.

(d) WG4: Testing early intervention approaches through rigorous controlled trials.

In recent years a number of leading European clinical scientists (Belgium, The Netherlands, UK) in the autism field have been undertaking 'first phase' controlled (randomised) intervention trials focused on promoting and enhancing social communication and language skills. These have used a variety of social-communication and behavioural strategies, including the promotion of joint

attention, imitation and social engagement skills both directly delivered by therapists and parents also trained in these methods. These pilot studies have found that language, developmental and social outcomes can be improved. One difficulty in the field of early intervention in autism is that different intervention approaches, whilst often sharing some features in common, contain a different mix of techniques, procedures, theoretical underpinning and even philosophy. This has led to decades of stagnation and held back progress in developing appropriate local community delivered intervention services post-diagnosis in many European countries.

The ESSEA Action will enable clinical scientists who have been involved in intervention studies to utilise the archives of (videotaped) material of treatment sessions and outcomes to identify common and unique aspects of intervention approaches that have delivered a promising evidence-base. Another limitation in the field internationally has been the lack of common outcome measures in early autism intervention studies. The European groups who have conducted pilot and large-scale trials have used some common (or overlapping) outcome measures. WG4 will co-ordinate the combining of datasets from completed and ongoing intervention trials to look at change on common measures to identify consistent and inconsistent changes across different intervention programmes, as well as to determine the most reliable measures of outcome. This will lead in future to comparable trials (that would be suitable for funding under the FP7 Framework) of the same intervention programmes to be conducted across different European countries; specifically testing the 'transportability' of intervention programmes within different health care systems. The ESSEA WG4 would be the first group of international scientists to collaborate on autism intervention studies. The members of WG4 will draft the clinical guidelines on approaches to early intervention in autism.

Summary: Identification of common effective elements of intervention programmes and common outcome measures will significantly enhance methodology in autism treatment field.

Interplay between the goals and outcomes of the 4 WGs:

New scientific findings that emerge from the activities of WG1 studying 'at risk' siblings (e.g. early endophenotypic (cognitive) features of autism detectable in infancy) and WG2 looking at novel methods for measuring the early autism phenotype (e.g. individual level brain and behavioural responses, or combinations thereof) will, as the Action progresses, translate into novel objectives for WG3 and WG4 studying efficient screening items and effective interventions. Internationally,

basic science and clinical science in the autism field have been removed from one another. It is the cross-disciplinary nature of the scientists involved in the Action that will enable it to realise its potential to lead to novel, clinically-relevant scientific discoveries.

Throughout the Action the activities of the 4 WGs, under the direction of the MC, will include initiating appropriate STSMs via supporting ESR exchanges to other laboratories and each will receive input from the Action Think Tank of ESRs. These STMs have two main aims. First, to promote exchange of techniques from laboratories in different countries that have complementary strengths and expertise. Second, to train the next generation of ESRs in the interdisciplinary scientific methods necessary for the study of early autism. Although STSMs will be commissioned by the WGs (with approval by the MC), and thus will be responsive to demand and needs identified as the COST Action progresses, potential topics include: pooling and analysis of data on developmental regression in the 'at risk' sibling studies (WG1); novel analysis of multiple methods (eye tracking and EEG) of neuroimaging paradigms with infants (WG2); item-level analysis of screening instruments to develop shorter most efficient screens (WG3); and cross-validation of outcome measures to be used in early intervention studies (WG4). Due to the synergy between the activities of WG1 and WG2, and WG3 and WG4, respectively, it is anticipated that the groups might hold joint or overlapping WG meetings in Years 2 and 3 of the Action. In Years 3 and 4 of the Action a particular focus will be on translation of the basic science findings that emerge from WG1 and WG2 into the collaborative activities of the more applied activities of WG3 and WG4. If desirable, a joint WG meeting to ensure the success of such translational activity will take place, as decided by the MC. Another mechanism to enhance interplay between the scientific activities and mission of the 4 WGs will be the establishment of (nationally funded) jointly supervised PhD studentships within- and between-participating countries in Years 2, 3 and 4 of the ESSEA COST Action.

E. ORGANISATION

E.1 Coordination and organisation

The activities within the Action will be co-ordinated by the Management Committee (MC). The MC will elect 4 Working Groups (WGs; detailed in Section E.2) and approve the Leader and Co-Leader of each. Each participating country will have up to two representatives on the MC. Wherever possible, gender representation and representation from Western and Eastern European

countries will be balanced on the MC; and gender representation, representation from Western and Eastern European countries, and Early Stage Researchers (ESR) status on the WGs. An ESR representative (rotating on an annual basis) will be elected to serve on the MC. All members of the MC will be investigators with nationally funded research on early autism. The MC and each WG will meet twice each year of the Action.

A Core Group (CG) will consist of the Chair and Vice-Chair of the MC and the Leader of the 4 WGs. The CG will meet for one day preceding the two biannual (one day-and-a-half) meetings of the MG. Each of the 4 WGs will have two biannual (two days-and-a-half) meeting.

The CG and ultimately the Chair will have responsibility for ensuring that the Action is on timetable and that specified objectives are met. The Chair of the MC will be responsible for liaison with and reporting to their COST National Co-ordinator (CNC) and with the Action Scientific Secretary (ASS).

Where appropriate, and within the COST funding rules, the MC and WGs will consider inviting guest lecturers/advisors to a meeting of the MC, WGs, Summer Schools or Year 4 ESSEA Early Autism Conference. These guests will be invited on the basis of expertise that complements and extends that of Action members.

The CG and the MC will be jointly responsible for the management and the organisation of the key elements of the Action necessary to ensure its success. These elements include: the organisation and co-ordination of STSMs and ESR exchange visits; the two Summer Schools for ESRs in Years 2 and 3; the ESR Action Think Tank to ensure that ESR input into the WGs, the MC and the organisation of the Summer Schools is tangible; the 'ESSEA Early Autism Conference' in Year 4; establishment and maintenance of the Action website; other dissemination activities (outlined in Section H); and organisation and co-ordination of the co-supervision of doctoral (PhD) students.

The Summer Schools (Years 2 and 3) and Conference (Year 4) will provide distinctive milestones and a timetable against which progress towards achievement of the primary and secondary aims of the Action can be monitored. Summer Schools (Years 2 and 3) will be 3 to 5 day meetings primarily aimed at training the next generation of leading figures in the study of early autism field (ESRs). Senior researchers will also contribute but the Schools will be planned in conjunction with ESRs via discussion with the ESR Action Think Tank. The latter will be primarily an e-forum accessed via the ESSEA Action website; although if it is desirable a face-to-face meeting of one ESR from each participating country will be arranged, approved by the MC.

Short Term Scientific Missions (STSMs) are an important vehicle for collaboration and exchange of knowledge, technical expertise and data pooling or joint analysis. These will be undertaken on an as-and-when basis when immediate, short-term questions arise and will be implemented by short-term visits by ESRs to laboratories in a different country (from 1 to 3 months). These will be suggested by the appropriate WG and will report on their activities and achievement to the MC via their WG. Usually STSMs will result in a dedicated academic publication arising from the collaboration.

Internally and externally facing information regarding the Action activities will be via the dedicated ESSEA website. This will have functionality for members of each of the levels of organisation to e-communicate (MC members, WG members, CG members, ESRs) with each other in an efficient manner. In the first 6 months of Year 1 of the Action the ESSEA dedicated website will be established which will contain information about scientific activities conducted by the Action. This will have dedicated access to partners and allow ESRs and partners to access (anonymised) shared datasets for ongoing analysis and generation of new questions that address the scientific focus; to be fed back to and approved by the appropriate WG and the MC. The ESSEA dedicated website will be a 'live' working instrument that is regularly updated in terms of both function and content throughout the lifetime of the Action.

Planning for the 'Early Autism' European Conference scheduled to take place in Year 4 will begin in Year 3; supported, if appropriate and agreed by the MC, by a separate Conference Executive Committee.

A bi-monthly e-newsletter will update all participants on the progress towards the Action aims and remind them of next steps. The ESSEA website will also have dedicated pages for national autism advocacy and parent organisations (under the umbrella of Autism Europe) to learn about progress of the Action (see Section H Dissemination); in the native language of each participating country. The 'ESSEA Early Autism Conference' in Year 4 will be organised in consultation with these groups.

E.2 Working Groups

There will be 4 Working Groups:
WG1: The study of genetically 'at risk' younger siblings of an older child with a diagnosis.
WG2: The application of novel methods for studying young children and infants.
WG3: Testing how well screening instruments work in prospectively identifying cases.
WG4: Testing early intervention approaches through rigorous controlled trials.
Each WG will be responsible for co-ordination and delivery of the activities within their sphere that contribute to achievement of the Action primary and secondary aims. The Leader of each WG will be a member of the CG and will be responsible for reporting on progress towards achieving milestone to the MC on an annual basis. Each WG will have a Co-Leader to ensure continuity of activity when the Leader is indisposed and for support and advice. The MC and each WG will meet twice a year. Where the need arises, and with approval of the MC, additional virtual MC and WGs discussions will be held via videoconferencing or Skype. The CG will have two face-to-face meetings each year, immediately preceding the MC meetings.

E.3 Liaison and interaction with other research programmes

The main ongoing and recent research and policy programmes with which the Action will interact are the FP7 funded PSYCH-CNVs, EAHC ENSCAP and the DG-SANCO (European Public Health Alliance) funded EAIS. Interaction will naturally occur through the joint participation of investigators in the ESSEA Action who are involved in PSYCH-CNVs, ENSCAP and EAIS. However, a formal level of interaction will also be guaranteed by ensuring that at least one member of the MC is participating in these other European funded programmes and by having a standing item on liaison on the MC meeting agenda. Where appropriate participants from these will be invited to contribute to WG meetings, SSs and the Year 4 ESSEA Early Autism Conference.
As set out in Section B.4, the scientific focus and activities of the Action are very different to that of PSYCH-CNVs and ENSCAP but there might be opportunity for collaboration and joint-working with WG1; depending on the pace and nature of discoveries in the field. EAIS is not a scientific activity but a policy initiative. There will be synergy with the activities of WG3 and WG4 with

outcomes from the Action providing a scientific evidence-base for European clinical practice guidelines on early identification and intervention that will underpin future European policy, depending on future DG-SANCO initiatives.

E.4 Gender balance and involvement of early-stage researchers

This COST Action will respect an appropriate gender balance in all its activities and the Management Committee will place this as a standard item on all its MC agendas. The Action will also be committed to considerably involving early-stage researchers. This item will also be placed as a standard item on all MC agendas.

Wherever possible, gender representation and representation from Western and Eastern European countries will be balanced on the MC; and gender representation, representation from Western and Eastern European countries, and Early Stage Researcher (ESR) status on the WGs. Summer Schools and STSMs will be planned in conjunction with ESRs via discussion with the ESR Action Think Tank. Gender balance for participation in Summer Schools and STSMs exchange visits will be monitored by the MC. Another area where consideration of gender balance and the contribution (and profile) of ESRs will be monitored is in conference attendance and presentations (see Section H Dissemination) and senior author role on academic publications arising from the Action.

The autism field is generally one in which female participation in science is high compared to some other areas of basic and clinical science; though this varies from discipline to discipline. The ESSEA Action is interdisciplinary and particular attention will be paid to gender balance where representation of females has been less strong (e.g. psychiatry, genetics).

The activities and outputs from WG3 will specifically allow the Action to identify whether girls are under-identified by clinical services (compared to boys) at a young age but are identified at a higher more comparable rate by the application of systematic screening instruments.

F. TIMETABLE

The Action will have a total duration of 4 years. The timetable for the meeting of the Management Committee (MC); Core Group (CG); Working Groups (WGs); Summer Schools (SS) and ESSEA COST Action ‘Early Autism Conference’ is as follows:

YEAR 1

1st and 2nd meetings CG (months 3 and 7 of Action)

1st and 2nd meetings MC (months 1 and 7 of Action)

1st and 2nd meetings WG1 to WG4 (months 3 and 9 of Action)

YEAR 2

3rd and 4th meetings CG (months 13 and 19 of Action)

3rd and 4th meetings MC (months 13 and 19 of Action)

3rd and 4th meetings WG1 to WG4 (months 15 and 21 of Action)

1st SS (month 22 of Action)

YEAR 3

5th and 6th meetings CG (months 25 and 31 of Action)

5th and 6th meetings MC (months 25 and 31 of Action)

5th and 6th meetings WG1 to WG4 (months 27 and 33 of Action)

2nd SS (month 34 of Action)

YEAR 4

7th and 8th meetings CG (months 37 and 43 of Action)

7th and 8th meetings MC (months 37 and 43 of Action)

7th and 8th meetings WG1 to WG4 (months 39 and 45 of Action)

ESSEA Early Autism Conference (month 46 of the Action)

	Year 1		**Year 2**		**Year 3**		**Year 4**	
MC/CG Meetings	1st MC/CG	2nd MG/CG	3rd MC/CG	4th MC/CG	5th MC/CG	6th MC/CG	7th MC/CG	8th MC/CG
WG1 to WG4 Meetings	1st WG	2nd WG	3rd WG	4th WG	5th WG	6th WG	7th WG	8th WG
SS and ESSEA Early Autism Conference				1st SS		2nd SS		ESSEA Early Autism Conference

After the initial (1st) meeting of the MC and the election of the WGs and CG; the MC, CG and 4 WGs will conduct activities throughout the full 4 years of the Action. The first 6 months of WG activities in Year 1 will focus on knowledge exchange about ongoing and future studies. The 2nd

WG meetings will propose an action plan of activities for Year 2 and Year 3 which will be submitted for approval by the MC at the end of Year 1. The Action website will be established within 3 months of the Action commencing and by 6 months will have full functionality in terms of communication between MC, CG, WG and ESR Action Think Tank members; as well as co-ordination with and dissemination to external national parent groups and Autism Europe. An initial roster of STSMs will be proposed by each WG for approval by the MC at the 2nd WG meetings. Each WG will propose additional STSMs at one meeting per year (4th WG meeting; 6th WG meeting). Planning for the 1st SS will begin at the 3rd MC meeting; and planning for the 2nd SS will begin at the 5th MC meeting. Year 4 will concentrate on planning for the ESSEA Early Autism Conference and other dissemination activities.

G. ECONOMIC DIMENSION

The following COST countries have actively participated in the preparation of the Action or otherwise indicated their interest: Bulgaria, Croatia, Czech Republic, Denmark, France, Germany, Island, Ireland, Israel, Italy, Netherland, Norway, Poland, Portugal, Spain, Sweden, Turkey and United Kingdom. On the basis of national estimates, the economic dimension of the activities to be carried out under the Action has been estimated at 72 Million € for the total duration of the Action. This estimate is valid under the assumption that all the countries mentioned above but no other countries will participate in the Action. Any departure from this will change the total cost accordingly.

H. DISSEMINATION PLAN

H.1 Who?

The audiences for dissemination of the Action's outcomes include a wide range of different stakeholders. These include international researchers in the autism field; clinicians and educators who work in services for children with autism and their families; the wider autism community (including parents/carers and people with autism themselves), national organisations that provide

information to the public about autism and advocacy groups; national government policy makers and officials with responsibility for healthcare and education systems; and European level policymakers responsible for health, education, society and finance.

H.2 What?

Due to the wide range of audiences a number of different dissemination mechanisms will be required to effectively disseminate the key outcomes and findings of the Action.

I – Academic audiences

(a) Academic publications. ESSEA participants will prepare papers for submission to international scientific peer-review publications. These will include both state-of-the-art reviews of current knowledge (Year 1) and new findings and analyses that arise from STSMs and ESR exchanges (Years 2 to 4). The WG Leaders and MC members will give advice on publication outlets to ensure that high quality international journals are targeted to maximise the impact of the Action outcomes internationally. Examples include (but are not restricted to): Autism Research, Autism, Journal of Autism and Developmental Disorders; Child Development; Developmental Psychology; Journal of Child Psychology and Psychiatry; Journal of the American Academy of Child & Adolescent Psychiatry; Developmental Science; Biological Psychiatry.

(b) Academic conferences. ESSEA participants, in particular ESRs, will be encouraged to present ongoing and final findings at leading autism, child psychiatric, neuroscience and developmental conferences. Examples include (but are not restricted to): International Meeting for Autism Research; Autism Europe; Society for Research in Child Development; International Society for Infant Studies; European Developmental Psychology Society Conference; Cognitive Neuroscience Society.

(c) ESSEA Early Autism Conference: This conference to be held in Year 4 will be an opportunity the deliver the main scientific and clinical/policy outcomes of the Action. It will combine both scientific presentations of some of the main findings as well as Discussion Fora and Workshops held around (i) new and emerging technologies for studying early autism convened by WG1 and WG 2; and (ii) the clinical practice guidelines on screening and intervention to be written and presented by WG3 and WG4, respectively.

The MC will ensure that the issue of gender balance and the role and profile of ESRs is upheld in conference presentations and authorship/contribution to academic papers; including appropriate naming as senior author on outputs.

II – Clinicians and educators

The products of WG3 and WG4 will in part be targeted at educating practitioners in health and education across Europe. Relevant disciplines include paediatricians, psychiatrists, psychologists, speech and language pathologists, nursery nurseries, community physicians, teachers and special needs co-ordinators. Although the harmonised best practice guidelines on early identification, screening, diagnosis and intervention will only be produced towards the end of the Action interim findings will be summarised via the ESSEA website. Participants will use national organisations in each country to publicise this facility.

III – The wider autism community and general public

(a) The ESSEA COST Action dedicated website will have an internal password protected sector for working documents and sharing datasets amongst its scientific participants. It will also have an 'externally facing' functionality summarising for the broader autism community and the general public the activities and the findings (in easy read format) of the Action as they emerge. These will be available in multi-lingual formats to maximise publicity across Europe. This will be updated at least every 2 months throughout the lifetime of the Action. Interested members of the public will be able to sign up to an e-newsletter that will be sent quarterly summarising the activities of the Action and new findings.

(b) Attendance at national parent/charity meetings and conferences. Many of the Action participants play a healthy and active role in national parent charities and groups that hold meetings for parents, professionals and people with autism. Participants will advertise the establishment of the Action during Year 1 and report on activities, findings and outcomes in Years 2, 3 and 4.

The MC will solicit feedback from parent and advocacy organisations in a number of European countries via participants with local contacts in the first half of Year 1 to ensure that the broader autism community has an input into the Actions aims, activities and dissemination. Many national and European parent advocacy and information agencies have user-friendly websites and links to the ESSEA website information will be posted on these (see www.autismeurope.org and www.nas.org.uk for examples of information websites).

IV – National and European policymakers

Several routes will be taken to ensure appropriate communication of the Action outcomes with national and European policy makers, in particular in the healthcare and education field; as well as in the Science policy and funding arena. The clinical practice guidelines on screening and intervention to be written by WG3 and WG4, respectively, will be launched at national meetings by the appropriate professional bodies (paediatricians; speech therapists; psychologists; psychiatrists). These will naturally feed into the policy guidance that such groups are asked to make by civil servants in many European countries. Where outcomes have European policy implications these will be reported to the appropriate European organisations (EAHC, DG-SANCO; ERC).

H.3 How?

The MC will include Dissemination as a standing agenda item at all of its meetings. From the outset of the Action, the 'branding' of the Action as the ESSEA (Enhancing the Scientific Study of Early Autism) Action will take place across all Action activities, organisational groups and website of the participants and their host institutions – linking into the ESSEA website to ensure high visitor traffic. Annually, the MC will ask the WGs to collate all dissemination activities that its members

have undertaken in the past year. These will be shared with all participants and posted in a user-friendly format on the website. By the start of Year 3 the MC will have approved a clear dissemination plan and timetable for dissemination of the final outcomes; including but not limited to (i) basic science and technological findings; (ii) the Year 4 ESSEA Early Autism Conference; and (iii) the European clinical practice guidelines on screening and early intervention.

The ESSEA website will be used as a multi-lingual platform for dissemination, in particular to non-academic communities (for whom peer-reviewed journal articles and conferences form the primary dissemination channel). It will have portals for both professionals (summarising findings as they emerge and the final set of good practice guidelines) and for the pay community and the public (in particular parents and family members). If feasibility and resources allow there will be a 'chatroom' facility to allow members of the public to ask questions to the ESSEA network about its ongoing activities and findings as well as to allow community public discussion of the research advances as they emerge. See Canadian example of an informative public website at: www.cairn-site.com.