



EU-AIMS Clinical Network Newsletter 2015



SUMMER NEWSLETTER 2015

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Network Update

2015 has been a very productive year for the EU-AIMS Clinical Network. Our network of sites has expanded to include 92 clinical and/or research ASD centres spread across 37 countries.

The network includes over 40 partners from EU-AIMS/ESSEA Cost Action Network/ECNP, as well as additional sites across Europe. We are extremely proud of the large network of expert ASD centres that has come together since we began forming the network in spring 2013.

We continue to be delighted by the positive response to the aims we put forward over the last couple of years. Our first aim, to collect information about ASD

cohorts and assessment methods, received an excellent response rate (please refer to page 2 for a detailed update) and the positivity continued with our second aim to pool secondary datasets to create a valuable resource for the network (please also refer to page 2 for a detailed update).

We are also excited to develop a network of sites capable of carrying out future trials in ASD (page 3), as well as to coordinate with other European autism initiatives (please refer to page 4).

As always, regular updates on the progress of the clinical network can be found at <http://www.eu-aims.eu/clinical-trial-network//>.

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Clinical Network development update for 2015

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Pooling datasets across member sites to offer a unique platform for collaboration

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Develop clinical infrastructure for future clinical studies

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Updates on publication and involvement with ASD-EU

Data Sharing

We have been actively pooling existing clinical datasets across the network. The aim of this collaborative effort is to provide members with a resource to address informative questions that have the potential to advance the science of ASD.

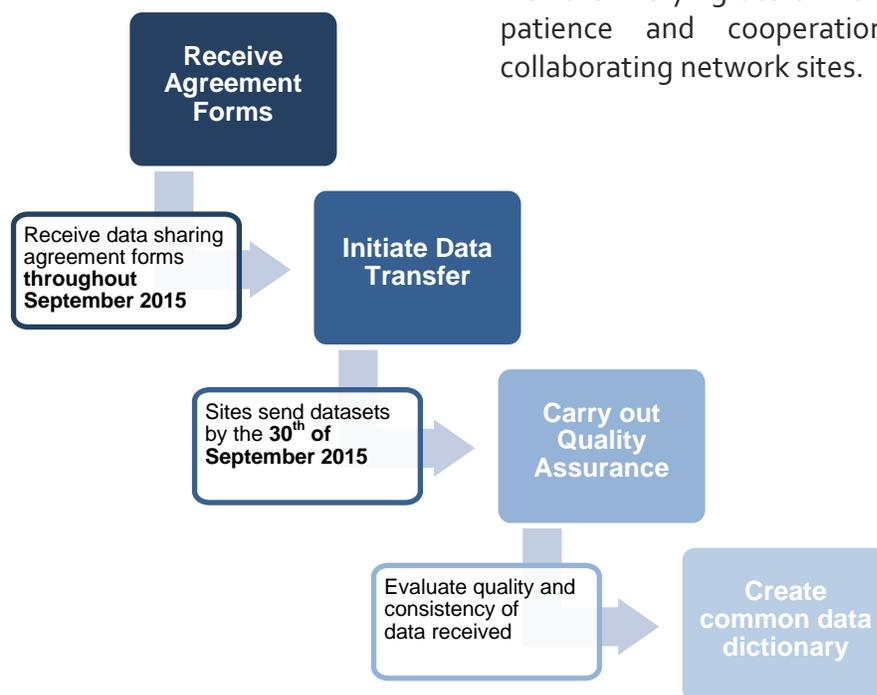
17 sites have already shared phenotypic, behavioural and cognitive data on a range of outcome measures.

A data inventory will be set up to document, annotate and describe this data so that information is useable by all participating members. Detailed descriptions of variables and records will be made available by a common data dictionary.

We are currently in the process of finalising data sharing agreements with interested member sites, as well as supporting the final transfer of datasets of participating members.

Before we can create a common data dictionary, we are going to carry out a range of quality assurance checks.

We acknowledge the time and effort data pooling demands and we are very grateful for the patience and cooperation of collaborating network sites.



Through an online survey, we obtained information about ASD patient cohorts and diagnostic characterisation undertaken across centres.

The results of this survey were published at the end of 2014 in ECAP (see information about the paper below).

Key results include the following:

A large proportion of centres reported using 'gold standard' measures such as the ADI-R and ADOS for ASD patient characterisation.

Questionnaire measures such as the SCQ and SRS were also commonly used.

We hope that in future the EU-AIMS clinical network will help the development of services and capacity across the whole of Europe, as well as encouraging comparability and harmonisation of diagnostic practice across centres that will aid future transnational clinical studies.

Development of a European 'Trial-ready' network

As part of the effort to build an EU-AIMS clinical network of major autism sites in Europe, we are developing with our colleague Lauren Boak from Roche a network of sites capable of carrying out future clinical trials in ASD.

Based on the information provided by sites in the site survey, we are currently assessing the infrastructure and training needs of sites in order to identify existing resource/capacity gaps.

A follow-up questionnaire will be sent out soon to sites to help us capture additional information in regards to 'trial readiness' of these sites.

We believe that this will not only build capacity within Europe for the conduct of future trials, but will also contribute towards a more unified approach to research in ASD within Europe in the clinical sciences.

Site-specific assessment of 'trial readiness'

Qualification Criteria for 'Trial Readiness' 

Site Name: _____
 Contact: _____
 Focus: Clinical/Hospital Research / Academic Clinical & Research

Past Experience with Clinical Trials																
1	Has the site been involved in clinical trials in the last 5 years? <input type="checkbox"/> Yes (please go to question 2) <input type="checkbox"/> No (please go to question 7)															
2	How many clinical trials has the site been involved with in the last 5 years? <input type="checkbox"/> 1-2 <input type="checkbox"/> 6-10 <input type="checkbox"/> 3-5 <input type="checkbox"/> 10+															
3	Has the site been involved in clinical trials in ASD and/or other patient groups and what was the nature of the trials?															
	<table border="1"> <thead> <tr> <th>ASD Individuals</th> <th>Non-ASD Individuals</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> Pharmacological</td> <td><input type="checkbox"/> Pharmacological</td> </tr> <tr> <td><input type="checkbox"/> Industry</td> <td><input type="checkbox"/> Industry</td> </tr> <tr> <td><input type="checkbox"/> Interventional</td> <td><input type="checkbox"/> Interventional</td> </tr> <tr> <td><input type="checkbox"/> Observational</td> <td><input type="checkbox"/> Observational</td> </tr> <tr> <td><input type="checkbox"/> Phase 4 Observational</td> <td><input type="checkbox"/> Phase 4 Observational</td> </tr> <tr> <td><input type="checkbox"/> Genetic studies</td> <td><input type="checkbox"/> Genetic studies</td> </tr> <tr> <td><input type="checkbox"/> Imaging studies</td> <td><input type="checkbox"/> Imaging studies</td> </tr> </tbody> </table>	ASD Individuals	Non-ASD Individuals	<input type="checkbox"/> Pharmacological	<input type="checkbox"/> Pharmacological	<input type="checkbox"/> Industry	<input type="checkbox"/> Industry	<input type="checkbox"/> Interventional	<input type="checkbox"/> Interventional	<input type="checkbox"/> Observational	<input type="checkbox"/> Observational	<input type="checkbox"/> Phase 4 Observational	<input type="checkbox"/> Phase 4 Observational	<input type="checkbox"/> Genetic studies	<input type="checkbox"/> Genetic studies	<input type="checkbox"/> Imaging studies
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<input type="checkbox"/> Genetic studies	<input type="checkbox"/> Genetic studies															
<input type="checkbox"/> Imaging studies	<input type="checkbox"/> Imaging studies															
4	What patient groups have been involved in clinical trials at the site? <input type="checkbox"/> ASD <input type="checkbox"/> Anxiety Disorder <input type="checkbox"/> ADHD <input type="checkbox"/> Eating Disorders <input type="checkbox"/> ODD <input type="checkbox"/> Bipolar Disorder <input type="checkbox"/> CD <input type="checkbox"/> Schizophrenia <input type="checkbox"/> OCD <input type="checkbox"/> Fragile X <input type="checkbox"/> Depression <input type="checkbox"/> Other															
5	Has the site had experience conducting clinical trials in ASD in the following age groups? <input type="checkbox"/> Infants (0-4 years) <input type="checkbox"/> Children (5-12 years) <input type="checkbox"/> Adolescents (13-18 years) <input type="checkbox"/> Adults (18+ years) <input type="checkbox"/> N/A - site has not conducted clinical trials in ASD															
6	Has the site had experience conducting clinical trials in patient groups other than ASD in the following age groups? <input type="checkbox"/> Infants (0-4 years) <input type="checkbox"/> Children (5-12 years) <input type="checkbox"/> Adolescents (13-18 years) <input type="checkbox"/> Adults (18+ years) <input type="checkbox"/> N/A - site has not conducted clinical trials in other patient groups															
7	Staff & Training															

EU-AIMS Data 'Trial Ready' Criteria

What was the nature of the trials carried out at your site?

What patient groups have been involved in clinical trials at the site?

EU-AIMS Annual Meeting

The 3rd EU-AIMS Annual Meeting took place in Paris, France on 12th & 13th April. At the meeting, the progress of the clinical network was shared with the consortium and was very well received.

As part of the meeting, a video was created that outlines how EU-AIMS contributes to Autism research (see link here: <https://youtu.be/xXuxi7dfVno>)



Recent Publications

de Bildt A, Sytema S, Zander E, Bölte S, et al. (2015) **Autism Diagnostic Interview-Revised (ADI-R) Algorithms for Toddlers and Young Preschoolers: Application in a Non-US Sample of 1,104 Children.** *J Autism Dev Disord* 45(7): 2076-2091

Salomone E, Beranová Š, Bonnet-Brilhault F, Briciet Lauritsen M, et al. (2015) **Use of early intervention for young children with autism spectrum disorder across Europe.** *Autism: Advance online publication.*

Salomone E, Charman T, McConachie H, Warreyn P; Working Group 4, COST Action 'Enhancing the Scientific Study of Early Autism' (2015) **Prevalence and correlates of use of complementary and alternative medicine in children with autism spectrum disorder in Europe.** *Eur J Pediatr.*: Advance online publication.

Salomone E, Charman T, McConachie H, Warreyn P. (2015) **Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with ASD in Europe.** *Child Care Health Dev.*: Advance online publication.

For more publications, please go to <http://www.eu-aims.eu/publications/>

EU-AIMS Updates

EU-AIMS, in partnership with the Neuroscience School of Advanced Studies (NSAS), will be hosting a one-week workshop from the 3rd-10th of October 2015 on

'Translational neuro-developmental perspectives on autism spectrum disorders'

in Bressanone, Südtirol.

EU-AIMS has provided **6 travel awards** for internal members and **4 awards** to external PhD students and early career researchers.

The EU-AIMS website will be updated to include a list of all sites who are members of the EU-AIMS clinical network. We may be in contact to obtain relevant information to help us update the site.

We are very pleased to announce the appointment of Julian Tillmann, who is going to join the clinical network team in October.



With best wishes from the clinical network team,

Julian Tillmann & Karen Ashwood

EU-AIMS is also collaborating with Autism Spectrum Disorders in Europe (ASDEU), a new trans-European project to increase understanding of autism and to improve care and support for people with autism.

ASDEU is a three-year programme run by a consortium of 20 groups from 14 EU member states and is funded by the Directorate-General of Health and Consumers of the European Commission (DG-SANCO)

(For further information, please visit <http://asdeu.eu/>)

We would like to thank all the members of the EU-AIMS clinical network for their ongoing support and enthusiasm.

All the best from,

Clinical Network Co-Leads, Tony Charman & Jan Buitelaar; Project Coordinator, Will Spooren; Academic Lead, Declan Murphy