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INFORMATION SHEET



**Study Title:** People with autism detained within hospitals: defining the population, understanding aetiology and improving care pathways (The mATCH study)

**Workstream Ia**

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You are being asked to take part in research.

You can talk to others about this research study. This can be anyone you like.

Please ask if there is anything that you do not understand.

**Who are the Researchers?**

1. Dr Peter Langdon from the University of Kent and Hertfordshire Partnership University NHS Foundation Trust.
2. Dr Regi Alexander from Partnerships in Care Limted and the University of East Anglia.
3. Professor Sabyasachi Bhaumik from Leicestershire Partnership NHS Trust.
4. Dr John Devapriam from Leicestershire Partnership NHS Trust.
5. Professor Conor Duggan from Partnerships in Care Limted.
6. Professor Lee Shepstone from the University of East Anglia.
7. Dr Ekkehart Staufenburg from Hertfordshire Partnership University NHS Foundation Trust.
8. Mr David Turner from the University of East Anglia.
9. Professor Essi Viding from University College London.

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|  | **We want to find out:*** We have developed a way of putting people who are in hospital who have autistic spectrum conditions into different groups.
* We want to know whether this is a good idea.
* We think that this might help improve hospital care.
* We want to know what you think about our ideas.
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|  | **Do I have to take part in this research?*** NO, you do not have to take part in this research.
* If you say YES, you can change it to NO later on.

**What happens if I say yes?*** You will be asked to join a focus group.
* The group will be made up of clinical staff who work with people with autistic spectrum conditions, as well as people who have autistic spectrum conditions and their families.
* There will be six people in the group.
* During the group, we will tell you about our project.
* We will tell you about our way of putting people who are in hospital who have autistic spectrum conditions into different groups.
* We will ask you to discuss this with each other and see whether you agree.
* We would like you to give us some feedback.
* We will take your feedback and use it to change our way of group people.
* The focus group will take one day.
* The meeting will be audio-recorded.
* We will provide lunch.
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|   | **Payment*** It will take a whole day to complete this study.
* We will pay your travel expenses.
* As a small token of appreciation, we will offer to pay you £50.00.
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|  | **Could bad things happen if I do the research?*** We do not think it likely that anything bad will happen.
* However, if anything is upsetting, we will talk to you and try to help you.
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|  | **Could good things happen if I do the research?*** By saying yes, you will help us to understand whether putting people with autistic spectrum disorders into different groups can help improve care in hospitals.
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|  | **Will information about me be kept private?** * Yes, the information we have will be kept private, but:
	+ People who are in charge of making sure that the researchers are following the rules may look at our records.
	+ We would like to keep the information we collect and use it in future studies. We will ask you if you are happy for us to do this – you can say no.
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|  | **What happens at the end?*** The results will be written about. No names will be given.
* We may quote you. However, we will never tell anyone your name.
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|  | **Who is organising and giving money for the research?*** The National Institute for Health Research (NIHR) is paying for the research.
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|  | **Has the research been checked?*** People have looked at the study to check it is safe.
* People have also checked to make sure that everyone gets good information before they start.
* The people who have checked this project are called an NHS Research Ethics Committee.
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|  | **What if you are unhappy about the research?*** You can talk to the researchers first if you want.
* You can make a complaint to Hertfordshire Partnership University NHS Foundation Trust or the University of Kent.
* We will give you information about how to complain.
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|  | **Contacts:*** If you want any extra information, have some further questions, or you wish to complain, you can call or write to:

**Dr. Peter Langdon****Senior Lecturer in Clinical Psychology and Disability****Willowbank****Hertfordshire Partnership University NHS Foundation Trust****Hospital Road****Little Plumstead****Norwich NR13 5EW**His phone number is: 01603 711178His email address is: P.E.Langdon@kent.ac.ukThere is a website about this project. The address is <http://www.kent.ac.uk/match>  |
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INFORMATION SHEET



**Study Title:** People with autism detained within hospitals: defining the population, understanding aetiology and improving care pathways (The mATCH study)

**Workstream Ib**

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You are being asked to take part in research.

You can talk to others about this research study. This can be anyone you like.

Please ask if there is anything that you do not understand.

**Who are the Researchers?**

1. Dr Peter Langdon from the University of Kent and Hertfordshire Partnership University NHS Foundation Trust.
2. Dr Regi Alexander from Partnerships in Care Limted and the University of East Anglia.
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8. Mr David Turner from the University of East Anglia.
9. Professor Essi Viding from University College London.

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|  | **We want to find out:*** We have developed a typology of autistic spectrum conditions.
* We want to test these out by asking you to characterise a series of clinical vignettes according to this typology.
* We would also appreciate hearing any feedback you have on our typology.
 |
|  | **Do I have to take part in this research?*** NO, you do not have to take part in this research.
* If you say YES, you can change it to NO later on.

**What happens if I say yes?*** You will be one of five clinicians who have experience of working with people who have autistic spectrum conditions.
* We will work with you to develop ten clinical vignettes based on patients with an autistic spectrum condition. These will need to be patients you have worked with and we will need to describe their clinical presentation and history.
* You and the other four clinicians will be asked to independently characterise all fifty vignettes using our typology.
* Once this is complete, we will compare ratings together as a group. We will invite you to discuss your ratings, and we will ask you to share any feedback.
* This session will be audio recorded.
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|   | **Payment*** It may take a few days to write the clinical vignettes.
* It will take a whole day to complete this study when rating the 50 vignettes.
* We will pay your travel expenses.
* We will provide lunch.
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|  | **Could I be harmed?*** We do not think it likely that anything bad will happen.
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|  | **Is my taking part helpful?*** By taking part, you will help us to understand and refine our typology.
* This will help us to move forward with our work programme, and may help us to eventually improve hospital care pathways for people with autistic spectrum conditions.
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|  | **Will information about me be kept private?** * Yes, the information we have will be kept private, but:
	+ People who are in charge of making sure that the researchers are following the rules may look at our records.
	+ We would like to keep the information we collect and use it in future studies. We will ask you if you are happy for us to do this – you can say no.
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|  | **What happens at the end?*** The results will be written about. No names will be given.
* We may quote you. However, we will never tell anyone your name.
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|  | **Who is organising and giving money for the research?*** The National Institute for Health Research (NIHR) is paying for the research.
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|  | **Has the research been checked?*** People have looked at the study to check it is safe.
* People have also checked to make sure that everyone gets good information before they start.
* The people who have checked this project are called an NHS Research Ethics Committee.
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|  | **What if you are unhappy about the research?*** You can talk to the researchers first if you want.
* You can make a complaint to Hertfordshire Partnership University NHS Foundation Trust or the University of Kent.
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INFORMATION SHEET



**Study Title:** People with autism detained within hospitals: defining the population, understanding aetiology and improving care pathways (The mATCH study)

**Workstream IIb**

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You are being asked to take part in research.

You can talk to others about this research study. This can be anyone you like.

Please ask if there is anything that you do not understand.

**Who are the Researchers?**

1. Dr Peter Langdon from the University of Kent and Hertfordshire Partnership University NHS Foundation Trust.
2. Dr Regi Alexander from Partnerships in Care Limited and the University of East Anglia.
3. Professor Sabyasachi Bhaumik from Leicestershire Partnership NHS Trust.
4. Dr John Devapriam from Leicestershire Partnership NHS Trust.
5. Professor Conor Duggan from Partnerships in Care Limited.
6. Professor Lee Shepstone from the University of East Anglia.
7. Dr Ekkehart Staufenburg from Hertfordshire Partnership University NHS Foundation Trust.
8. Mr David Turner from the University of East Anglia.
9. Professor Essi Viding from University College London.

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|  | **We want to find out:*** We are testing whether there are different groups of people with autistic spectrum conditions in hospital.
* We are doing this in order to work out whether we can make better care pathways for people with autistic spectrum conditions.
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|  | **Do I have to take part in this research?*** NO, you do not have to take part in this research.
* If you say YES, you can change it to NO later on.

**What happens if I say yes?*** You will meet with a researcher.
* You will be asked to complete questionnaires.
* You will be asked to do some puzzles and tasks.
* You will use a computer for some of the puzzles and tasks.
* These questionnaires, puzzles and tasks will help us to understand you better.
* Some of these puzzles and tasks will provide us with information about the sorts of things you are good at doing, and the sorts of things that you may find difficult.
* Some of the questionnaires will have questions about your mental health.
* Some of the questionnaires will have questions about autism, feelings, and your general health.
* It might take three to four hours to finish the study.
* We would like to look at your hospital records. We would like to know about your health, your medication, your risk, and any previous psychological assessment questionnaires you have completed. We will take this information only with your permission and it will be kept secret.
* Once you start, you can take a break and finish later.
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|   | **Payment*** If you complete our study, we would like to give you £20.00 as a way of saying thank-you for giving up your time.
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|  | **Could anything bad happen?*** We do not think it likely that anything bad will happen.
* If you find anything upsetting, we will talk to you, and try to help you.
* If we think you or anyone else is at risk of harm we will tell your clinical team about this risk.
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|  | **Could anything good happen?*** By taking part, you will help us understand autistic spectrum conditions better.
* You will help us to improve hospital care pathways for people with autistic spectrum conditions.
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|  | **Will information about me be kept private?** * Yes, the information we have will be kept private, but:
	+ People who are in charge of making sure that the researchers are following the rules may look at our records.
	+ We would like to keep the information we collect and use it in future studies. We will ask you if you are happy for us to do this – you can say no.
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|  | **What happens at the end?*** The results will be written about. No names will be given.
* We will publish our findings in a journal. This is like a magazine where we write about what we did and found out.
* We will put our results on our website. This is <http://www.kent.ac.uk/match>
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|  | **Who is organising and giving money for the research?*** The National Institute for Health Research (NIHR) is paying for the research.
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