

# Autism Transition to Adulthood Group (ATAG) Research Project

## Participant Information Leaflet

### We invite you to take part in a research study

- This information will help you decide if you want to take part in our research study.
- It is important that you understand what the study is about and what you would be asked to do if you took part.
- Please take time to read the information in this leaflet.
- If you do not understand any information or want more details, please contact us.
- You might want to talk about the study with your family members, friends, or other people who support you. You can also share this leaflet with them.

### Summary of things you need to know

You can find out more about the study in this leaflet:

- We are inviting 16–25-year-olds who have received a diagnosis of Autism to take part in a research study called the **Autism Transition to Adulthood Group (ATAG) Research Project**.
- People who take part (called *participants*) will have a 50:50 chance of attending the new group called Understanding You, Discovering You (UYDY) or receiving the usual health and social care offered in their area. This will be decided by a process called randomisation.
- We want to find out whether the UYDY group helps autistic young people as they reach early adulthood.
- Participants will be sent **questionnaires** to complete **before the treatment starts, and then at 8, 16, and 24 weeks** after they join the study. The questionnaires will ask about well-being, feelings about being autistic, and health and social care usage.
- Participants will receive a £10 gift voucher each time they complete the questionnaires.
- Participants who receive usual care will have the option to receive UYDY after their 24-week follow-up questionnaires are complete.

### Who are we?

We are a group of autistic people, autism researchers and professionals, from the organisations you can see listed above. We are motivated to do work to help improve the lives of autistic young people.

### Contact

For general enquires about the study, please contact the research team.

Email address:  
Atag@bath.ac.uk

Tel:  
07812707347



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## 1. Why are we doing this study?

We know that the transition from being a young person to becoming an adult can be difficult for lots of people, and that autistic people may face unique challenges.

We want to see if the online autism transition to adulthood group (ATAG) could be useful to support autistic young people to manage this transition to adulthood.

The group aims to:

- help autistic young people learn more about autism
- connect with other autistic young people
- learn self-advocacy and problem solving skills
- know when and how to get support from others

We want to find out if it is possible to find 70 people who agree to take part, and if they are willing to continue taking part in the study. It will tell us if it is possible to do a bigger study to see if the intervention is effective. In this study we want to find out:

- Can we find autistic young people to take part in the research study?
- Do participants stay in the study long enough to complete the follow-up questionnaires?
- Is the UYDY group acceptable to participants?
- What support do people in the usual care group get offered?
- How should we design a bigger study to find out if the UYDY group works?

## 2. Why have I been asked to take part?

**You have been invited to take part in this study because you are autistic and aged between 16- and 25-years-old.**

You have been sent this leaflet because you either asked us to send it to you, or because you have volunteered to hear about research opportunities.

The next part of the Information leaflet tells you about what will happen if you would like to take part in the research.

For an overview of the study see the ***'Flow diagram about the ATAG Study'*** on the next page (page 4).

### 3. Flow diagram about the ATAG study

#### Invitation to take part

Read the participant information leaflet and discuss with friends/family

#### Expression of interest and eligibility screening

If you are interested in taking part in the research study:

- Complete the online Expression of Interest form.
- Then a member of the study team will let you know if:
  - The study is not suitable for you to take part at this time; or
  - It is suitable for you to take part and to arrange your initial online research appointment

#### First research appointment

During this appointment with [the support with of one researcher](#) you will:

- Discuss the study and ask any questions.
- Show the researcher a medical letter confirming your Autism diagnosis.

You then have the option to have the support of a researcher OR complete the following independently:

- Complete the consent form.
- You will then complete the study questionnaires (e.g. about your well-being, feelings about being autistic, and other support you have).
- Pass on supporter study pack (if applicable).

We will offer you a £10 voucher upon completion of this appointment.

You will be randomly allocated to receive either Autism Transition to Adulthood Group (ATAG) or usual care.

#### Group

Receive six sessions of the online autism transition to adulthood group (ATAG)

or

Receive information about usual care for autistic young people

#### Questionnaires & Follow up

- [At 8, 16, and 24 weeks](#) after you agree to take part you will complete an online questionnaire either independently or with support from a researcher.
- £10 gift voucher offered upon each completed timepoint.
- If you received usual care, [after your complete your 24-week follow-up questionnaire you can choose to attend the online UYDY group sessions.](#)

#### Optional:

#### Study Interview





#### 4. Do I have to take part?

**No.** It is your choice whether you take part in this study or not.

- **If you are interested in taking part**, please complete the **online Expression of Interest form**

<https://uniofbath.questionpro.eu/atagEOI>

- **If you decide to take part**, you are also free to leave the study at any time without giving a reason
- **If you decide *not* to take part**, your usual care will not be affected in any way.
- **If you have any questions**, or you do not understand any part of this information leaflet, please contact us using the details on the front page.

#### 5. If I decide to take part, what happens next?

##### Expression of interest & eligibility



The first step is to fill out the expression of interest form:

**If your responses show that the study is not suitable for you at this time:**

We will let you know as soon as possible and thank you for your interest. We will then get rid of identifiable information that we have about you, for example, your name. We will keep the other data you shared with us, for example, your age and gender.

##### **If you meet the criteria to take part:**

We will tell you that you are potentially eligible to take part in the study. We will arrange a time to have the **first research appointment**. This appointment will be on a video call, with a member of the study team.

##### **If you are potentially eligible but no longer want to take part:**

We will ask if we can contact you to talk about what you thought about the study information provided, and why you decided not to take part. This is optional. If you are not interested, then you will not be asked to do anything else.

##### First research appointment

This appointment may take up to 90 minutes. At the appointment, a researcher will explain what taking part in the study involves, ask questions to check you are still eligible, and answer any questions you may have.

You will be asked to show a letter or document confirming your clinical diagnosis of autism from your GP or Autism service.

You will then be asked if you want to do the following with support from a researcher or to complete it independently:

1. complete a consent form showing that you understand the study and agree to take part.
2. complete some questionnaires.

Once you have done this, the research team will let you know whether you are

3. allocated to receive either the UYDY group or usual care.

At this point you are **a participant in the study**.

##### 6. Allocation to UYDY or usual care

As we do not know if the UYDY group is helpful autistic adults, we have a second group of participants who will get the support that is usually available to autistic young people (Usual Care).



The group that you will be allocated to will be decided through **randomisation**.

This means you will have an equal chance of receiving either the UYDY group or Usual Care.

This is done using computer software called *Sealed Envelope* which tells the researcher which group you have been assigned to at random. You will not be asked to do anything.

The research team will complete this process after your first research appointment.

You will then be sent an email explaining the outcome and what the next steps are. We will also write to your GP telling them that you are involved in the study.

The reason randomisation is used is it means that people are randomly assigned to UYDY and CAU. This means that the participants in each group will be as similar to one another as possible. It would not be fair to let participants choose which group they are allocated to.

### Group: UYDY

If you have been **allocated to UYDY** you will be assigned to a group with other autistic young people. The groups will be run by Ambitious about Autism, a national autism charity. Your group facilitator will contact you to give you more information about the group and to plan your first session. Each session will last 60 minutes, will be held on a video call, and will be with around seven other autistic young people. The groups will have two facilitators, and one of these will be autistic.

The group aims to:

- help autistic young people learn more about being autistic
- connect with other autistic young people
- learn self-care skills
- know when and how to get support from others

### Group: Usual Care

If you have been **allocated to Usual Care** we will give you information about support that is available to you. This will include the standard health and social care available in your area for autistic people between 16-25 years.

You can also discuss the other support options that are available to you in your area with your GP, or if you have contact with one: a support worker, social worker or education professional.

After you have completed your 24-week follow-up questionnaires, we will contact you to invite you to ATAG. You will not be asked to fill out any more questionnaires by the research team.

### 7. Questionnaires and Follow-up



You will be asked to complete follow-up **questionnaires at 8, 16, and 24 weeks** after your initial research appointment.

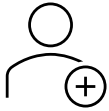
You can complete these online, or with help from a researcher via video call or telephone. Each time you complete the follow-up questionnaires you will receive a £10 gift voucher to thank you for your time.

If you need help to complete the questionnaires, the research team will make all reasonable adjustments to assist with this. Similarly, a carer/family member or



friend can provide support, but they are told to not to answer any questions for you.

## 8. Supporter Study



If you tell us that you have a carer or supporter, with your consent, we would like to invite them to take part in a separate study. This will investigate their well-being and quality of life over the time you are taking part in the study. It is up to you to define who your supporter is, but where possible, it would be someone who knows you well and is likely to be providing you with support throughout your involvement with this study. This might be a family member, partner, or professional support worker. If you are happy for us to approach your supporter, then we will provide you with a study information pack and ask you to provide it to them as soon as possible.

You are still able to take part in the research if your supporter does not want to take part, or if you do not have a supporter.

Similarly, if your supporter does agree to take part, they can stay in the study if you decide to stop taking part.

## 9. Will I be asked to do anything else?

### Study Interview

If you agree to be contacted, a researcher will invite you to take part in an interview about your experience of the study overall. This is **optional**. If you **do not wish to take part in the study interview you can still take part in the main study**.

You can ask any questions you may have about this with a researcher at the start of the interview study.

If you do not wish to take part in the main research, you can still take part in an interview (to discuss why you chose not to take part). This will provide us with really useful information.

If you do decide to take part in the interview study, a researcher will contact you to arrange the best time to do this. This may be via video call, over the telephone, or by another preferred method. You will be sent a consent form to read before the interview takes place.

At the start of the interview the researcher will answer any questions you may have.

The interview may take up to 45 minutes and the researcher will ask you about your expectations and experience of the study and the support you received.

If you agree to take part in the interview study, the interview will be recorded on secure, encrypted audio recorders and transferred onto secure computer servers at the University of Bath to help with analysis. The audio file will then be deleted from the recorder.

All electronic data will be transcribed in part or fully by University of Bath employees, or their authorised representatives. The data will then be stored on a secure computer server at the University of Bath.

We will do our best to ensure that no one will be able to tell you took part in the ATAG study interviews, as all identifiable information will be removed from the transcripts. Any information that you may provide during the interviews will be treated as confidential.

The University of Bath will securely retain audio-recorded data and may use anonymised quotations for training,



teaching, research and publication purposes for this and future studies.

If you agree, anonymised transcripts of the interviews may be made available by controlled access to other researchers outside of the ATAG study. We will ensure you cannot be identified.

If you agree, data from the anonymised transcripts may be used for purposes not related to this study, but it will not be possible to identify you from them.

### **10. How long does the research study last?**

The overall study is expected to run through to **June 2025**. However, you will only remain in the study for **24 weeks**.

### **11. What are the possible benefits of taking part?**

You may find that taking part improves your well-being, but there is no guarantee of this. You may also benefit from the extra contact that comes with being part of the study.

Even if you do not receive a direct benefit from taking part in this study, your involvement will help to improve future support for autistic young people.

Please remember that taking part in this study should not replace other services you may be receiving for any social care, physical or mental health problems. You should keep getting support from your GP and other services as usual.

### **12. What are the possible disadvantages of taking part?**

The first research appointment may last up to 90 minutes. You may find it tiring to complete the questionnaires. We will try to

ensure you are comfortable and you can take one or more breaks as needed.

We estimate that it may take up to 45 minutes to complete each of the follow up study questionnaires. Some people will take less time, and others might take longer.

If you take part in ATAG, you might find that some of the topics covered are distressing, for example talking about challenges in your life. We will help you seek further support if you need it during or after an UDY session. You will be able to request to speak with a member of staff in a breakout room during sessions, if needed.

### **13. Can I take part in the ATAG research if I am already taking part in another research study?**

We are unable to enroll you in this research study if you are already taking part in another interventional study which aims to improve your well-being. This includes the research studies 'STRATA' (at the University of Bristol) and ADEPT-2 (at the University of Bath).

Please talk to the research team about any other research that you may be involved in, or considering, as they will be able to advise you on your suitability for the ATAG research project and possible options for the future, if it is not suitable at this time.

### **14. Will I receive anything for taking part?**

We will offer £10 in gift vouchers for completing each set of questionnaires at the start and then at 10, 16, and 24 weeks (£40 in total for the study).





### **15. Will the information I provide be kept confidential?**

The information you provide to the research team will be treated as confidential and will only be used for the purpose of the study, unless you tell the research team or UYDY group facilitator that you or someone else is at risk of harm, or that you have or intend to, commit a crime. If this happens, the research team will have to inform the relevant authority. We will do our best to discuss this with you first.

Data about you will be given a code that makes it impossible to identify you, except by our research team.

Data with personal details will be used by the study team to contact you during the study.

Personal data will only be kept for up to 12 months after the study has ended. After 12 months these details will be destroyed. The purpose for keeping them for 12 months after the study has finished is to notify you about the results of the study.

Coded data, with all personal details removed, will be stored on password-protected computers for 5 years, in accordance with University of Bath guidelines.

Your personal information will not be written on any reports about the study or to anyone outside of the study team, and no one will be able to identify you.

With your consent, data collected in this trial may be used in future ethically approved research studies on the understanding that all information may be shared anonymously with other researchers i.e., it will not contain any information about your name, date of

birth or contact details so no one will be able to identify you. It will continue to be kept securely and remain confidential.

You can view information from the Health Research Authority on the use of patient data in research by accessing: [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)

### **16. Can I stop taking part after the study has started?**

**Taking part is voluntary.** If you decide you no longer wish to take part, you are free to leave the study at any time during the 24 weeks.

You do not have to give a reason and your medical care and legal rights will not be affected. If you do withdraw from the study we would confidentially keep the information we had already collected about you, for the purposes of the study only. We might ask if you would be willing to discuss your reasons for leaving the study with a researcher.

### **17. What happens when the study is finished?**

Once you have returned your final study questionnaire at 24 weeks your part in the study will be complete. If you were allocated to usual care you will then have the opportunity to take part in the UYDY group.



The overall results of the study will be published in medical journals and shared with other healthcare professionals interested in this area of research at conferences.



People who take part will also be sent results of the study via a newsletter.

### 18. Who funded this study and who is the lead organisation for the study?

This study is funded by the National Institute of Health Research which supports NHS and social care research.

The full title for this research study is: *Peer-group intervention to promote successful transition to adulthood for autistic people: A feasibility RCT*

The study is led by a team of experienced clinical psychologists, social care professionals, autistic young people, and researchers, supported by members of an autistic advisory group

The study is sponsored by the University of Bath who is responsible for ensuring the research meets its contractual, legal and financial obligations.

The study partners include: Ambitious about Autism, National Autistic Society, University of York, and University College London.

### 19. Who has reviewed the study?

This study has been reviewed by the Wales 5 Research Ethics Committee who have provided approval for this study to be conducted.

### 20. What if there's a problem?

If you have a concern regarding your care, please discuss this with your GP or contact 111. If you experience a life-threatening emergency, or feel you cannot keep yourself safe, you should attend your

nearest A&E or phone 999. You will also be offered a leaflet with the contact details of local and national mental health support networks and autism support services.

If you become unable or unwilling to continue in ATAG, we would withdraw you from the study.

In the unlikely event that something should go wrong, the University of Bath has Public Liability insurance in place.

### 21. How do I make a complaint?

If you have a concern about any aspect of the study, please contact the ATAG study team who will do their best to answer your questions by phone (07812707347), or email ([atag@bath.ac.uk](mailto:atag@bath.ac.uk)).

If you remain unhappy with any aspect of the study, please email the sponsor at [pro-vc-research@bath.ac.uk](mailto:pro-vc-research@bath.ac.uk)

### 22. What are the next steps?

1. Complete the expression of interest form online or return this to us using the pre-paid envelope provided.
2. Please pass the 'supporter pack' onto your supporter so they can decide if they wish to be involved in this research.
3. If you are eligible to take part, the study team will be in touch to record your consent and arrange your first study appointment.

Thank you for taking the time to read this information. Please keep a copy for your records.