PDA Research Priority Setting

Summary of findings

In 2022, the PDA Society began a process of defining the top unanswered PDA research questions. The PDA community, professionals and researchers were invited to share their top unanswered questions through a survey, to which 551 people responded. Over 3,000 questions were proposed, which were refined to 1,146 unique questions. A further two stages of analysis were undertaken, refining these questions further to 175 and then 39 questions, summarised by nine overarching 'key questions'. This report details these research priorities, and the methodology applied to reach these questions.

In producing this report, the PDA Society wishes to extend its sincere appreciation to everyone who contributed to this research priority setting process. The survey responses contained many heartfelt responses detailing the challenges faced by the PDA community underlying the basis for why more PDA research is so urgently needed. The PDA Society is a small charity with limited resources. We have endeavoured to apply a robust methodology overseen by the PDA Society team but recognise that with greater resources there will have been opportunities to improve the process applied. We hope though that the questions detailed provide a helpful basis to inform PDA research priorities and provides an evidence base for research funding.

The nine research priorities identified were (in no particular order):

- What are the origins of the experience of the PDA profile, including the specific nature of the demand avoidance?
- How do people experience PDA, and the world around them, day-to-day?
- What impacts a PDA person's quality of life and what changes would improve outcomes?
- How can professionals be better informed and services better configured or adapted to meet needs of PDA people?
- How can specific needs and strengths of individual PDA people be better understood to make a difference to them?
- How should we best and most usefully define and describe PDA?
- What relational and therapeutic approaches help and what harm a PDA child or adult?
- What learning environment and approaches are effective in meeting a PDA learner's needs?
- How do a PDA person's needs change over time?

Context

Pathological Demand Avoidance (PDA) is widely but not universally understood to be a profile on the autism spectrum, involving the avoidance of everyday demands and the use of 'social strategies' as part of this avoidance. The PDA Society is a registered charity providing PDA information, support and training to PDA people, their supporters, and professionals. Last year the charity directly supported over 4,500 people, with 750,000 people accessing information through our website. The PDA Society aims to increase acceptance and understanding of PDA people, and to improve outcomes for PDA people and their supporters by focusing everyone involved on what helps.

At the beginning of 2022, the PDA Society launched a five-year strategy. This included a research objective to: "Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed, informing policy and practice, with improved outcomes for PDA individuals." In May 2022, the PDA Society began a research priority setting exercise, bringing together professionals and the PDA community to identify and prioritise the top unanswered questions in respect of PDA research. In defining these priorities, the aim was to stimulate new research interest, focus existing research efforts on the most pressing questions and provide an evidence base for research funding. This report is the outcome of that research priority setting exercise.

Survey and analysis

To begin the process of identifying the top unanswered PDA research questions, the PDA Society produced a survey for the PDA community and professionals to complete. The survey was designed with PDA people and their supporters, alongside input from researchers and other professionals known to the PDA Society. 551 people responded to the survey, providing over 3,000 individual research questions. Of those who responded, 52% identified as parent/main carers, 23% as a PDA person, 16% as a professional, 5% as a supporter and 2% as an academic researcher.

Survey data was analysed in three stages, during which the suggested research questions were categorised and refined to 39 questions, grouped under nine overarching themes. There is more detailed information about this process, our methodology and the survey respondents below in Appendix one, and the survey questions can be found in Appendix two.

Research questions

Below is a list of the 39 questions identified as an outcome of our research priorities consultation. They are grouped under nine overarching key questions. As research on PDA is in its infancy, all of these overarching questions were considered important, so no ranking was applied and they are listed in no particular order. They are diverse in nature, and fall under different fields, such as medical, psychological, social and educational research and policy.

What are the origins of the experience of the PDA profile, including the specific nature of the demand avoidance?

- What causes PDA (e.g. genetic, environmental)?
- Are there observable differences in the brain and nervous system of PDA people?
- Do PDA people experience physiological differences? If so, how can a better understanding of these inform approaches to support?
- What is the relationship between PDA and neurodevelopmental conditions and how can a better understanding inform and improve support?
- What is the relationship between PDA, mental health and trauma and how can a better understanding inform and improve support?
- How do PDA people experience hormonal changes (e.g. puberty, menopause)?
- What co-occurring conditions do PDA people commonly have and what can we learn from this (e.g. Ehlers-Danlos, Myalgic Encephalomyelitis)?

How do people experience PDA, and the world around them, day-to-day?

What impacts a PDA person's quality of life and what changes would improve outcomes?

How can professionals be better informed and services better configured or adapted to meet needs of PDA people?

- How can the process of identifying PDA best meet the needs of PDA people?
- How does a PDA person's demography (e.g. age, sex, gender identity, ethnic background, sexuality) influence their needs and experiences?
- How does the neurotype of a PDA person's parent/carer(s) and wider family impact their quality-of-life outcomes?
- Are PDA people at greater risk of suicide and self-harming behaviours and if so how can they be better supported?
- What is the impact of the current health, education and social care and criminal justice system on PDA people?
- Across health, social care, education and work, what are the institutional barriers to meeting the needs of PDA people and how can these be addressed?
- What is the prevalence rate of PDA people within the criminal justice system and what can we learn from their experiences to inform and improve the system?
- What is the prevalence rate of PDA people within the care system and what can we learn from their experiences to inform and improve the system?
- What is the prevalence of exploitation and abuse experienced by PDA people, and what impact does this have?
- How can we ensure the lived of experiences of PDA people and their supporters are heard, believed, valued and acted on by professionals?
- How can inpatient units (e.g. Tier 4 services) better meet the needs of PDA people?
- What are the average quality of life outcomes for PDA people and what are the variables that impact these outcomes?
- How do PDA people experience demand avoidance day-to-day?

How can specific needs and strengths of individual PDA people be better understood to make a difference to them?

How should we best and most usefully define and describe PDA?

- What does PDA research to date tell us?
- What are the diagnostic criteria for PDA and are they sufficiently distinct to enable a PDA diagnosis?
- Are existing diagnostic tools for autism and approaches for supporting autistic people sufficient to meet the needs of PDA people?
- Is it appropriate to identify and/or diagnose PDA given our current levels of understanding?
- Does the term 'Pathological Demand Avoidance' accurately reflect the experiences of PDA people and (whether accurate or not) what impact has this terminology had on them?
- What is the prevalence rate of PDA in the general population and neurodivergent population?
- What are the levels of awareness and understanding of PDA outside the UK?
- What are the communication needs of PDA people and how can these needs be met?
- How do PDA people experience masking and how does this compare to the experiences of neurodivergent people who are not PDA?
- What are the common strengths of PDA people and how can we ensure these are celebrated?

What relational and therapeutic approaches help and what harm a PDA child or adult?

What learning environment and approaches are effective in meeting a PDA learner's needs?

How do a PDA person's needs change over time?

- What parenting approaches help and what harm a PDA child?
- What types of relationships do PDA people form and how can a better understanding of these relationships inform and improve support?
- Where a PDA adult needs care and support, what approaches help and what harm?
- When a PDA person experiences distressed behaviours that risk causing harm to themselves and/or supporters, what are the best approaches that help?
- What learning environment and approaches best meet PDA learners' needs?
- Are there clinical and/or complimentary approaches (e.g. medication, therapies) that improve quality of life outcomes for PDA people?
- Where a PDA adult is living independently, what self-care approaches help to enable this?
- How do a PDA person's needs change over time and how can this understanding be used to inform and improve care (including self-care) and support?
- What are the needs of supporters (e.g. family, friends) of PDA people and how can they best be met?

Next steps

Moving forward, these research priorities and questions will be shared with researchers, funders and policy makers to influence future research having the greatest possible chance of improving lives for PDA people. This will be part of the following actions committed to by PDA Society:

- Advocating for the formation of a PDA Research Hub within an internationally renowned research setting
- Together with this setting, forming a steering group of academics, policy influencers and funders to secure progress towards answering the questions we have identified
- Building relationships with early career researchers to support them to explore these themes further

Appendix One: Methodology

Survey

To begin the process of identifying the top unanswered PDA research questions, the PDA Society produced a survey for the PDA community and professionals to complete. The survey was designed with PDA people and their supporters, alongside input from researchers and other professionals known to the PDA Society. In response to feedback from PDA adults, an earlier version of the survey was re-worked to give people more autonomy in respect of how much detail they wished to give. As an outcome, respondents could either answer one main question (Question 2) and then skip to the end of the survey or go through a series of more structured questions (Questions 4 to 11) depending on their preference. See Appendix two for a copy of the survey.

The survey was opened on the 15th May 2022 and closed on the 14th June 2022 and hosted on Microsoft Forms. The survey was promoted through the PDA Society's social media platforms (Facebook, Twitter, Instagram, LinkedIn) through the PDA Society's newsletter and website. In using these distribution methods, the reach was principally limited to people known to the PDA Society although efforts were made to extend this with individual emails. Once the survey was closed the findings were analysed by the PDA Society. It had originally been then intention of the PDA Society to publish these findings by the end of 2022, however given the number of responses and analysis time required, it was necessary to extend this by several months.

Respondents

551 people responded to the survey request providing over 3000 individual questions. Of those who responded 52% identified as parent/main carers, 23% as a PDA person, 16% as a professional, 5% as a supporter and 2% as an academic researcher. Respondents had the opportunity to select multiple answers when answering the question "Which best describes your interest in PDA?" so some people identified across multiple categories of person. When asked about ethnicity, 82% identified as white, 13% as mixed/multiple ethnic groups, 1% as Asian/Asian British, 1% as Black/ African/Caribbean/Black British and 3% said they would prefer not to answer the question. 55% of respondents identified as neurodivergent, 88% identified as women and 79% identified as heterosexual/straight. 69% of respondents gave their geographic location as the UK. The next two main geographic locations were USA/Canada (17%) and Australia/New Zealand (10%).

Analysis: First stage

The first stage of analysis refined the number of questions asked from over 3,000 to 1,436 unique responses. To refine the questions at this stage, it was decided that we would identify all unique questions. The responses were read, and individual questions were extrapolated from the responses, increasing the number initially. These were first categorised into themes, then duplicate responses were removed as well as those without direct relevance to the survey questions. By completing this exercise, we were left with 1,436 unique responses.

During this process, the following observations were made:

- Where examples had been provided in the survey questions, these featured highly in the responses. Recognising that this could bias the weight of responses, it was decided that no recurrence value would be placed on these at this stage.
- Where respondents were invited to offer more than one answer this resulted in large numbers of questions within each response, which meant the need to extract responses from the larger text. This meant the survey results took a significantly longer time to analyse than originally anticipated.
- Given the nature of the survey, the questions asked in the survey elicited very personal responses which were specific to the individual. This meant at times the answers given could be identifying. To maintain respondent anonymity any identifying information was removed.
- Several respondents used the questions asked as an opportunity to share their feedback on the survey itself. This feedback was noted but these questions were not bought forward to the second stage of analysis.

Analysis: Second stage

The second stage of analysis refined the number of questions asked from 1,436 to 175. A process of grouping similar questions was undertaken. Recognising the potential loss of integrity of the original questions, it was decided at every stage to have a method of moving through each stage of refinement to preserve the ability to scrutinise the answers. We identified that having not calculated the frequency of responses at stage one we may lose the weight of these responses and for latter stages a scoring system was used moving forward. It is acknowledged that the prevalence of responses at the first stage was lost by the method used to refine questions during this first stage.

Having identified themes in the first stage of analysis, each response in the second stage was coded with a two-letter code representing the theme and subset as well as a two-digit code per response. Working through one theme at a time, several questions were either used or expanded upon which encompassed as many common responses as possible, for example: “How will…”, “when will…” and “what is needed for…” would be combined to create one question as it related to the subject being referenced. Working through each theme if it was felt the response was already covered by a preceding question, the response code was applied to this question and at times to retain integrity the original response was applied to more than one question. The result of this analysis left 175 questions.

Analysis: Third stage

The third stage of analysis refined the number of questions asked from 175 to 39. This stage applied a similar methodology as the second stage but was undertaken by a different member of the PDA Society team, as an additional check and balance to the analysis undertaken to that point. Similar questions were grouped resulting in 39 groups of questions, and then an overarching question defined using the text from the questions for each grouping. As an outcome, 39 questions were identified which encapsulated the 175 questions that had emerged from the second stage of analysis. These were then further grouped under the nine ‘key questions’ set out in sections 1 and 4 above.

Appendix two: Survey questions

PDA Research Priorities Consultation Survey

Top unanswered questions about Pathological Demand Avoidance (PDA)

Introduction

In this short survey we'll ask you to tell us your top questions about Pathological Demand Avoidance (PDA). The results of the survey will help us to define the top ten "unanswered questions" about PDA. This will then inform a national call-to-action for more high-quality PDA research. The survey is anonymous and will be open until

1. **The next section tells you more about the survey. Would you like to read this or skip and start the survey?** Please select your option and then click 'Next'

   ◯ Go to the next section

   ◯ Start the survey

About the Survey

Context

This year the PDA Society's focus on PDA Day (15th May) is research. More research is key because 70% of people say lack of understanding about PDA is a barrier to getting help, and research will lead to better understanding, improved practice and better outcomes for PDA individuals and their families.

Promoting high quality research, informed by what matters most to the PDA community, is one of our 5-year goals. To do this we're asking you what questions you have about PDA. Your answers will help define the top ten PDA research priorities, informing a national call to action for PDA research.

This survey is open to anyone with an interest in PDA research. You may be a PDA person, a parent of a PDA person, partner of a PDA adult, a professional supporting PDA people, a PDA researcher or have another connection.

Once this survey is closed, we'll analyse the results, identifying common questions and themes. We'll then produce a "long list" of questions and undertake a second survey inviting people to let us know their priorities based on this list. This will then result in a short list of questions, from which the top ten unanswered questions about PDA will be defined.

Terminology

For some the term 'Pathological Demand Avoidance' accurately and appropriately reflects their experience, as their demand avoidance is innate and all-consuming. Others prefer 'Pervasive Drive for Autonomy', 'Pretty Darn Awesome' or another version of the PDA acronym. Professionals may refer to PDA as 'autism with a PDA profile', a 'demand avoidant profile', 'extreme demand avoidance' or use another term. For the purpose of this consultation, we use the term 'PDA' throughout.

Data Processing

This survey is being undertaken by the PDA Society, a registered charity with registration number 1165038. Any personal information shared will be kept on a confidential and secure database in connection with the conduct, analysis, and follow-up of this survey, but won't be used for any other purpose. We won't pass your details on to any third parties. More information about the handling of your data can be found on our PDA Society website. https://www.pdasociety.org.uk/privacy-policy/.

Main Question

2. **What is your top unanswered question(s) about PDA?**

   If you're not sure yet, you can leave this section blank.

3. **The next section includes structured headings to help you think through your top unanswered question(s) about PDA. Would you like to go to this or skip if you've already told us your answer?** Please select your option and then click 'Next'

   - ◯ Go to the next section
   - ◯ Skip the next section

Other Questions

In this section we'll ask you what questions you would like to see answered about PDA under six headings. You can submit multiple questions, a single question or no question at all. If you're unclear what each question is referring to, we've given some examples below.

- **Underlying factors of PDA**
  Which comes first, anxiety or need for control? Can PDA be inherited? What role does the autonomic nervous system play? Might ADHD or other co-occurring conditions be a factor?
- **Identification of PDA**
  From what age can PDA be identified? Can someone be PDA and not Autistic? Is it possible to have a reliable 'scale' for measuring all PDA traits?
- **Experience of being PDA**
  Why can a PDA person do something one day and not the next? What does it mean to have an internalised presentation of PDA? How can you mask and be PDA?
- **Care and support needs**
  What's needed for young people to access learning and adults to access work? What do PDA people need to live independently? How could in-patient units improve care? How do needs change over a PDA person's lifetime?
- **About what helps**
  Do PDA approaches make a difference? What do PDA approaches look like in learning environments versus the workplace? What types of therapies or coping strategies are helpful?
- **Ongoing quality of life**
  How does PDA impact mental health? Are PDA people at increased risk of PTSD from

4. What question(s) do you have about the underlying factors of PDA?

5. What question(s) do you have about the identification of PDA?

6. **What question(s) do you have about the experience of being PDA?**

7. **What question(s) do you have about care and support needs?**

8. **What question(s) do you have about what helps?**

9. **What question(s) do you have about ongoing quality of life?**

10. **Is there anything else to do with PDA or progressing PDA research that you'd like to share with us?**

11. **If you haven't already told us your top unanswered question(s) about PDA and would like to do so now, please tell us here.**

12. **In the next section we ask you to tell us a bit more about yourself. Would you like to go to the next section or skip it?** Please select your option and then click 'Next'

- ◯ Go to the next section
- ◯ Skip the next section

Further Questions

In this section we ask you to tell us a bit more about yourself. This section is optional and you're welcome to select 'prefer not to answer' for any question asked.

13. **Which best describes your interest in PDA? (Please tick all that apply)**

- ☐ PDA adult (over 18)
- ☐ PDA young person (under 18)
- ☐ Parent/Main Carer
- ☐ Spouse/Partner (not carer)
- ☐ Wider family (not carer)
- ☐ Healthcare professional
- ☐ Social care professional
- ☐ Education professional
- ☐ Other professional (e.g. third sector)
- ☐ Academic researcher
- ☐ Prefer not to answer
- ☐ Other

14. **What is your geographic location?**

- ◯ England
- ◯ Wales
- ◯ Scotland
- ◯ Northern Ireland
- ◯ Republic of Ireland
- ◯ Channel Islands
- ◯ U.S.A/Canada
- ◯ Australia/New Zealand
- ◯ South Africa
- ◯ Europe
- ◯ Prefer not to answer
- ◯ Other

What is your ethnic group?

(Choose one option that best describes your ethnic group or background)

15. White

- ◯ English/Welsh/Scottish/Northern Irish/British
- ◯ Irish
- ◯ Gypsy or Irish Traveller
- ◯ Any other white background, please describe below
- ◯ Other

16. Mixed/Multiple ethnic groups

- ◯ White & Black Caribbean
- ◯ White & Black African
- ◯ White & Asian
- ◯ Europe
- ◯ Any other Mixed/Multiple ethnic background, please describe below
- ◯ Other

17. Asian/Asian British

- ◯ Indian
- ◯ Pakistani
- ◯ Bangladeshi
- ◯ Chinese
- ◯ Any other Asian background, please describe below
- ◯ Other