

# BMJ Open Documenting the untold histories of late-diagnosed autistic adults: a qualitative study protocol using oral history methodology

Elizabeth Pellicano <sup>1,2</sup>, Wenn Lawson,<sup>1,2</sup> Gabrielle Hall,<sup>1,2</sup> Joanne Mahony,<sup>1,2</sup> Rozanna Lilley,<sup>1</sup> Catherine Davis,<sup>3</sup> Samuel Arnold <sup>2,4</sup>, Julian Trollor <sup>2,4</sup>, Michael Yudell<sup>3</sup>

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<sup>1</sup>Macquarie School of Education, Macquarie University, Sydney, New South Wales, Australia

<sup>2</sup>Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia

<sup>3</sup>Dornsife School of Public Health, Drexel University, Philadelphia, Pennsylvania, USA

<sup>4</sup>Department of Developmental Disability Neuropsychiatry, University of New South Wales, Sydney, New South Wales, Australia

## Correspondence to

Professor Elizabeth Pellicano;  
liz.pellicano@mq.edu.au

## ABSTRACT

**Introduction** Receiving a diagnosis of autism in adulthood is increasingly common for a subset of individuals who were either misdiagnosed in childhood or missed out on a diagnosis altogether. This qualitative study, coproduced with autistic people, invites late-diagnosed autistic adults to share their life histories to (1) understand better the consequences of living without a diagnosis, (2) elucidate what precipitates an autism diagnosis in mid-to-late adulthood and (3) identify the perceived impact of receiving that diagnosis.

**Methods and analysis** Oral histories have been a successful way to uncover overlooked and marginalised voices. We therefore adopt qualitative, oral history methodology in this study to understand these adults' experiences, especially of living in an era when autism was not well known. We will recruit 24 participants who will (1) have been born before 1975, (2) have received a clinical, autism diagnosis after the age of 35, (3) be English-speaking and (4) have spent most of their childhood and adulthood living in Australia. Participants will take part in four sessions, including the main, qualitative, oral history interview, through a range of possible formats to facilitate inclusion. The interview data will be analysed using reflexive thematic analysis.

**Ethics and dissemination** The protocol has received institutional research ethics approval from Macquarie University's Human Research Ethics Committee (Ref.: 52019556310562). This study will yield understanding of the life experiences of autistic adults, especially middle-aged and older Australians, should inform more effective diagnostic practices and provide insight into the key factors that might promote resilience and enhance quality of life in autistic people. The findings will be disseminated to academic and clinical audiences through journal articles and conference presentations and to the autistic and autism communities through accessible reports. The interviews will also be prepared for digital archiving, which will enable ongoing access for future generations and communities.

## INTRODUCTION

Autism was once a rare diagnosis.<sup>1</sup> Yet this is no longer the case, with prevalence estimates

## Strengths and limitations of this study

- This study is a collaboration between non-autistic academic partners, autistic coresearchers and an Autistic Advisory Group, who all actively participated in making decisions about the research and ensured that the methods are thorough, respectful and supportive of our autistic participants.
- Oral histories will offer a detailed and granular understanding of the individual and collective experiences of those interviewed and can provide clinicians, policymakers, service providers, researchers and the broader autism community insight into these lives.
- A selection bias may exist, particularly towards those who are willing to consent and able to convey orally their life history.
- The oral histories reflect the experiences of specific late-diagnosed autistic adults and may not be generalisable to other autistic adults in Australia, other countries or cultural groups.

in high-income countries of between 1% and 2%.<sup>2,3</sup> The rise in autism prevalence is often attributed to the expansion of the diagnostic criteria for autism in the late 1980s and 1990s,<sup>4</sup> including recognition of an autism 'spectrum'<sup>5</sup> and greater public awareness.<sup>6</sup> Many individuals being diagnosed as adults, even as older adults,<sup>7</sup> were either misdiagnosed in childhood or never diagnosed—leading to what some have referred to as the 'lost generation' of autistic adults<sup>8</sup> (we use 'identify-first' language ('autistic person') rather than person-first language ('person with autism'), because it is the preferred term of our autistic coresearchers, of autistic activists<sup>9</sup> and many autistic people and their families<sup>10</sup> and is less associated with stigma).<sup>11</sup>

Being diagnosed as autistic in adulthood is not straightforward.<sup>12</sup> Autistic adults in the UK have reported an average diagnostic delay of just over 5 years, from the point at



which they first considered they may be autistic until receiving an autism diagnosis.<sup>13</sup> Less than half of these adults reported ‘satisfactory’ experiences of the diagnostic process, often feeling misunderstood, ignored and even dismissed by health professionals—sentiments that appear especially true for autistic women.<sup>14–16</sup> General practitioners acknowledge the particular complexity of diagnosing adults, especially in light of common, co-occurring mental health conditions<sup>17</sup> and the lack of clarity with regards to the referral pathways.<sup>18</sup>

Qualitative work has yielded some insights into the reasons why adults seek a diagnosis. Many reports seeking help and/or an autism diagnosis during treatment for a mental health condition such as anxiety or depression.<sup>13,14</sup> Others realise that they might be autistic while navigating the diagnostic process on behalf of their children.<sup>19</sup> Many also report that a persistent feeling of being somehow different from others<sup>20</sup> often leads them to seek a diagnosis.<sup>21</sup> While the diagnostic process and its immediate aftermath are often perceived to be an ‘emotional roller-coaster’,<sup>16,20</sup> many adults report the ways their lives have changed for the better since receiving a diagnosis and formally identifying as autistic.<sup>22</sup> Despite often-significant ongoing challenges in their everyday lives, with little or no postdiagnostic support,<sup>13,23</sup> they nevertheless describe a period of self-discovery and acceptance<sup>16,20,21</sup> and a sense of belonging as they engage with others in the autistic community.<sup>24,25</sup>

Much less is known, however, about what late-diagnosed adults’ lives were like before they received an autism diagnosis—and especially how they survived, thrived and/or experienced distress. Normative approaches to autistic adult outcomes, which focus on the rates of employment or postsecondary education, living independently and having friends, often paint a discouraging picture of their lives.<sup>26,27</sup> There is a limited understanding, however, of what a ‘good life’ means to autistic people and which factors play a critical role in helping them to participate in education, employment and community life, in the ways that matter most to them.<sup>28</sup> These factors, for the most part, have remained elusive, especially for those individuals without an additional intellectual disability.<sup>27,29</sup> Listening to, and learning from, the life histories of those who went through childhood without a diagnosis could serve better to inform diagnostic practices and ways of improving the lives of autistic people, though identification of risk and resilience factors and appropriate support.

This project, coproduced with autistic people, seeks to do just that using oral history methodology. In oral history projects, the aim is to record recollections of people and groups to preserve their voices and stories. This material provides historians and other social scientists with access to the source material of enormous depth, breadth and potential.<sup>30</sup> Oral histories allow for a multitude of points of view and give a voice to individuals and groups who have been marginalised in conventional histories, by allowing them to tell their own stories.<sup>31,32</sup> While there is a burgeoning

literature on qualitative research examining the lived experiences of autistic people and their families,<sup>33</sup> the use of oral history—which situates people’s stories within a particular time and place—has rarely been used.

In this study, we adopt oral history methodology to understand the life histories of a particular group of individuals: those who are now in mid-to-late adulthood and who grew up at a time when autism was virtually unknown both to the medical community and the general public. We also plan to make these oral history interviews accessible online, providing interested scholars and the public with easy access to a record of the lives of those interviewed.

## METHODS AND ANALYSIS

### Study aim

This study aims to understand late-diagnosed adults’ life histories and experiences and, in so doing, to identify some critical factors that promote the life chances and opportunities of autistic people.

### Objectives

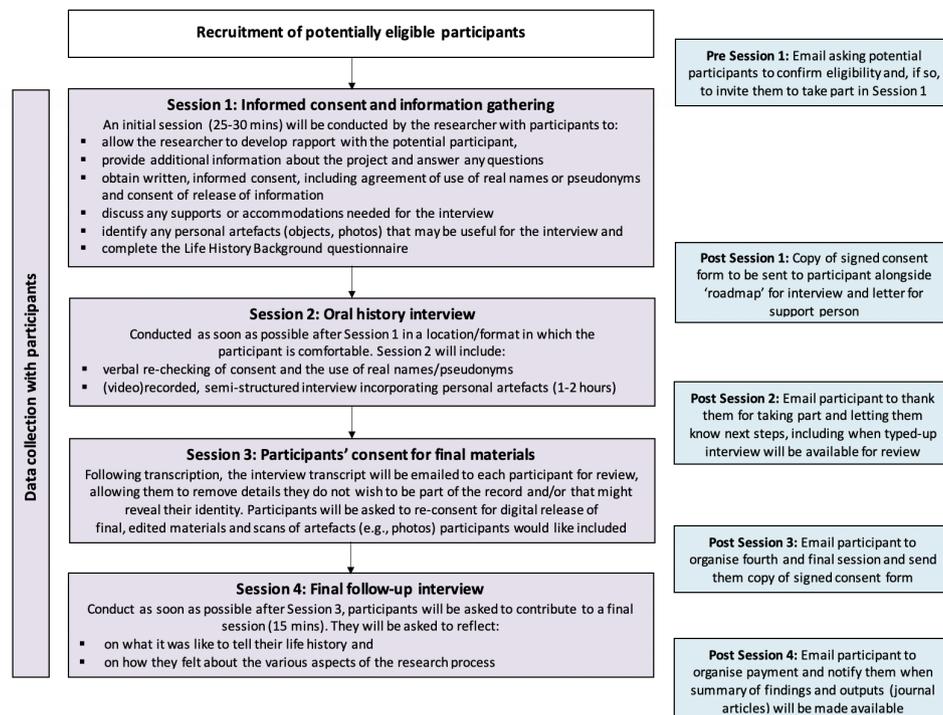
1. To conduct oral history interviews with late-diagnosed autistic adults in order to (a) understand better the consequences of living without a diagnosis for a significant portion of their adult lives, (b) elucidate what precipitates an autism diagnosis in mid-to-late adulthood and (c) identify the impact that receiving a diagnosis has had on their lives.
2. To situate these adults’ views and experiences within a particular time and place in recent history.
3. To prepare these interviews for digital archiving and therefore access for future generations and communities.

### Study design

A qualitative, oral history study in which we adopt a disability oral history approach,<sup>34</sup> record the stories related to a person’s sense of self and their perceptions and actions set within a historical context. It is underpinned by the beliefs that (1) the late-diagnosed autistic adults have unique experiential expertise of their (positive and negative) experiences both before and after having received an autism diagnosis and (2) oral history methods provide the opportunity to determine a shared set of experiences and group identity. Our design allows for in-depth reflection from interviewees and also examines the broader social context of living as autistic before and after a diagnosis in Australia.

### Sample and recruitment

Late-diagnosed autistic adults will be recruited via community contacts through convenience sampling (snowballing) methods. We will rely on referrals from an initial group of participants (through the Cooperative Research Centre for Living with Autism; ‘Autism CRC’) to generate additional participants, through Australian self-advocacy groups, clinician and researcher networks and, especially,



**Figure 1** Schematic of study design.

social media (Twitter, Facebook) and online fora, where there is a vibrant autistic community.

Our aim is to interview 24 adults, with a preference for a range of genders,<sup>35</sup> to capture the heterogeneity of autistic experiences and to ensure a sufficient number of oral histories for archival purposes. To be eligible, participants must (1) be born before 1975, that is, before autism appeared in the Diagnostic and Statistical Manual-III<sup>36</sup> and before the beginning of the surge of autism diagnoses in the 1980s, (2) have received a clinical diagnosis of an autism spectrum condition after the age of 35, (3) be English-speaking, (4) have spent most of their childhood and adulthood living in Australia and (5) provide written informed consent. These inclusion criteria, developed in collaboration with our autistic partners, sought to ensure that participants had spent their childhood and a significant portion of their adulthood living without an autism diagnosis and perhaps not knowing they were autistic and had grown up at a time when autism was unknown to clinicians, educators and the broader public. These criteria also meant that we captured the currently under-served group of individuals in mid-to-late adulthood.<sup>37</sup>

### Data collection

Participants' involvement comprises four separate sessions (figure 1). In *Session 1* (~60min), participants meet the interviewer via high-quality web conferencing (or an alternative, preferred format such as face-to-face, if feasible, over the phone or via email) to establish rapport, give informed consent to take part in the study, discuss the required paperwork and the main interview questions and the potential inclusion of artefacts (photographs, objects) to prompt discussion during the oral history. Interviewers

also encourage participants to (1) identify specific supports or accommodations during or after the main interview (*Session 2*) and (2) nominate a 'support person' (eg, a trusted carer, partner or friend). Following *Session 1*, participants are sent a list of main interview questions, a personalised support person letter and a bespoke list of local psychological support services/organisations in case of distress during the main interview (see below).

Soon after, participants meet with the interviewer once again for *Session 2* (~1–3 hours). This session conducted via the participants' preferred means of communication (either via high-quality web conferencing, face-to-face, if feasible, or over the phone or email), comprises the main, digitally recorded oral history interview. The interviewer begins by verbally rechecking participant consent. Participants are then asked questions about different life stages to (1) ascertain how individuals later diagnosed as autistic lived with their differences in an era when autism was less known, (2) show how individuals survived, thrived or experienced distress and adversity, without a diagnosis, (3) identify which factors influenced individuals to seek out a diagnosis and (4) understand the differences in their lives pre and postdiagnosis (see online supplementary file 1). The interview is semistructured, with the interviewer asking several open-ended questions that are sufficiently flexible to allow the interviewee to tell their life history in their own way. Prompt questions help the interviewer to gain more detailed information. Participants are also encouraged to incorporate any personal artefacts into the telling of their life history, which will be scanned/photographed for later archiving, alongside the digitised interview.



Traditionally, oral histories have been recorded face-to-face. In this project, we anticipate that most interviews will be conducted via web conferencing, according to the preferences of participants and interviewers (all of whom are late-diagnosed autistics; see below), but participants will be able to choose to take part through their preferred format, if feasible. Zoom web conferencing facility (<https://zoom.us>), which has audio-visual recording capabilities, is the preferred platform. We are using Zoom H5 recorders for face-to-face recordings (which record WAV files with a sampling rate of 48 kHz and a sampling resolution of 24 bit) with two external microphones (Rode M3, stand-mounted—one recording the Zoom online audio and another the interviewer). The interviewer uses over-ear headphones (Sennheiser HD 280 Pro) during setup to check the sound quality of the recording, including checking for extraneous noises.

Approximately 1 month after the main interview, the interviewer contacts the participant to take part in *Session 3* (~30 min), conducted via web conferencing or another preferred format. Prior to this session, the interviewer sends the interview transcript to the participant for review. At this point, they are able to remove details that they do not want to include in the final record, including any scanned personal artefacts. After reviewing the materials, participants are asked to consent for digital release of the final, edited (if requested) materials.

Finally, and soon after *Session 3*, the participant is invited to take part in *Session 4* (~15–30 min), during which they will be asked to offer their thoughts and reflections on the experience of telling their life history, and on the research process itself. Specifically, they were asked (1) why they were interested in sharing their life history (and making it publicly accessible—or not), (2) what they thought/hoped this project might achieve and (3) their experiences of being interviewed by an autistic, as opposed to a non-autistic, researcher.

The first three sessions are being conducted by research assistants who are late-diagnosed autistics (GH and JM) and the final session by senior researchers (EP and WL).

### Patient and public involvement

Participatory methods are garnering momentum in autism research as a means of ensuring that research is relevant to people's lives, tailored to their needs and consistent with their values.<sup>38–41</sup> In the spirit of this approach, this protocol has been designed and implemented in partnership with autistic people, especially those with experiential expertise of receiving a late (adult) diagnosis. Our approach follows the National Health and Medical Research Council<sup>42</sup> statement on consumer and community engagement and the UK's INVOLVE guidelines<sup>43</sup> to ensure genuine (non-tokenistic) involvement. The research team includes four autistic coresearchers (WL, CD, GH and JM), three of whom (WL, GH and JM) are late-diagnosed and two of whom (GH and JM) are employed as research assistants on the project. These autistic coresearchers have been actively involved since

the beginning of the project, resulting in collaborative decisions in regards to methodology, including eligibility criteria, sampling characteristics, the nature and content of each interview and the procedure itself (see [figure 1](#)). Their involvement ensured that the methods described in this protocol are thorough, respectful and supportive of our autistic participants' needs and wishes.

The project has also had input and oversight from an Autistic Advisory Group comprised of three autistic adults who are reimbursed for their time and expertise. The Autistic Advisory Group provided detailed feedback on the data collection methods and participant information (including inclusion criteria), especially encouraging the use of Plain English text throughout; the inclusion of images to accompany text and the reformatting of documents to include more space making them easier to read. All study information documents were significantly revised following their input. We will use the Guidance for Reporting Involvement of Patients and the Public - 2 (GRIPP2) guidelines<sup>44</sup> to ensure quality reporting of our community involvement in the published articles.

### DATA ANALYSIS

Interviews are transcribed verbatim and the data are analysed using thematic analysis.<sup>45</sup> Our analysis will adopt an inductive ('bottom up') approach (ie, without integrating the themes within any pre-existing coding schemes or preconceptions of the researchers) to identify patterned meanings in the data set within an essentialist framework (to report the experiences, meanings and reality of the participants).

Since thematic analysis is an active process of construction, two to three researchers will begin by reflecting on how their positionality impacts data interpretation. Next, the researchers will independently familiarise themselves with the data by listening to and watching the recordings and (re)reading the transcripts. Codes will then be assigned to the data extracts. The analysis team will confer regularly to discuss preliminary codes and agree on consistent codes that could be applied to each transcript for all groups, recoding the initial transcripts where necessary. The team will liaise several times to review the themes and subthemes, focusing on semantic features of the data (ie, 'staying close' to participants' language), checking to ensure that themes are coherent for coded extracts and the entire data set, resolving discrepancies and deciding on the final definitions of themes and subthemes. Analysis will therefore be iterative and reflexive, moving backwards and forwards between data and analysis.

### ETHICS AND DISSEMINATION

#### Informed consent

Participants are asked to provide informed, written consent to (1) take part in the interviews, (2) identify themselves in the resulting outputs, (3) digitally record the interviews and (4) preserve the interviews and other

approved archival materials in a publicly accessible online location. They will be asked to provide consent in Session 1 and confirm it in Sessions 2 and 3. Participants may withdraw from the research project, without prejudice or consequence, until the time at which the materials are analysed and/or made available in a digital repository.

### Ethical considerations

Ethical approval for the current study was obtained from Macquarie University's Human Research Ethics Committee (Ref. no: 52019556310562). Three specific ethical issues were highlighted, including (1) confidentiality and anonymity, (2) power dynamics and (3) researching potentially sensitive topics.

### Confidentiality and anonymity

Critically, it is common practice in oral history methods to *identify* participants, in the same way that individuals are usually identified in historical narratives. This approach is markedly different from most published research on autism, which deidentifies participants as is the norm in qualitative social science. The decision not to deidentify people reflects a deliberate effort to enable participants to claim ownership of their own history.<sup>46</sup> The Participant Information and Consent (PIC) Form (see online supplementary files 2 and 3) clearly states that the participant may choose whether to allow their identity and image(s) to be revealed. The digital recordings and transcripts from the main interview (Session 2) will therefore *not* be anonymised unless specifically requested by participants. If participants wish to remain anonymous, potential identifiers will be omitted or masked (names, countries, organisations, voice and so on) and a pseudonym will be used.

We aim to archive the audio-visual recordings, unless there are technological issues with these recordings, if participants express a preference for the video footage not to be archived, or if they have chosen to remain anonymous. Participants will have the opportunity to examine their materials in Session 3 and decide if and how their materials will be archived.

Some participants may be willing to consent to take part in the interview, but not to be recorded and/or to make their recordings publicly available. In these cases, participants' wishes will be respected, and their transcriptions (if consent was provided for recording) or interviewer notes (if consent was not provided for recording) will be used only for thematic analysis.

Original hard copies of interview consent forms will be stored securely. These are scanned and stored electronically, along with interview transcripts and recordings, on a secure online server (CloudStor). Only the research team has access to these hard copies and electronic files. Unlike the interview and materials from Sessions 2 and 4, the information that participants provide in the Life History Background Questionnaire (completed prior to Session 2; see online supplementary file 4) remains confidential. Participants are provided with identity (ID)

numbers and these are used on this questionnaire. The resulting data are kept securely in both hard copy and electronically. Data are stored in a separate location from that containing the name-ID number associations. Participants' 'materials' (as defined in the Consent for Release Form; see online supplementary file 2) are retained in perpetuity (with participants' written, informed consent).

### Power dynamics

In research, there is typically a power imbalance between the researcher and the participant ('the researched'), such that the researcher directs the process while the participant responds.<sup>47</sup> This power imbalance is especially salient in the field of autism, in which autistic adults report feeling disenfranchised in the research process.<sup>48</sup> Researchers are encouraged to reduce these power differentials by effectively eliciting the opinions of seldom-heard voices and valuing them as experts by experience,<sup>49</sup> thus reducing the epistemological divide.<sup>50 51</sup>

We have sought to minimise the power differential in four ways. First, our use of oral history methods, which literally gives 'voice' to marginalised and seldom-heard communities.<sup>52</sup> Second, we have adopted a participatory approach in which autistic partners have been involved—and thus shared power—in the project's decision-making. Third, we provide participants with detailed information about each stage of the process (including providing the main interview questions) in order to help address feelings of uncertainty and of being objectified. Finally, the oral history interviews are being conducted by late-diagnostic autistic research assistants, which we hope will enable empathetic interactions. This approach is consistent with Milton's<sup>53</sup> theoretical account – which suggests that those with similar experiences can more straightforwardly form connections and mutual understanding – and with empirical work,<sup>54</sup> which demonstrated greater rapport and more effective communication between matched (autistic–autistic) than mismatched (autistic–non-autistic) dyads in a communication task. Consequently, it is hoped that participants will feel respected in the research process.

### Researching potentially sensitive topics

People often gain an important sense of satisfaction from telling their life history<sup>46 52</sup> but it is possible that participants may also experience challenging emotions and recollections, despite being willing interviewees. This issue is important for autistic adults, who may have experienced, or are currently experiencing, additional mental health issues, including suicidal ideation,<sup>55–58</sup> and trauma.<sup>59</sup> We sought to mitigate this potential risk in five ways. First, in Session 1, prior to the main interview, the interviewer discusses the PIC Form with participants, highlighting the possibility that some issues raised during the interview could be emotional for them. The interviewer asks the participant to identify a support service (eg, a local doctor) or trusted person. Even if they do not wish to nominate any such service/person, the participant



is provided with a dedicated letter for a support person, which provides information about the project and reasons why the participant might get in touch (see online supplementary file 5), in addition to a bespoke list of contact details of local psychological support services.

Second, during Session 2 (the main interview), participants are able to take a break at any stage of the interview and/or tell us that they would prefer not to answer a particular question. During Sessions 1 and 2, the interviewer discusses potential ways for participants to let the interviewer know that they would like a break/to stop (see online supplementary file 1). They are also able to stop the interview at any time—without giving a reason.

Third, to manage any instances in which the participant shows distress during the interview, our interviewers have been prepared by senior researchers and psychologists (WL and EP) and adhere to a specific protocol,<sup>60</sup> which provides a step-by-step procedure to guide interviewers' responses to such distress (see online supplementary file 6). If a researcher notices that any participant is visibly distressed, or the participant reports their distress, the researcher will suggest a break and ask whether the participant would like to continue the interview. If the distress is sufficiently marked, the researcher will stop the interview immediately and follow the procedures in the protocol, referring specifically to the participant's preferred support provider/person and other key contacts (local psychological support services, anonymised helplines).

Fourth, immediately following the main interview—and even if the participant did not show any obvious signs of distress—the interviewer encourages the participant to speak to their designated support person or to a local psychological support service/national (anonymised) mental health helplines if they have felt worried or upset as a result of their interview discussions. Our interviewers will offer to contact the participant's support person or any of the listed psychological support services on their behalf, if preferred by the participant.

Finally, the day after their main oral history interview, we email the participant to thank them for taking part and also to check on how they are feeling. We also provide the participant with details of psychological support services and helplines and encourage them to speak to their support person.

It is also possible that significant issues might be raised for our autistic researchers, who also received late diagnoses. They too have been asked to (1) consider specific ways of looking after themselves both before and after the interviews with participants, (2) check-in with senior researchers and (3) seek external help and advice, when necessary.

## DISSEMINATION

Participants' testimonies will represent a significant piece of autistic/disability history and, in the spirit of oral history projects around the globe, others may wish to use this information for their future research. We

will therefore ensure that these interviews are digitally archived and made publicly available for ongoing access by interested others, into the future.

Furthermore, the findings and learnings from these adults' life histories will be disseminated to academic and clinical audiences through journal articles and conference presentations and to the broader autistic and autism communities through an accessible report and visual snapshot.

**Twitter** Elizabeth Pellicano @liz\_pellicano, Julian Trollor @3DN\_UNSW and Michael Yudell @publicshealth

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not required.

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## ORCID iDs

Elizabeth Pellicano <http://orcid.org/0000-0002-7246-8003>

Samuel Arnold <http://orcid.org/0000-0003-2900-223X>

Julian Trollor <http://orcid.org/0000-0002-7685-2977>

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