



Developing a quality-of-life measure for autistic children and young people in schools

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Abstract

Aim: To develop a quality-of-life measure to be used by both school staff and autistic children and young people (CYP) in schools, in which public and community involvement (PCIE) is at the heart of the research. **Method:** A prevalence questionnaire survey will be conducted with 20 primary and secondary schools across Kent, Surrey, and Sussex (KSS). 10 semi-structured interviews will be conducted with autistic CYP. This will inform development of a quality-of-life measure for autistic CYP. **Results:** Work so far has included PCIE in the early stages of the project, in which young people, school staff and collaborators have contributed to the study set up and designing study materials. **Conclusion:** With PCIE included in the planning of the project, the research team is confident that this will be useful further along in the project with dissemination and validating and implementing a quality-of-life measure for autistic CYP in schools.

Introduction

Referrals for autism assessment are increasing, with mean referral rates doubling between 2015 and 2019¹. With it taking a year or more to reach a diagnostic conclusion², autistic children and young people are left unidentified and without access to support they desperately need. A lack of support can impact on an autistic child's outcomes in adult life, including living independently, job employment and retention, having social relationships, experiencing poor mental health and quality-of-life^{3,4,5,6,7,8}. These problems can be exacerbated in areas of deprivation, where the prevalence of autism is seldom reported, like in Kent Surrey and Sussex^{9,10}. Despite this, there are limited specific measures of quality-of-life for autistic children. The Paediatric Quality of Life Inventory (PedsQL) has been used to measure quality-of-life in autistic CYP, however, this is a generic measure of quality-of-life in children. There is also a quality-of-life measure for autistic adults (ASQoL)¹². Given the evidence around negative outcomes for autistic adults, it is paramount to identify and intervene early to improve their overall quality-of-life as they enter adulthood.

Aim: To develop a quality-of-life measure for autistic children to be used in schools to advocate and prescribe for their own needs.

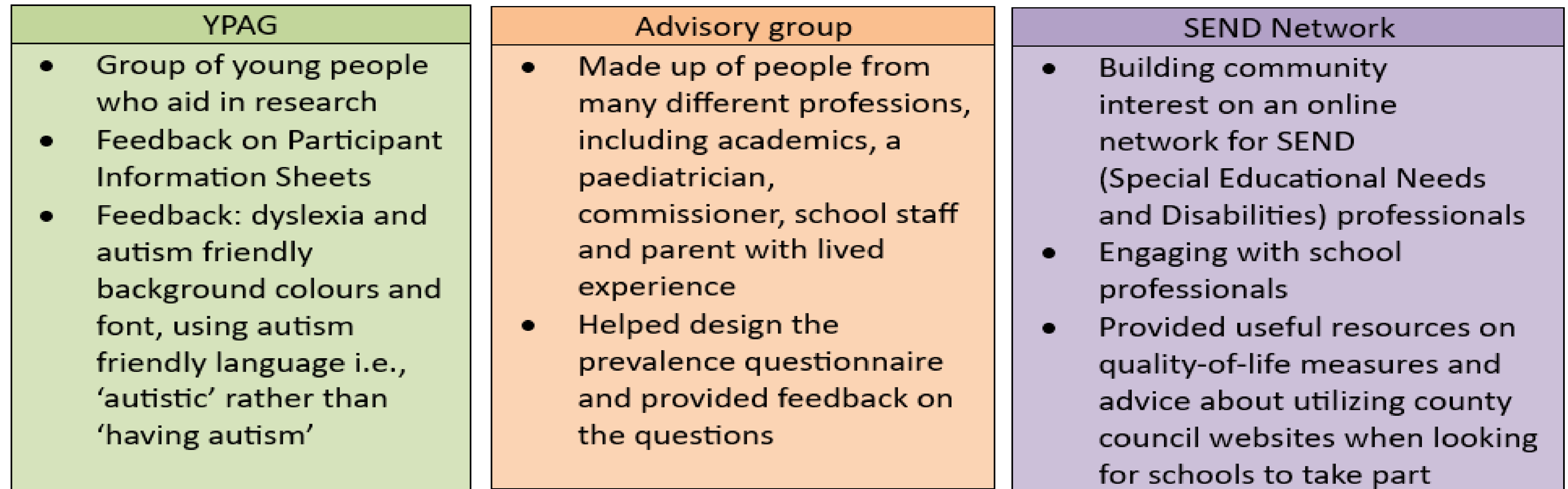


Figure 1. Public and community involvement so far.

Methods

Firstly, a prevalence questionnaire will be administered across 20 schools (10 primary, 10 secondary schools) to get an estimate of autism prevalence in KSS. The questions will focus on:

- How many children are on the school roll?
- How many children have a diagnosis of autism?
- How many children are suspected of being autistic?

Secondly, 10 semi-structured interviews with autistic CYP will be conducted. The purpose of these interviews will be to find out what support is currently in place for autistic CYP in school and what they need to help them manage their autism and the issues they face daily.

So far

An important part of this research in these early stages is involving the public and working with people from different backgrounds to gain new perspectives. This includes working with:

- **Young Person's Advisory Group (YPAG)** providing feedback on study materials, including Participant Information Sheets
- **Expert Advisory Collaborator Group** providing feedback on school prevalence questionnaire
- **SEND Network** providing advice and strategies for recruiting from schools

Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	
Broadening literature review																						
Writing protocol and applying for ethics																						
Recruitment																						
Data collection																						
Data analysis																						
Final report writing																						
Dissemination events																						
Supervisor meetings																						
Advisory group meetings																						
YPAG meetings																						

Figure 3. GANTT chart of study activities.

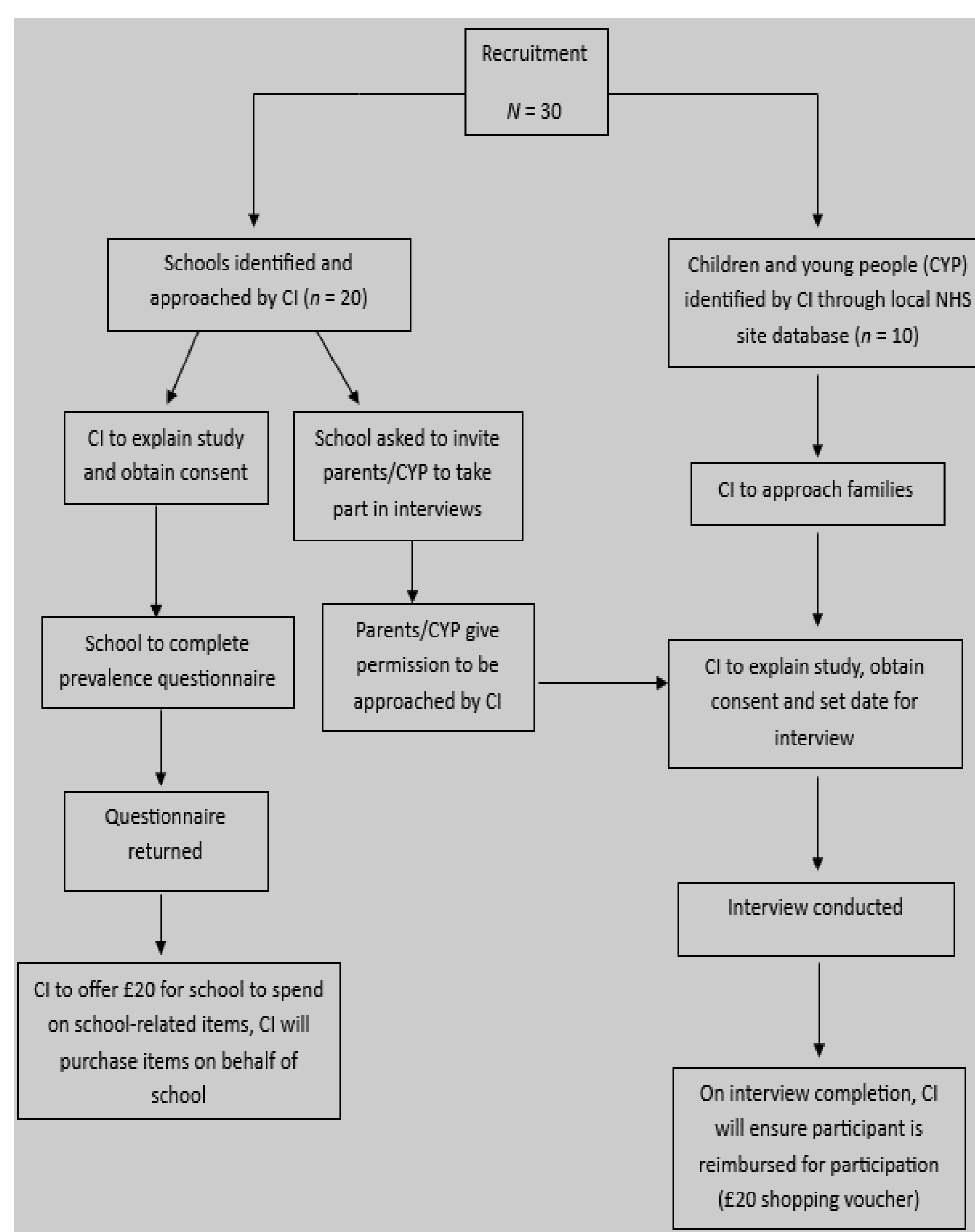


Figure 2. Participant flowchart.

Next steps

In the next stages of the project, PCIE will be embedded into the recruitment, data collection and dissemination of the findings, for example:

- Feedback to YPAG again with initial findings at halfway point
- Working with schools, who will assist with recruitment
- Dissemination of the findings and working with schools and young people to validate and implement the use of the quality-of-life measure in schools

What this research adds

Developing a quality-of-life measure for autistic CYP will allow for self-advocacy and for autistic CYP to prescribe for their own needs. Autistic CYP will be able to voice the support they need and provide school staff with a tool to provide support, regardless of diagnosis status and waiting lists.

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References

1. Parr, J., Wigham, S., Farr, W., Reddy, V. and Male, I. (2021) 1123 UK childhood autism diagnostic services survey 2020: Evidence for challenges and innovations. *BMJ Publishing Group Ltd.*
2. Male, I., Farr, W., Bremner, S., Gage, H., Williams, P., Gowling, E., Honey, E., Gain, A. and Parr, J. (2023) An Observational Study of Individual Child Journeys through Diagnostic Pathways, and Associated Costs, in the UK National Health Service. *Frontiers in Rehabilitation Sciences*, 4.
3. Hendricks, D. R. and Wehman, P. (2009) Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24, pp. 77-88.
4. Howlin, P., Moss, P., Savage, S. and Rutter, M. (2013) Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52, (6), pp. 572-581.
5. Kirby, A. V., Baranek, G. T. and Fox, L. (2016) Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *OTJR: Occupation, Participation and Health*, 36, (2), pp. 55-64.
6. Levy, A. and Perry, A. (2011) Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*, 5, (4), pp. 1271-1282.
7. Magiati, I., Tay, X. W. and Howlin, P. (2014) Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34, (1), pp. 73-86.
8. Seltzer, M. M., Shattuck, P., Abbeduto, L. and Greenberg, J. S. (2004) Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10, (4), pp. 234-247.
9. Leekam, S. R., Nieto, C., Libby, S. J., Wing, L. and Gould, J. (2007) Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders*, 37, (5), pp. 894-910.
10. Tebrugge, M., Nandini, V. and Ritchie, J. (2004) Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders?—An epidemiological study in Kent, UK. *BMC Pediatrics*, 4, (1), pp. 1-7.
11. Varni, J. W., Seid, M. and Rode, C. A. (1999) The PedsQLTM: Measurement model for the pediatric quality of life inventory. *Medical Care*, 37, (2), pp. 126-139.
12. McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C. and Rodgers, J. (2018) Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders*, 48, pp. 1596-1611.