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N. Stogiannos, J.M. Harvey–Lloyd, B. Nugent, A. Brammer, S. Carlier, K. Cleaver, J.P. McNulty, C. Sá dos Reis, C. Malamateniou,

Autism-friendly MRI: Improving radiography practice in the UK, a survey of radiographer practitioners

Introduction

Autism spectrum disorders (ASD) refer to a wide spectrum of disorders, ranging from mild to severe signs and symptoms.1 Clinical manifestations of these disorders exhibit great variations depending on age, language level and cognitive ability.2 The prevalence of ASD has reportedly increased during the last five years; a United Kingdom (UK)-wide study attributes the increase in prevalence rates to a better diagnosis of ASD.3 It has been estimated that the prevalence of autism in the UK is around 1%,4 with more than 700,000 autistic individuals living in the UK. The United States (US) Department of Health and Human Services has recently reported that one out of 54 children aged eight years old has been identified as autistic.5,6 With regards to gender, males are three times more likely to be affected by ASD compared to females.7 However, much of the prevalent data of autism relates to our assumed understanding of its aetiology and a presumption that ASD has been correctly identified in the first instance. Our ability to accurately diagnose ASD early, by understanding the signs and symptoms, as well as how they may present in both sexes, is impacted by a lack of evidence. Autistic individuals may experience challenges in social interaction and both verbal and nonverbal communication.8 Moreover, some restricted and stereotyped behaviours and activities can often be identified among autistic patients.9 Hyper- or hypo-reactivity to sensory stimuli, avoidance of eye contact, difficulties to interpret gestures and body language and impaired social skills, are all associated with ASD.10 In addition, autistic individuals exhibit higher rates of depression and anxiety symptoms compared to neurotypical individuals.11

Early and accurate diagnosis is vital for autistic people in order that they benefit from evidencebased early interventions, which can improve their quality of life. It has been reported that ASD can be safely diagnosed by the age of two.12 However, socioeconomic status, race, ethnicity, gender and ASD severity may have a significant impact on the age at which diagnosis is made.13,14 Evidence shows that Caucasian children are more likely to be diagnosed as autistic compared to Black or Hispanic children, hence creating discrepancies and enhancing health inequalities between these groups.15 A diagnosis of autism can sometimes be confirmed by an MRI scan. MRI scans can also be used to identify common clinical concerns such as musculoskeletal, migraines or injuries after accidents or falls, as in the neurotypical population.

The narrow bore of the MRI scanners, the acoustic noise from the gradients and the fact that scanning often occurs in isolation without a clinician present, in conjunction with the increased rates of anxiety and sensory sensitivities reported among autistic individuals, may pose significant challenges to patients when undergoing MRI examinations. Some of these patients may safely undergo MRI scanning only under sedation or general anaesthesia which, in some cases, may have unwanted side-effects, such as respiratory depression, and inability to maintain an airway. Such

procedures also involve significant extra time and resources.16,17 There is currently a small but growing body of evidence on how to optimise healthcare for autistic service users,18,19 the lack of which has been shown to result in poor health quality and outcomes for this population.18 The lack of customisation and personalisation of healthcare services also extends to medical imaging and specifically to MRI, but information is still sparse. This study aimed to explore the perspectives of UK radiographers in relation to MRI scanning of autistic individuals, to map out their current knowledge and understanding in relation to autism, to understand radiographic practices and approaches used for autistic service users, and to identify potential training needs for the radiography workforce in these areas. This is a pilot study, part of a wider study, which has performed a systematic review of the currently available adjustments in the field of MRI scanning,17 and also another survey which is addressed through the autistic service users.

Methods

This study received research ethics approval through the School of Health Sciences, City University of London Research Ethics Committee under the ethics reference number ETH1920-1988.

The study employed a mixed methods questionnaire design, as both qualitative and quantitative elements have been used.20 The data collection tool consisted of an online survey with 23 questions (see online supplementary material).

The questionnaire was constructed online, using a dedicated survey software called Qualtrics (Qualtrics, Provo, Utah, USA), for ease of distribution and for facilitating preliminary data analysis. A pilot questionnaire was tested by five expert practitioners and researchers before online distribution to ensure its face and content validity.21

This questionnaire included both open-ended and closed type questions, which corresponded into the following categories: a) general demographics of radiographer practitioners, b) assessing radiographic practice before, during and after the MRI scan of autistic individuals, c) knowledge, experience and understanding of autism by practitioners and their ability to recognise autistic patients, d) training gaps and needs of radiographer practitioners, e) barriers and facilitators to making a MRI scan truly autism-friendly, and f) availability and knowledge of local protocols and legislation for the care of autistic service users. Finally, the respondents were encouraged to write any comments and/or suggestions related to scanning autistic patients in the MRI context. Data was collected anonymously to ensure respondents would feel free to report challenging cases and poor practice without worrying that, either their accounts would be scrutinised, or that professional relationships with colleagues would be compromised, both of which fall beyond the scope of this project.

All UK MRI radiographers were invited to fill in this questionnaire. A snowball sampling technique was employed, as optimal to capture the perspectives of the wider MRI radiographer community in the UK22 from the National Health System (NHS), private, and research clinical settings. This technique is a cost-effective way of sampling and facilitates recruitment of hard-to-reach populations,23 but needs constant monitoring of responses and thorough data cleaning.

This survey was electronically distributed by three main recruitment agencies after gatekeeper's approval was gained (The Society and College of Radiographers, the British Association of Magnetic Resonance Radiographers, and the Scottish MRI Leads Group), as well as to the co-authors' research and professional networks of MRI radiographers across the UK. The survey was forwarded to agencies' leads who distributed it to their members and also advertised it on their social media pages on Twitter, Facebook and LinkedIn.

The survey was launched on December 16, 2020, and the data collection period lasted for two months, until February 15, 2021. Electronic reminders were sent out once monthly by the researchers to the gatekeepers during the data collection period, a well-established technique to increase the response rate in online surveys.24

Data analysis was performed using the SPSS statistics software, version 26 (IBM, SPSS Inc., Chicago, USA). Descriptive statistics was used to interpret the results in terms of absolute numbers and frequencies, such as basic demographics, while graphs were also used to depict correlations, when useful and relevant.

Key points were classified in themes using a thematic analysis methodology for all open-ended questions, adapted for simplicity from Braun and Clarke.25

Results

A total of 130 valid responses were received, after data clearing and removal of partial or incomplete responses. Valid responses included all those where all of the demographics and some of the practice-based questions were included; this corresponded to approximately a 50% completion of the questionnaire and answers with over 30% completion were also hand-searched to ensure no meaningful data was missed and were included in the analysis. Different questions received different number of responses. The percentages presented in the results of this study refer to the number of responses received for each question, as not all questions were equally answered by the respondents.

Demographics

Table 1 below summarises the demographic data of all the participants. The respondents (n ½ 130) were mainly female radiographers, accounting for 71.5% of the responses (Table 1). This is reflective of the proportion of females to males in the profession (77% of radiographers are female) (personal communication with the Society of Radiographers). Also, most of the respondents were MRI radiographer practitioners (74.6%), followed by Superintendent radiographers (19.2%). There was a good distribution of experience among the respondents, with over half of them (52.3%) reported having more than 10 years' experience in MRI. Finally, radiographers within the Greater London area accounted for almost a quarter of the respondents (22.3%), followed by radiographers from Scotland (13.9%), with proportionate representation of all other areas of the UK.

Knowledge, experience and understanding of autism by MRI radiographers

While most of the respondents (n ¼ 129, 86.8%) have confirmed to have scanned an autistic patient in MRI, 7.8% of them were unsure, while 3.9% of them have not scanned an autistic patient before. Also, 1.6% of them reported that they have scanned autistic patients, albeit in another imaging modality.

Only 42.9% reported that they can confidently recognise an autistic individual, while 15.1% answered that they could not recognise them. Interestingly, 42.1% of participants were uncertain as to whether they were able to confidently recognise them.

Most of the respondents reported a previous experience related to the preparation (n ¼ 112, 86.6%), positioning and scanning (93.7%) of autistic individuals, as well as a previous interaction with the carer(s) regarding the procedure (84.8%). Furthermore, 16.9% of the respondents stated that they have previously trained radiographers on scanning autistic patients. Only 7.1% reported being actively involved in creating local guidelines for autism in their respective MRI department.

When identifying autistic patients, most of the respondents agreed to a certain degree that most patients present with lack of eye contact (26% strongly agree and 61% somewhat agree), challenging communication skills (23.3% strongly agree and 56.7% somewhat agree), extreme anxiety (24.4% strongly agree and 53.7% somewhat agree), sensory issues (35.5% strongly agree and 50.4% somewhat agree), and repetitive movements (14.8% strongly agree and 59% somewhat agree) (Fig. 1). Regarding other types of presentation, respondents identified impaired social interactions (0.8%), increased distraction (0.8%), the need to feel in control (0.8%), lack of cooperation (0.8%), hyperactivity (0.8%), attention to details (0.8%), and the need for staff to use simple instructions to avoid sensory overload (0.8%). Finally, many have suggested that, as this is a spectrum, every patient is unique, therefore these expressions may not apply to everyone.

In terms of required knowledge to optimally care for an autistic service user, the majority of the respondents (n ½ 122) supported the need to recognise an autistic patient (70.5%) and to optimally communicate with them (87.7%) and their carers (61.5%), and to deal with challenging behaviours (80.3%) (Fig. 2). Most of them (90.1%) identified understanding patient's needs as a learning priority, while optimisation/modification of the MRI examination and ensuring safety of autistic patients were also identified as priorities by 64.7% and 63.1% of respondents, respectively. One of the respondents (0.8%) felt that understanding the varying spectrum of ASD and how this affects patients is vital, while installing new MR equipment to address their needs was also reported (0.8%). The value of spending some time with the National Autistic Society (NAS) and/or specialist nurses was also reported by radiographers as a good way of gaining knowledge (0.8%)

Radiographic practice before the MRI examination

Many radiographers (n ½ 112) reported being initially informed of the patient's condition verbally by the carer(s) (70.5%) or by the patients themselves (26.7%), with information being present on the request card (70.5%) or as alerts on the Radiology Information System (RIS) of the department (28.5%) (Fig. 3).

Radiographers were verbally informed by another healthcare professional (24.1%) or administrative staff (10.7%). Important to note that 8.9% of the radiographers reported that the patient's condition was not communicated to them beforehand by anyone.

Other responses revealed that radiographers were only occasionally informed about the patient's condition, or that there was often a combination of the above ways of communication. In clinical research settings, radiographers reported being informed directly by the research team.

When it came to pre-scanning adjustments (n ½ 109), most respondents (84.4%) reported adjusting their communication style according to the patient's needs, and also devoting time to explain the procedure to them and their carers (80.7%). In addition, the majority of the respondents allowed a pre-visit to the department, so the patients knew what to expect (57.7%), and also kept the number of staff involved to a minimum (62.3%). Over one third of the MRI radiographers asked a play specialist, where available, to prepare the patient for the scan (34.8%), while only 17.4% of them used a patient story/pathway for preparation.

Radiographic practice adjustments during the MRI scan

Most of the respondents (84.4%) who answered this question (n ½ 109) reported adjusting their communication style according to patient's needs and allocating time to explain the procedure to them and their carer(s) (80.7%). Over half of radiographers reported adjusting the lighting in the room (69.7%) and the volume and tone of their speaking voice (63.3%), while 36.6% of them

adjusted positioning practices to avoid touching the patient (Fig. 4). Also, many of them optimised the MRI examination, by using motion-resistant sequences or motion-correction software (65.1%), reducing the scan duration (64.2%), or reducing the acoustic noise during the scan (33.9%). Nearly one out of four (22.9%) ensured that no other people could be seen or 3 heard by the patient. Finally, 8.2% of the respondents reported making other type of changes, such as encouraging patients to bring their own music/audio book, contacting the carer(s) to discuss the patient's needs, using mock scanners for simulation, running noisier sequences such as Diffusion-Weighted Imaging (DWI) last, or preferring scanning these patients under general anaesthesia. Finally, none of them reported making no adjustments to the MRI examination. Training gaps and needs related to making autism-friendly adjustments for MRI scanning

Three quarters of MRI radiographers (75.6%) in this question (n ¼ 123) reported having received no training on the topic, with only 8.1% of them having received training. In addition, 16.3% of the respondents reported that although not formally trained, they have gained personal experience outside of work, which helped them cater for autistic patients. Among the radiographers who received training, 10% reported receiving formal university training, 10% online training, 30% of them attended a short course, 20% of them received mandatory training at the hospital, and 30% of them reported other forms of training, such as self-research related to ASD, training during previous employment, or a combination of those.

Most of the respondents (63.8%) felt that autism training should follow an online format, followed by skills (63%) and theoretical training (50.4%). Onsite training (39.4%), simulation (36.1%) and role playing (31.9%) followed, while 5.8% were interested in other training formats, such as that tailored to each MRI unit, observational, or onsite training, using already available equipment. In addition, directly interacting with carers of autistic patients or learning from resources of the NAS would enable radiographers to understand autistic peoples' needs. Finally, access to guidance was underlined as vital by the respondents (n ½ 119).

Barriers to and facilitators of creating autism-friendly MRI scans as identified by radiographers

As depicted in Table 2, radiographers who answered this question (n ¼ 106) identified lack of relevant training and knowledge as a major challenge when managing autistic patients in the MRI department (41.5%), followed by lack of onsite Special Educational Needs (SEN) experts (38.6%) and lack of relevant guidelines (37.7%). Four of the respondents felt that time constraints are a major challenge. Finally, the burden of the acoustic noise, lack of communication with the referring consultants, and lack of understanding from other members of staff were also highlighted as challenges. Only 1.6% of the respondents felt that they did not face any challenges at all.

MRI radiographers who answered this question (n ¼ 111) identified help from the carer(s) of autistic individuals as the most helpful aspect (73.8%), followed by the scheduling of additional time to scan autistic patients (57.6%) (Table 3).

Communication between the radiographer and the patients regarding their condition and needs was highlighted as essential for a successful MRI examination (45%), followed closely by facilitatory collaboration of the patient (43.2%). Two of the respondents reported that personal experience related to autistic patients is an enabling factor, while communication and training alongside empathy were also highlighted by the respondents as useful attributes to a successful examination.

Local protocols and legislation

Interestingly, two out of three radiographers (66.7%) reported that they are not aware of the Autism Act 2009 (the number of respondents who answered this set of questions ranged between n ½ 118 and n ½ 120).

This study also explored the availability of local protocols for imaging autistic patients among UK MRI departments. Most of the respondents (n ¼ 120, 64.2%) reported an absence of such protocols, while only 10.8% of them reported having established local protocols. Potentially of concern is that a quarter of the respondents (25%) reported that they are not sure if such a protocol exists at their department.

Most of the respondents (n ¼ 118, 44.1%) reported not having a SEN lead to assist in the management of autistic patients. Only 21.2% of them reported positively and the remaining were unsure.

The qualitative data was analysed to identify the respective emerging themes. These key themes are depicted in Table 4 and will be discussed below.

Discussion This study attempted to identify the main aspects of MRI scanning related to autistic individuals, in the context of current practice, reasonable adjustments as available and used, and *training of MRI radiographers*.

Importance of optimal healthcare service to autistic individuals

The importance of providing a safe, tailored, and person-centred healthcare service to autistic individuals is paramount for their health outcomes and has been well-documented in the literature.18,26 The National Institute for Health and Care Excellence (NICE) has issued specific guidelines regarding person-centred care of autistic individuals, and it has clearly stated that it should be supported by evidence-based information tailored to each person's needs.27 Moreover, the recently published guidance from the NHS Health Education England28 states that 'advanced clinical practitioners in learning disability and autism have the interpersonal and communication skills to engage in effective, appropriate interactions with people, families, carers and colleagues in the clinical environments and roles in which they practise'. Hence, MRI radiographers should engage in appropriate training to gain these qualifications and skills. Physical environment, practitioner training and knowledge and service user-provider communication have been found to play a pivotal role in healthcare of autistic individuals.29,30 These are in line with the findings of this study, with our respondents highlighting any adjustments related to the MRI unit environment and the patient-radiographer communication.

Knowledge of autism

There is a known lack of general knowledge related to the presentation of autistic people among healthcare professionals.31 In addition, existing literature suggests that many healthcare professionals have only a basic knowledge of the clinical and behavioural characteristics of ASD.32

These findings are consistent with the results of this study, as most of the radiographers were unsure on how to recognise an autistic individual, or how to identify the main clinical signs of autism. This is important, because if they are aware, they can plan ahead to adapt and prepare the MRI unit environment for autistic patients. Otherwise, the MRI examination may offer poor patient experience resulting in diminished image quality, low success rates, or repeats.

Legislation around autism

This study also highlights that the majority of radiographers were not aware of the Autism Act 2009.33 This Act was published in 2009, as part of the autism strategy 'to improve the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts'. 33 This Act 'has brought some great changes to the way that autistic patients access support'. 34 Different versions of this guidance exist across the UK, and radiographers should have been made aware of the respective recommendations, as applicable in their geographical area of work.

However, it hasn't fully materialised yet into changes in all healthcare practices, including medical imaging. Autism-related training Disappointingly, most of the healthcare practitioners, including radiographers, do not routinely receive comprehensive formal training related to autism, or they receive only brief training.29,35 Unfortunately, this also applies to medical students and paediatric trainees, who have recently demonstrated a poor knowledge regarding ASD.36 The respondents have also highlighted that a lack of relevant training is the greatest barrier when scanning autistic individuals. This is consistent with previous studies that identified lack of training as a barrier to personalised healthcare.19 As a consequence of these findings, radiography-related academic curricula and radiographers' work-place training should be expanded and adapted to include knowledge of autistic individual's clinical presentation, main challenges, preferences, sensitivities and MRI-specific requirements.

Thankfully, our study shows that the radiography workforce is very willing to learn more, placing training at the top of the challenging factors for safe and efficient MRI scanning. This study highlighted that most of the radiographers would prefer an online training format. Interprofessional education (IPE) has also been found to greatly improve knowledge and clinical skills through enhanced teamwork and communication37 and should be considered within this context. Furthermore, radiographers should be supported, when feasible, by SEN specialists, or be given the knowledge and skills to practice, based on SEN training, to ensure the provision of safe and effective care. This proved to be vital, as lack of SEN specialists was identified as a key challenge by radiographers, as most settings in this survey did not have a SEN specialist available to assist with autistic patients.

Need for establishing guidelines

Given the lack of standardisation of radiographic services for autistic patients, there is an urgent need for recommendations for practice to help radiographers optimise care for autistic individuals. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit for Healthcare Providers offers some useful guidance, with generic resources for healthcare professionals, while the Autism Healthcare Accommodations Tool (AHAT) identifies helpful individualised strategies.26,38 Specialised, evidence-based, radiography-specific autism-friendly imaging recommendations need to be developed in a similar way that radiography clinical practice guidelines have been developed for dealing with patients with dementia.39 Such guidance should serve to improve radiography practice, make the examinations safer, the service more efficient, and improve patient and carer experience for truly personalised care of autistic patients.

Effective communication as a key factor

Many differences were noted relating to how radiographers are informed about autistic patients. These differences might introduce several difficulties, and information that comes with advance notice through the system is always preferable. In the absence of formal training, established guidelines or adequate communication during booking the MRI scan, our data shows that radiographers have to often rely on last minute information, which may be sub-optimal planning and managing reasonable adjustment provision and for patient, carers and healthcare staff experience. Despite awareness of the challenges of autistic individuals, there was still a lack of communication of an autistic patient's arrival for an MRI scan in 8.9% of the respondents. Not surprisingly, given the lack of relevant information or adequate communication for the smooth running of an examination, radiographers placed communication with the carers or the patients at the top of the enabling factors for a successful MRI scan.

Optimal communication is vital to achieve high-quality care and improved patient experience and satisfaction.40,41 Effective communication has been found to improve trust between the patient and the radiographer,42 while the benefit is even greater when dealing with autistic individuals.43 The results of this study, also in line with the published literature, confirm the pivotal role of communication, as an enabling factor of successful MRI examinations of autistic service users. Optimal communication can reduce anxiety exhibited by autistic individuals.44,45

In addition to this, the importance of adjusting the healthcare environment for autistic individuals was also highlighted by this study, in line with published literature.46 Most of the radiographers reporting using specific adjustments to the environment to facilitate scanning of these patients as described above.

Limitations

This study received 130 valid responses. Whilst the accurate number of MRI radiographers in the UK is not known, it is appreciated that 130 radiographers might be a small proportion of it. However, the diversity in the geographical distribution and area of working, as well as years of practice and gender, allows for a well representative sample of UK radiographers. Hence, it might well reflect the number of UK-based MRI radiographers who have had experiences of and interest in scanning autistic patients. In addition, due to the data collection of this survey overlapping with the second national lockdown in the UK, and due to the radiographers working on the frontline during this period, the recruitment was inevitably impacted. As the qualitative data of this study was not enough to constitute a full paper, it was therefore used to support the themes of this paper.

Conclusion

The results of this UK-wide survey are in line with findings of previously published literature. A general lack of knowledge and training related to autism, lack of formal guidelines aimed at the radiography workforce, and lack of standardisation of practice appear to create challenging conditions for radiographers. However, effective communication between healthcare teams, with the patients and their carer(s), a well-adjusted physical environment, and tailoring of the examination are key components of a patient and person-centred, successful MRI examination. Further work is needed to highlight and test reasonable radiography-specific adjustments and to standardise autism-friendly MRI approaches for a personalised examination and optimal experience for autistic service users and their carer(s). Additionally, training initiatives in undergraduate and postgraduate radiography curricula should be considered to equip the radiographers with the necessary knowledge, skills and attitudes to manage and care for autistic service users and their carer(s).

Conflict of interest statement

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data Supplementary data to this article can be found online at <u>https://doi.org/10.1016/j.radi.2021.09.003</u>.

References

1. Lord C, Elsabbagh M, Baird G, Veenstra-Vanderweele J. Autism spectrum disorder. Lancet 2018;392:508e20. https://doi.org/10.1016/2FS0140-6736(18) 31129-2. 2. Bal VH, Kim SH, Fok M, Lord C. Autism spectrum disorder symptoms from 2 to 19: implications for diagnosing adolescents and young adults. Autism Res 2019;12:89e99. https://doi.org/10.1002/2Faur.2004. 3. McConkey R. The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): a comparison of the four countries in the United Kingdom. Support Learn 2020;35(2):132e43. https://doi.org/10.1111/1467-9604.12296. 4. British Medical Association. Autism spectrum disorder [online] Available from: https://www.bma.org.uk/what-we-do/population-health/childhealth/autismspectrum-disorder. [Accessed 1 May 2021]. 5. Campisi L, Imran N, Nazeer A, Skokauskas N, Azeem MW. Autism spectrum disorder. Br Med Bull 2018;127:91e100. https://doi.org/10.1093/bmb/ldy026. 6. Maenner MJ, Shaw KA, Baio J, Washington A, Patrick M, DiRienzo M, et al. Prevalence of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2016. MMWR Surveill Summ 2020;69:1e12. https://doi.org/10.15585/ mmwr.ss6904a1. 7. Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. J Am Acad Child Adolesc Psychiatry 2017;56:466e74. https://doi.org/10.1016/j.jaac.2017.03.013. 8. Park HR, Lee JM, Moon HE, Lee DS, Kim BN, Kim J, et al. A short review on the current understanding of autism spectrum disorders. Exp Neurobiol 2016;25: 1e13. https://doi.org/10.5607/2Fen.2016.25.1.1. 9. Parmeggiani A, Corinaldesi A, Posar A. Early features of autism spectrum disorder: a crosssectional study. Ital J Pediatr 2019;45:144. https://doi.org/ 10.1186/s13052-019-0733-8. 10. Masi A, DeMayo MM, Glozier N, Guastella AJ. An overview of autism spectrum disorder, heterogeneity and treatment options. Neurosci Bull 2017;33:183e93. https://doi.org/10.1007/2Fs12264-017-0100-y. 11. Strang JF, Kenworthy L, Daniolos P, Case L, Wills MC, Martin A, et al. Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. Res Autism Spectr Disord 2012;6: 406e12. https://doi.org/10.1016/j.rasd.2011.06.015. 12. Zwaigenbaum L, Bauman ML, Choueiri R, Kasari C, Carter A, Granpeesheh D, et al. Early intervention for children with autism spectrum disorder under 3 years of age: recommendations for practice and research. Pediatrics 2015;136: S60e81. https://doi.org/10.1542/peds.2014-3667E. 13. Jo H, Schieve LA, Rice CE, Yeargin-Allsopp M, Tian LH, Blumberg SJ, et al. Age at autism spectrum disorder (ASD) diagnosis by race, ethnicity, and primary household language among children with special health care needs, United States, 2009-2010. Matern Child Health J 2015;19:1687e97. https://doi.org/ 10.1007/s10995-015-1683-4. 14. Mazurek MO, Handen BL, Wodka EL, Nowinski L, Butter E, Engelhardt CR. Age at first autism spectrum disorder diagnosis: the role of birth cohort, demographic factors, and clinical features. J Dev Behav Pediatr 2014;35:561e9.

https://doi.org/10.1097/dbp.00000000000000097. 15. Hodges H, Fealko C, Soares N. Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. Transl Pediatr

2020;9:S55e65. https://doi.org/10.21037/2Ftp.2019.09.09. 16. Hallowell LM, Stewart SE, de Amorim e Silva CT, Ditchfield MR. Reviewing the process of preparing children for MRI. Pediatr Radiol 2008;38(3):271e9. https://doi.org/10.1007/s00247-007-0704-x. 17. Stogiannos N, Carlier S, Harvey-Lloyd J, Brammer A, Cleaver K, McNulty J, et al. A systematic review of person-centred adjustments to facilitate Magnetic Resonance Imaging for autistic patients without the use of sedation or anaesthesia. N. Stogiannos, J.M. HarveyeLloyd, B. Nugent et al. Radiography xxx (xxxx) xxx 8 PROSPERO CRD42020196864. [online] Available from: https://www.crd.york. ac.uk/prospero/display_record.php?ID%CRD42020196864. 18. Care Quality Commission. Out of sight-who cares? A review of restraint, seclusion and segregation for autistic people, and people with learning a disability and/or mental health condition [online] Available from: https:// www.cqc.org.uk/sites/default/files/20201218_rssreview_report.pdf. [Accessed 21 April 2021]. 19. Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, et al. "Respect the way I need to communicate with you": healthcare experiences of adults on the autism spectrum. Autism 2015;19(7):824e31. https://doi.org/ 10.1177/1362361315576221. 20. Schoonenboom J, Johnson RB. How to construct a mixed methods research design. Kolner Z Soziol Sozialpsychol € 2017;69:107e31. https://doi.org/10.1007/ 2Fs11577-017-0454-1. 21. Rubio D, Berg-Weger M, Tebb SS, Lee ES, Rauch S. Objectifying content validity: conducting a content validity study in social work research. Soc Work Res 2003;27:94e104. https://doi.org/10.1093/swr/27.2.94. 22. Kirchherr J, Charles K. Enhancing the sample diversity of snowball samples: recommendations from a research project on anti-dam movements in Southeast Asia. PloS One 2018;13:e0201710.

https://doi.org/10.1371/2Fjournal.pone.0201710. 23. Sadler GR, Lee HC, Lim RS, Fullerton J. Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. Nurs Health Sci 2010;12(3):369e74. https://doi.org/10.1111/j.1442-2018.2010.00541.x. 24. Christensen AI, Ekholm O, Kristensen PL, Larsen FB, Vinding AL, Glumer S, et al. The effect of multiple reminders on response patterns in a Danish health survey. Eur J Publ Health 2015;25:156e61. https://doi.org/10.1093/eurpub/cku057. 25. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77e101. https://doi.org/10.1191/1478088706qp063oa. 26. Nicolaidis C, Kripke CC, Raymaker D. Primary care for adults on the autism spectrum. Med Clin 2014;98(5):1169e91. https://doi.org/10.1016/j.mcna.2014.06.011. 27. National Institute for Health and Care Excellence. Autism spectrum disorder in adults: diagnosis and management [online] Available from: https://www.nice. org.uk/guidance/cg142/resources/autism-spectrum-disorder-inadultsdiagnosis-and-management-pdf-35109567475909. [Accessed 15 March 2021]. 28. Health Education England. Advanced Clinical Practice: capabilities framework when working with people who have a learning disability and/or autism [online] Available from:

https://www.skillsforhealth.org.uk/images/services/cstf/ACP_ in_LDA_Framework.pdf. [Accessed 5 July 2021]. 29. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. J Autism Dev Disord 2019;49:3387e400. https://doi.org/10.1007/s10803-019-04049-2. 30. Calleja S, Islam FMA, Kingsley J, McDonald R. Healthcare access for autistic adults. Medicine (Baltim) 2020;99(29):e20899. https://doi.org/10.1097/ 2FMD.000000000020899. 31. Morris R, Greenblatt A, Saini M. Healthcare providers' experiences with autism: a scoping review. J Autism Dev Disord 2019;49:2374e88. https://doi.org/ 10.1007/s10803-019-03912-6. 32. Corsano P, Cinotti M, Guidotti L. Paediatric nurses' knowledge and experience of autism spectrum disorders: an Italian survey. J Child Health Care 2020;24(3): 486e95.

https://doi.org/10.1177/2F1367493519875339. 33. The National Archives. The autism Act 2009 [online] Available from: https:// www.legislation.gov.uk/ukpga/2009/15. [Accessed 2 May 2021]. 34. National Autistic Society. What is the autism Act? [online] Available from:

https://www.autism.org.uk/what-we-do/campaign/not-enough/about-theautism-act. [Accessed 1

May 2021]. 35. Dillenburger K, McKerr L, Jordan JA, Keenan M. Staff training in autism: the one-eyed wo/man.... Int J Environ Res Publ Health 2016;13(7):716. https://

doi.org/10.3390/2Fijerph13070716. 36. Austriaco K, Aban I, Willig J, Kong M. Contemporary trainee knowledge of autism: how prepared are our future providers? Front Pediatr 2019;7:165.

https://doi.org/10.3389/2Ffped.2019.00165. 37. Tsilimingras D, Gibson Scipio W, Clancy K, Hudson L, Liu X, Mendez J, et al. Interprofessional education during an autism session. J Commun Disord 2018;76:71e8. https://doi.org/10.1016/j.jcomdis.2018.09.002. 38. Academic Autism Spectrum Partnership in Research and Education. Caring for patient on the autism spectrum: how autism can affect healthcare [online] Available from: https://autismandhealth.org/inc/content/pv_facfac_fac.pdf. [Accessed 26 March 2021]. 39. Society of Radiographers. Caring for people with dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) [online] Available from: https://www.sor.org/getmedia/559607e4-96e8-4153-

a86b2d71fccf242f/Caring_for_People_with_Dementia_a_clinical_practice_guideline_for_the_radiog raphy_workforce. [Accessed 26 March 2021]. 40. Hemsley B, Balandin S. A metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: informing new translational research. Augmentative Altern Commun (AAC) 2014;30(4):329e43.

https://doi.org/10.3109/07434618.2014.955614. 41. Newell S, Jordan Z. The patient experience of patient-centered communication with nurses in the hospital setting: a qualitative systematic review protocol. JBI Database System Rev Implement Rep 2015;13(1):76e87. 42. Pollard N, Lincoln M, Nisbet G, Penman M. Patient perceptions of communication with diagnostic radiographers. Radiography 2019;25(4):33e8. https:// doi.org/10.1016/j.radi.2019.04.002. 43. Academic Autistic Spectrum Partnership in Research and Education. Caring for patients on the autism spectrum [online] Available from: https://autismandhealth.

org/?a¼pv&p¼main&t¼pv_fac&s¼fac_fac&theme¼ltlc&size¼small. [Accessed 24 May 2021]. 44. Perry H, Eisenberg RL, Swedeen ST, Snell AM, Siewert B, Kruskal JB. Improving imaging care for diverse, marginalized, and vulnerable patient populations. Radiographics 2018;38:1833e44. https://doi.org/10.1148/rg.2018180034. 45. Brown AB, Elder JH. Communication in autism spectrum disorder: a guide for pediatric nurses. Pediatr Nurs 2014;40(5):219e25. 46. Hayes AL. Autism spectrum disorder: patient care strategies for medical imaging. Radiol Technol 2018;90(1):31e47.