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**CoRIPS Research Grant 155**

**£13,618 warded**

**Title: Understanding the needs of patients with autism spectrum disorders (ASD) who have been referred for or have undergone an MRI scan**

### **Principle Aim**

The main aim of this study is to explore the experiences of people with Autism Spectrum Disorders (ASD) who are visiting the MRI department. This will include people who have been scanned with MRI but also those who have been referred for one, to ensure the full patient journey is captured.

### **Primary research question**

What are the experiences of people with ASD visiting the MRI suite?

### **Secondary research questions**

- What information have they received prior to the MRI scan? Did they feel this was sufficient, relevant and appropriate?
- Which were the environmental factors (healthcare professionals attitudes, venue arrangement, MRI scanning room set up and conditions, communication) that facilitated the successful completion of the MRI scan and why/how?
- Which were the environmental factors that distracted them/overwhelmed them in the MRI suite and why/how?
- What improvements they would have liked to see in the communication and/or this environment to make their experience better and more autism-friendly?
- If they did not manage to complete their MRI scan, what alternatives have been offered to them?

### **Outcomes**

This is a proof-of-principle pilot study. Although some people at the spectrum might tolerate an MRI scan, some of them will find it totally unbearable. There is not published evidence about this and most data is anecdotal. Therefore many of the interventions to facilitate the completion of an MRI scans are often based on assumptions and preconceptions about autism. The PI has identified that there is

currently no written report or publication of the voice of people with ASD. Given the added complexity of the MRI department structure and equipment and the range of abilities and challenges of this population, it is imperative that a study to bring up their true preferences is conducted.

The primary outcome therefore would be to i) understand the range of experiences of people with ASD in the MRI department and ii) explore the need for more substantial modifications, to make the MRI environment truly “autism-friendly”.

The secondary outcomes would be to:

- i) appreciate the nature of these modifications/approaches (based on the participants’ suggestions) and if there is any scope for future low cost high impact innovations to be explored (links with small to medium enterprises and strategic planning can be explored through our enterprise manager, James Lambert and our Head of Department, Dr Karen Cleaver as part of a different future larger scale project)
- ii) understand which current practices seem to work to optimise the experience of people with ASD while in the scanner, and for that purpose we will be linking with researchers at a King’s College London project on patient and public perceptions on MRI scanning (Dr Jilka Sagar, project titled “The impact of patient involvement on studies using Magnetic Resonance Imaging”).
- iii) learn how to best communicate with people with ASD and their families/accompanying person in order to make their voice heard (we will be advised by experts in autism for this project (Dr Stella Tsermentseli at the University of Greenwich). The experience of Dr Jonathan McNulty would be vital while working with families of our target population, based on his previous research work related to the patient experience and with national and international public outreach projects.
- iv) bring together a network of future collaborators (including experts but also a patient and public partnership group) and advisors for a larger scale grant (The NIHR Research for Patient Benefit programme will be what we are targeting)
- v) disseminate this knowledge to raise awareness (conferences, papers)

## **Review of literature and identification of current gap in knowledge**

It is well documented that people at the autism spectrum find social integration and communication challenging, have difficulty to express and understand emotions and often experience the world through an altered sensory lens, which can make every day tasks overwhelming for them. These can lead to further anxiety, social isolation, depression and a variety of mental health problems. People with ASD need to be understood and supported to be able to fully integrate.

MRI scanning is an environment, which can be daunting to the general population. Historically MRI departments were located at the basement, with the rest of Radiology. The Faraday cage, required to isolate the MRI scanning room from the neighbouring departments to avoid interference with other medical equipment from the produced RF signals, meant that the MRI scanning rooms were often windowless or at least any windows were kept to the minimum. Also the MRI scanners, a heavy and rigid structure, can effortlessly cause claustrophobia and anxiety. This is particular relevant for some people with ASD, as when they become overwhelmed, they often seek a space to elope, an exit to de-escalate, regulate their feelings and relax. The MRI scanning room is a controlled area, with a heavy door that closes firmly to prevent any unexpected entry, making it an isolating environment. Also the distance of the patient in the scanning area from the radiographer/clinical practitioner behind the console (unlike bedside ultrasound scanning) does not allow for direct human interaction (rather than through the intercom system), which can create further anxiety. The intercom and panic button is often the only way patient and radiographer can communicate while scanning.

In addition there is sensory overload for the person lying down in the MRI scanner: loud banging noise from the gradients, often unexpected and differing in intensity and frequency, without any pattern, followed by equally unexpected silence at the end of a scanning protocol and the sound of the helium pump on the background, vibration of the examination table (particularly for diffusion imaging and functional MRI sequences), Velcro straps of the imaging coils in close contact with the patient's body and/or head (when brain imaging), lights on the ceiling that might flicker with different sequences, depending on the RF pulse applied. One has to wonder how individuals with ASD can cope in this room.

Some individuals at the autism spectrum are tolerating the scan well. However different interventions have been explored for people who cannot. These might include sedation, the use of behavioural management techniques to prepare the patients for the scan ahead, familiarisation during a pre-visit of the MRI department, time at the mock scanner or electronic three-dimensional simulation of the MRI department and suite on a portable device at home. All of these

interventions have shown success in scan completions. What these studies have not explored though is 1) the needs of people with ASD when they visit an MRI department and are scanned, 2) whether currently available interventions have actually improved the experience of the patients undergoing the scan and 3) whether it is worth exploring interventions that aim not to make the patient “MRI-ready” but to make the environment “autism-friendly”.

## **Methodology**

The methodology to be used will be an interpretative phenomenological approach, to explore the lived experiences of people with autism spectrum disorders in the MRI department. The epistemological approach employed will be Empiricism, as the theory supporting that “the origin of all knowledge is experience”. It emphasizes the role of experience and evidence, especially sensory perception, in the formation of ideas, and argues that the only knowledge humans can have is a posteriori (i.e. based on experience). This is in line with trying to break down any preconceptions about people with ASD and openly listen to what they say and what they need.

Four focus groups (with maximum 10 people per group) will be organised, one with experts in the field and the others with people, family and friends of people with ASD. One-to-one interviews will be arranged for those individuals with ASD that find it difficult to discuss in a large group to share their experiences. All interviews and focus groups will be audio recorded and transcribed. For the ones who prefer a survey type approach, a survey mapping the interview questions will be designed on the qualtrics.com survey interface.

Recruitment of study participants will be i) via email for the experts through the PI’s professional network and ii) via email and phone calls for the public/people with ASD through already established links with the national autistic society in the London branches but also local autism charities.

The sampling will be purposive-only those participants that are willing to offer their perspective and fulfil the inclusion criteria will be approached. Participants will need to be verbal or to be able to communicate with drawings, flashcards, electronic means (email, survey) or with the help of a relative/friend, who might act as facilitator in the discussion. All participants will have to be over 18 years of age. An informed written consent will have to be signed before hand.

Thematic analysis will help us discover the emerging themes and subthemes. The Nvivo software will be used, where feasible, otherwise notes/memos will be kept on transcripts of the focus groups, interviews and surveys.

Duration: the whole project from beginning to end will last 18 months (January 2019-July 2020).

Trustworthiness of data: An important step to ensure trustworthiness and credibility is to invest on the project's validity and reliability. To ensure this project will deliver on its intended aims there is a sound research design, a realistic timescale (please refer to the Gantt chart below), and appropriate methodology and data collection methods, as described above. This project has been informally discussed with members of the public and with individuals at the spectrum of autism. The design was also informed by input of experts in autism (Dr Tsermentseli, NAS, Dr Olga Bogdashina, Research Design Service at King's College), speech and language therapy (Mrs Zoe Ambrose), patient and public involvement (Dr Sagar Jilka), research and enterprise (Dr Karen Cleaver, Philips medical Systems, James Lambert) and medical imaging (Dr Jonathan McNulty, Dr Grainne McAlonan). Ethical concerns have been addressed (please see last paragraph below). Methodological triangulation will be employed to demonstrate validity in this research (Campbell and Fiske, 1959, Smith, 1975). Triangulation will ensure the findings are not artefacts specific to one data point of collection; in our case the 4 different focus groups to include ASD individuals, friends and family but also experts in autism will ensure all different perspectives will be heard. Additional interviews and a survey will be planned for those who will find it easier to discuss individually or via electronic communication, respectively, to ensure all feedback that can be incorporated will be part of this pilot study. Participants will be consulted following the interviews, to ensure the end-result conveys what the participants intended to say (member checking).

Ethical issues: Ethics approval will be sought from the University of Greenwich UREC. As the participants will be recruited through the autism charities, there is no need for NHS ethics approval. Informed written consent will be gained by all participants. The families of participants, when required, will be consulted and might be present to support them and act as facilitators, if needed. Data confidentiality and participant anonymity in all aspects of the research design will be maintained: collection, analysis and synthesis of research findings (Lunt and Fouche, 2010). The team will ensure a safe and trusting environment is established. Participants can exit at any time point, if they wish to. They can also withdraw their data at any point before the end of the study. Data will be saved in encrypted hard-drives in a drawer that operates with a lock and is located at the University premises and the office of the PI. If a mention of poor clinical practice is raised by any of the participants or their families, the relevant PALS team will be informed and they will be encouraged to liaise with them to discuss further.

## **Potential impact**

This study will highlight for the first time the actual experiences of people with ASD in the MRI department as said by them, without any preconceptions or assumptions but using their own words.

It will be a proof of concept pilot study to understand whether there is truly lack of understanding of the needs of this population and whether current measures used are actually making a difference.

As an exciting potential, it would be great to see what interventions would people with ASD feel might improve their experience in the MRI department. If this comes to fruition, it might form the basis of a larger scale project that can inform and hopefully change current practices in how we do MRI scanning for people with autism, for the benefit of the patients.

## **Dissemination Strategy**

Paper to be published on the experiences of the individuals with ASD, their families and friends in the Journal radiography, as per Gantt chart.

Another paper in an autism related journal.

A report will also be sent to the National Autistic Society.

A conference abstract will be submitted at the UKRC 2020 and ECR 2020 conferences.

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