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Autism and Research Using Magnetic Resonance Imaging

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Highlights

- Trouble laying still limits children with autism from completing research MRI.
- Scheduling conflicts limit availability of typically developing children for research MRI.

- Social script app associated with MRI completion.

Abstract

This qualitative study explored the experience of participating in a research study using magnetic resonance imaging (MRI) for children with autism spectrum disorder (ASD), typically developing (TYP) children, and their parent. It also assessed the feasibility, efficacy, and acceptability of the *Going to MRI for a Research Study* iPad application (app), developed by the primary author, available for use for MRI preparation. The app provides a description of the steps of the MRI procedure, from the child's perspective, outlining expected behaviors and responses. Ten English-speaking parent/child dyads (n = 20) participated in an audiotaped question guide-facilitated telephone interview about their experience in the MRI study. Participants confirmed the iPad app's feasibility, efficacy, and acceptability. ASD child/parent themes differed from TYP child/parent themes. More children with ASD who used the app completed the MRI than without it. The iPad app may help children with ASD complete MRIs in future studies.

Keywords

Autism, Magnetic resonance imaging, Social script, Procedure preparation, Introduction

Autism spectrum disorder (ASD) is a pervasive developmental disorder with documented abnormalities in brain structure and function, as compared with typically developing (TYP) counterparts ([Volkmar, 2011](#), [Wang et al., 2013](#)). The prevalence of ASD is one in 68 children in the United States for children 8 years old at select surveillance sites ([Centers for Disease Control and Prevention \[CDC\], 2014](#)). Approximately 38% of these children also have [intellectual disability](#) (intelligence quotient [IQ] <70; [CDC, 2014](#)). Persons with ASD display persistent social communication and social interaction deficits and restricted repetitive patterns of behavior, interests, or activities, and sensory sensitivities ([American Psychiatric Association, 2013](#)). Repetitive patterns of behavior may include movements (e.g., hand wringing) and/or vocalizations (e.g., scripted language). In addition, individuals on the spectrum often present with behavioral rigidities and exhibit challenging behaviors during transitions and/or changes in routine ([Johnson & Rodriguez, 2013](#), [Centers for Disease Control and Prevention \(CDC\), 2014](#)). These behaviors are markedly different from that of their TYP peers ([CDC, 2014](#)).

Given the neurologic underpinnings of ASD, research in neuroimaging is of great scientific significance and increasingly incorporated into study designs. Specifically, research studies have used neuroimaging techniques, such as magnetic resonance imaging (MRI) or diffusion tensor imaging, to examine brain structure and function in this population, including task-evoked brain responses ([Ismail et al., 2016](#)).

Problems with completing MRI in research studies and hospital settings for children with ASD are well documented. In hospital settings, children undergoing MRIs can experience anxiety, claustrophobia, and fear during the scanning experience and often require sedation ([Koller and Goldman, 2012](#), [Munn and Jordan, 2012](#)). Furthermore, the scanning environment presents unique sensory challenges for individuals with ASD (e.g., loud noises and/or the bed shaking). Parents of children with ASD can be anxious about MRI scanning as watching the child in the MRI is stressful for the whole family and may impact the successful completion of the MRI ([Simonoff et al., 2008](#)). Although previous research showed that repeated exposure to MRI

was associated with lowered anxiety in children with ASD ([Chapman, Bernier, & Rusak, 2010](#)), first-time MRI participation remains problematic.

Interventions to prepare children for MRI vary in approach and effectiveness. In the hospital setting, the strategies reported to be effective in reducing fear, anxiety, and claustrophobia and in reducing the need for sedation in children undergoing MRI include open MRI, practice in a mock MRI, audiovisual systems, cognitive [behavioral therapies](#), [guided imagery](#), and [pediatric preparation booklets](#); all were found to have some positive effect on at least one outcome ([Munn & Jordan, 2012](#)). Another approach is to perform the MRI at night as the child is more likely to sleep ([Nordahl et al., 2008](#)). Recent research reports on a multistep protocol using principals of applied behavior analysis at a larger research center that facilitated completion of MRI for children with ASD ([Nordahl et al., 2016](#)). Although multiple rewards can help TYP children aged 9 to 13 years complete MRIs ([Schlund et al., 2011](#)), there is limited literature on effective preparation of children with ASD for the new experience of research study using MRIs to decrease their stress and gain their compliance.

Our previous research found that ill or injured children and their parent had less anxiety (than the control group that received typical care) and challenging behaviors and better compliance with diagnostic imaging when nurses prepared them with an iPad application (app) that used a social script to foreshadow the imaging process and appropriate behavior ([Johnson et al., 2014](#)). Social scripts, which can be delivered via an iPad app, are words, pictures, video, and sounds that model acceptable participation in a procedure by referencing other's perspectives and providing the appropriate responses for the person about to undergo a procedure such as MRI ([Gray, 2003](#), [Thompson and Johnston, 2013](#), [Vandermeer et al., 2013](#)).

Currently, there is no research on the experience of children and their families on the experience of undergoing a voluntary research study using MRI studying research task-evoked measures. Likewise, there is no standard approach to preparing children with ASD for MRI in research studies.

The study had two aims:

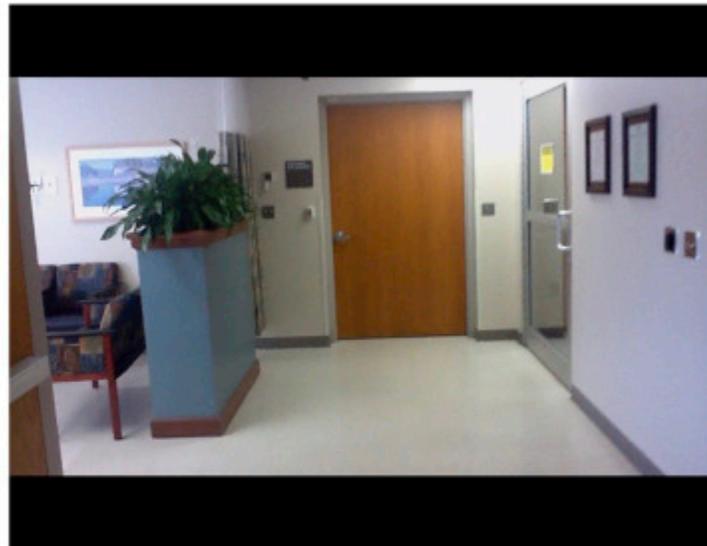
1. To assess the experience of participating in a research study using MRI for a child with ASD or a TYP child and an accompanying parent.
2. To evaluate the feasibility, efficacy, and acceptability of the *Going to MRI for a Research Study*© iPad© app consisting of research task, mock MRI scanner, MRI photographs, and audiorecording of the sound of the MRI scanner.

The *Going to MRI for a Research Study*© iPad© app

The *Going to MRI for a Research Study* iPad app, developed by the researchers, is a social script to prepare the child for the MRI. It is a story with a series of photographs of the research task, mock MRI scanner, real MRI scanner, and audiorecording of the sound of the MRI. The buttons on the app allow the user to hear the text read aloud or not and allows the user to

move backward and forward through the app at their own pace. Four representative screenshots of the app are presented herewith:

1. This photograph, on the opening screen of the app, foreshadows the child and parent's arrival at the MRI scanner to meet the researcher.



**I am taking part in a research study. My parent will be with me.
The first part of the study is just practice. I will go to the
building and meet the researchers at the front door.**

2. This is a photograph of the mock scanner and accompanying text.



Next, I will get to lay on a table and put my head in a small round circle. I will practice holding my head still, which is important for getting good pictures. I might get to practice with the soft button that I can use to get the researcher's attention.

3. This is a photograph of a participant in the MRI scanner and accompanying text.



The tech might say "time to do the next run" I might hear a loud beeping noise. That's okay the noises will stop when we are all done. I may need to keep laying still and do a task with the button. They will tell me what I need to do and thank me for doing it.

4. This is the final screenshot intended to decrease anxiety and motivate participation.



INTERESTING



Doing this MRI was interesting. I did a nice job!

Methods

Design

This study is part of a larger study on neural correlates of goal-directed behavior ([Salowitz et al., 2014](#)). The larger study had a mock scanner and an MRI with a research task involving movement of a joystick. The present study uses a retrospective qualitative approach. The principal investigator (PI) completed individual, one-time, audiotaped telephone interviews of children and parents using a structured question guide, after the completion of the MRIs.

Sample and/or Setting

The participants were 10 English-speaking parent/child dyads (five male children with ASD [aged 14.8 ± 1.2 years] and five [four male and one female] TYP [aged 14.2 ± 3.2 years]) who previously participated in a research study using MRI in the Midwest United States. Ten of the 20 participants in the larger study did not respond to our attempts to contact them. In the larger study, they may have been offered the option of using the *Going to MRI for a research study* social script iPad app. Likewise, they may or may not have used it in combination with other

procedure preparation of a verbal explanation and a mock scanner practice session. Individual interviews were performed with each mother and the child separately.

Regular daily medications were not withheld before testing. Prior diagnosis of ASD or TYP was confirmed with the Autism Spectrum Screening Questionnaire ([Ehlers, Gillberg, & Wing, 1999](#)) and the Autism Diagnostic Observation Schedule ([Lord, Rutter, & Le Couteur, 1994](#)), along with normal or corrected normal vision, and IQ >70 (high-functioning children), as measured with the Kaufman Brief Intelligence Test, Second Edition ([Kaufman & Kaufman, 2004](#)). Inclusion criteria were children with verbal IQ scores >70, normal or corrected to normal vision, no braces on teeth, and 12 to 18 years. Children received a \$20 gift card to thank them for their time.

Procedure

This study is part of a larger study approved by the institutional review board at the university. Informed consent was obtained from all individual participants included in the study. Participants and their parent were first asked if they used the social script iPad app to prepare for the prior MRI research study. The researcher followed one of two question guides for child participants and their parents in the present study depending on their use of the interactive iPad app. The first question guide was for children and parent who completed all or most of the interactive iPad app ([Figure 1](#)), and the second question guide ([Figure 2](#)) was for those who did not choose to use the iPad app.

I am interested in understanding what it was like for you/your child to undergo the MRI. Can you tell me what it was like?"

Tell me your thoughts about the iPad MRI story format and content on the iPad?

Do you think that the pictures and video helped you understand what to expect for the mock scanner MRI?

Do you think that the script helped you understand what to expect for the real MRI?

How easy was it to use the iPad?

Was the iPad story manageable in terms of time?

What part of the MRI was the most challenging?

Overall, what was the MRI like for you?

What did you find helpful about iPad story preparation?

What did you find helpful about Mock Scan preparation?

Tell me about your experience with scheduling your participation in the MRI?

What part of the research was the most challenging?

Do you have anything else about the research experience you would like to share?

What's it been like for you going through this whole experience?

Do you think that the process of using the iPad story before the MRI went well?

How do you feel about using the iPad?

Do you have anything else you would like to share?

Figure 1. Question guide for participants with the iPad app preparation. MRI = Magnetic resonance imaging.

I am interested in understanding what it was like for you/your child to undergo the MRI.

Can you tell me what it was like?"

What part of the MRI was the most challenging?

Overall, what was the MRI like for you?

What did you find helpful about Mock Scan preparation?

Tell me about your experience with scheduling your participation in the MRI?

What part of the research was the most challenging?

Do you have anything else about the research experience you would like to share?

What's it been like for you going through this whole experience?

Do you have anything else you would like to share?

Figure 2. Question guide for participants without the iPad app preparation. MRI = Magnetic resonance imaging.

After review of the iPad app, participants completed a 30-min mock scanning session to determine if the participant could tolerate the MRI environment. During the mock scan session, participants simulated lying down on a mock MRI bed while listening to an audiorecorded noise mimicking the sound in the MRI environment. Participants also were provided with ear plugs to practice wearing them before the actual MRI. Participants were monitored for signs of anxiety during the mock scan (e.g., worry statements, shaking, avoidance, etc.). After completion of the mock scan, participants were asked if they would be willing to complete the real MRI. If participants consented to return for the actual MRI, they were provided with an opportunity to review the app, and the research assistants answered any additional questions, as appropriate. MRIs took place anywhere from 1 to 14 days after the mock scan.

Data Analysis

Frequencies were calculated for app use, and MRI completion rates and demographics describe the sample. The demographics were collected on a questionnaire by the researcher during the telephone interviews to describe the sample. The audiotapes of the telephone interviews were transcribed verbatim into a word document by a coinvestigator on the research team.

Two researchers discerned themes via an iterative process, for participant experience with the research MRI, and the feasibility, efficacy, and acceptability of the app for those who chose to use it. Specifically, the PI and a coinvestigator read each participant transcript, highlighting quotations with labels, and then re-read transcripts before arriving at themes that emerged across cases ([Kohler Riessman, 2008](#)). The themes represent the participants' meanings of their experience preparing for the MRI and undergoing the MRI ([Holloway & Freshwater, 2008](#)). Next, the two researchers met in person, compared themes, and reached consensus for the themes using the supporting quotations from the transcriptions.

Results

Demographics

All parent/child dyads (N = 10 mothers and 10 children) were white, and most mothers were college educated with a bachelor's degree or higher (n = 8, 80%). The average age of the children with ASD was 14.8 ± 1.2 years and the TYP children 14.2 ± 3.2 years ([Table 1](#)).

Table 1. Demographics

Demographic category	Parent, N (%)	TYP child, N (%)	ASD child, N (%)
Gender			
Male	0	5 (100)	4 (80)
Female	10 (100)	0	1 (20)
Average age (y/SD)		14.2 (3.2)	14.8 (1.2)
White race	10 (100)	5 (100)	5 (100)
Highest degree			
High school	1 (10)		
Some college	1 (10)		
Bachelors or higher	4 (40)		

TYP = Typically developing children; SD = standard deviation.

MRI Completion Rates

Seven of the 10 children (70%) completed the MRI (n = 2 ASD with app; n = 1 no app but prior MRI experience; n = 1 TYP with app; and n = 3 TYP but no app). Three children (30%) did not complete the MRI (n = 2 ASD but no app; n = 1 TYP claustrophobic) ([Figure 3](#)).

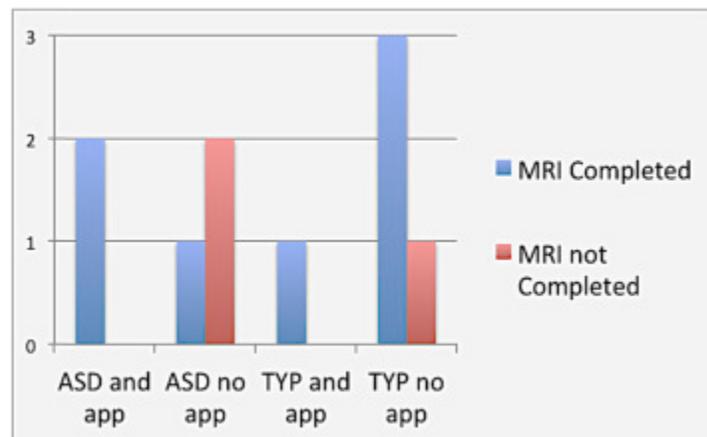


Figure 3. Frequency of magnetic resonance imaging completion by diagnosis and app use. MRI = Magnetic resonance imaging; ASD = autism spectrum disorder; TYP = typically developing children; App = iPad application going for an MRI.

Themes of Meaning Attributed to the MRI Experience

Different themes of meaning attributed to participation in the research study emerged from the transcripts for the ASD child/parent participants and the TYP child/parent participants. The themes and representative quotations for each theme are presented later.

Themes for ASD Child/Parent

There were two themes of the meaning attributed to the MRI experience for ASD child/parents. The two themes are *helping others with autism* and *hard to lay still*.

Helping Others With Autism

For the first theme, several parents stated that they participated in the MRI study to help others with autism. Parent 5 stated that “I think having a child with Asperger's and Autism can be extremely frustrating and challenging in itself that's why we are very prone to helping with anything ... We try a lot of different things to make his life better.” Parent 6 stated that “We explained to her about the greater good and helping out other kids with Autism.” Child 6 verbalized similar rationale for his participation: “Its knowing that I can make a difference about Autism because I have a second cousin ... he is on the low end of the spectrum. He is five and he is going to be six next month and he acts like a two-year-old... so I know I'm helping kids like him in the future.” Their desire to help others was complicated by the trouble they noted with trying to lay still, which is the second theme that emerged from the transcripts.

Hard to Lay Still

For the second theme, one mother of a child who volunteered for the research study, who did not use the iPad app, recalled not being called back by the research team to participate in the actual research study using MRI. She stated that “It was hard for him to lay still enough, and they never called us back to do the actual MRI because when we were in the simulated one... it was hard for him to lay still enough ... he kept having to adjust himself, so that is probably why we didn't get called back. I'm assuming.” She added that the most challenging part of the [research experience](#) was “probably to get my son to...ah...lie there without...ah...moving.”

The social script iPad app addresses the need to lay still and encourages the child to watch the movie and relax. One child noted what he found helpful about the iPad story preparation when he stated that “It helped me know what the MRI was like in terms of what it does and how we're going to do stuff because I need to know what's happening to do stuff without complaining.”

Themes for TYP Child/Parent

Themes of the meaning attributed to the MRI experience for TYP child/parent included the following: (1) good experience, (2) trouble fitting MRI on their schedule, and (3) mock scanner helpful.

Good Experience

For this first theme, several mothers of TYP children commented that the research study was a good experience. One mother stated that “I think it was helpful because ... it allowed her to use her mind outside of her school work and everything. I thought it was really helpful.” Parent 2 noted that “I just thought it was a good experience for her....I try to expose her to every and anything decent that I can and when she asked me about that I just thought it was a good idea, a safe situation and I went along with it.” Parent 4 stated that “It was a good learning experience.” Likewise, parent 10 noted that “I'm glad that he had the opportunity to do that. I think that both he and myself thought that this was an opportunity to do something that was potentially beneficial and that's always nice.”

Along with TYP parents, the TYP children in the study also found it to be a good experience. Child 7 stated that “I signed up for everything because I was interested in trying new things.” Child 8 stated that “I think it was interesting and I actually learned quite a bit more than I would just being home or probably reading from a book at the school or something.” He continued by stating that

It was kind of nice getting some for lack of a better term, hands on experience with this stuff and seeing what it's like. You know, being told what's going on because I've always, you know...I've always wanted to take a career in health, but I've never really been to a hospital before or even seen some of the stuff that was there. It was very educational. It was very nice.

Although the TYP children perceived that the experience was valuable, several TYP participants noted scheduling difficulty based on competing priorities and busy schedules.

Trouble Fitting MRI on Their Schedule

The second theme that emerged from the transcripts was trouble fitting the MRI on their schedule. Parent 4 stated that “Well, the hardest part was scheduling it with a busy kid, and getting a day that we could get him into (location). That was the hardest part.” Parent 8 recalled the following: “We had some frustration with the machine ... it wasn't available certain times when we tried to get there. So, it was probably more of an availability issue with reliability.”

TYP parents reported that fitting the research study into their schedule was more challenging than the actual MRI procedure, that is, laying still. Parent 8 stated that “Probably ...I don't think the being there and waiting...just trying to schedule it.” Likewise, parent 10 stated that “As [name of child] mentioned he has a pretty full schedule and fitting things in is sometimes challenging, but she (scheduler) made the process as painless as possible given our challenges.” She continued by stating that “But, once you're there it was easy-peasy, straightforward. You know, just get it done and move along on our way.”

Mock Scanner Helpful

TYP parents of children with no iPad preparation found the mock scanner helpful in preparing the child for the MRI. Parent 4 stated that “I thought that it was extremely helpful for my son because he really had no idea what to expect. So, to go into it (mock scanner) knowing that there were no expectations and that it was a trial and nothing was running to see what it was like. I thought that was extremely helpful.” Child 8 did not use the iPad app although it was offered because his “mother had an MRI and told him what to expect.” When asked about the mock scanner, he stated that “Oh...um... it did help me prepare for the position my body would be in for the MRI ... it kind of helped me, you know, prepare my body to be in a certain position for a long time.”

Feasibility, Efficacy, and Acceptability of the App

Participants described the iPad app's feasibility, efficacy, and acceptability ([Table 2](#)). Parent 6 explained that “I thought it was great because she is very much a visual learner ... for her to use the iPad is a good thing to not have to write anything per se with cursive because cursive is a challenge for her.” She also noted that “I think it is a great thing because she is in a generation that is so electronically knowledgeable and it is a comfort piece for them, so when you have an unknown that is making you very uncomfortable, it's nice to see that.”

Table 2. Evaluation of the iPad app

Evaluation type	ASD sample quotations	TYP sample quotations
Feasibility: ease of use	Very straight forward ... a great thing because she is in a generation that is so electronically knowledgeable and it is a comfort piece for them, so when you have an unknown (MRI) that is making you very uncomfortable, it's nice to see that. (Parent 6)	I thought it was very good that she was able to comprehend it and do very well. (Parent 2)
Efficacy: Helpful? Challenges?	Pictures helpful ...it (MRI) was pretty long, but it wasn't all that bad. (Child 6) It (iPad app) actually was really helpful with the MRI. (Child 6)	The actual test (research task with joystick) was more challenging as it got harder, but other than that, actually, it went well. (Parent 7)
Acceptability: what went well?	I thought it was great because she is very much a visual learner. (Parent 6) (MRI was) weird, but it was actually interesting. (Child 6)	It (iPad) went over everything in a good amount of time. (Child 7)

ASD = autism spectrum disorder; TYP = typically developing children; MRI = magnetic resonance imaging.

Discussion

The results demonstrate the feasibility, efficacy, and acceptability of the app as well as the effectiveness of the app for preparing three ASD children and their parent for completion of a research study using MRI. Most of the participants of the study ($n = 7$ [70%]; $n = 3$ ASD and $n = 4$ TYP) completed the mock scan and the MRI. However, two of the five participants with ASD (40%) without the iPad app did not complete the MRI. Reasons for not completing the

MRI for these children matches the past literature that children can experience anxiety, claustrophobia, and fear during the scanning experience ([Koller and Goldman, 2012](#), [Munn and Jordan, 2012](#)) making it hard to lay still.

In the present study, all three participants who used the iPad app (n = 2 with ASD; n = 1 TYP) completed the mock scan and MRI. The other child with ASD who completed the MRI without the app had undergone an MRI before. This finding of successful completion of a second MRI without special preparation matches previous research ([Chapman et al., 2010](#)). Likewise, in the larger study ([Salowitz et al., 2014](#)), most people got through the MRI.

Previous research on ill children with ASD in randomized controlled study with a social script iPad (n = 32) showed that parents of the children exposed to the app (n = 16) had lower state anxiety compared with the parents whose children were not exposed to the app (n = 16) (effect size, 0.33) ([Johnson et al., 2014](#)). Children exposed to the app had fewer externalized challenging behaviors than the control group (effect size, 0.56). The results demonstrate feasibility and efficacy of the intervention ([Johnson et al., 2014](#)).

In the present study, the three participants who completed the MRI after the mock scanner, but without the app, were TYP children. This finding of TYP participants completing MRIs matches previous research showing that the TYP children can complete MRI after preparation with mock scanning, without social scripts ([Munn & Jordan, 2012](#)). However, for children with ASD, even the rehearsal in the mock scan can be so stressful because of sounds and expectations ([Giarelli et al., 2014](#)) that they may not be able to lay still enough to complete the study MRI. In the present study, one mother of a child who did not use the iPad app noted that it was not possible to do the research study using MRI because her child could not lay still in the mock scanner.

The key themes from the interviews from ASD children and parents were a desire to help others with autism and finding it hard to lay still. These themes emerged from the [narrative analysis](#) of the mothers of the parent and children with ASD.

In contrast, three themes emerged for the meaning attributed to the MRI experience for TYP child/parent, namely it was a good experience, trouble fitting MRI on their schedule, and the mock scanner was helpful to prepare the child for the MRI. In fact, the mock scanner was enough to help them complete the research MRI.

Limitations

The study has admitted limitations. The sample size is small, and the children have IQ >70, thus the sample only includes children with ASD without [intellectual disability](#). No fathers volunteered to be interviewed in the study. We did not collect data about the [socioeconomic status](#) of the participants. Future research should include children with ASD and intellectual disability and fathers, as well as describe the socioeconomic status of participants to better capture the effect of the app on all children with ASD and the parent perspective. Future research with larger sample sizes may lead to supporting the bolder hypotheses that social

script-based apps could improve the number of volunteers in research using MRI studies and potentially their success in completing MRIs.

Conclusion

The findings from the present study underscore the differing perceptions of parents and children with ASD from their TYP peers about the research using MRI experience. These differences inform the clinical preparation by nurses that impact successful completion of MRIs. This finding could in turn lead to quality improvement investigations on the processes we have in place surrounding MRI preparation and possible changes to better the process including health care providers as part of interdisciplinary research teams.

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