

## Ethics Application form

### 1. Title of the research

SPHERE project at We the Curious

### 2. Name of Applicant, with their job title:

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### 3. Name of Supervisor (if applicant is a postgraduate or undergraduate student), with their job title:

Professor Ian Craddock  
Director of SPHERE

### 4. Other investigator(s) involved, with their job title:

N/A

### 5. Source of funding and grant code:

EPSRC, EENG RB1650

### 6. Does this source of funding place any restrictions on public dissemination (publication, etc.) of results of the research? If yes please say what these are.

No

### 7. Background and aims of the research:

The SPHERE Interdisciplinary Research Collaboration (IRC) is developing a platform of healthcare sensors, however the private and personal nature of healthcare applications necessarily restricts the scope for meaningful public engagement. The aim of the study described here is to undertake some research using SPHERE sensors in such a way that it can be easily shown to the public.

We the Curious is currently a partner of the SPHERE project. The science centre, which is located near the harbourside in central Bristol, has recently undergone a re-branding and launch of a new manifesto. One of pledges of their new manifesto is to **open up science in our city**, and working to involve audiences with active, local research. The main focus of their work is to challenge public engagement within research by curating engagement that allows our visitors to actively participate and engage at different levels of

the research process, not just passively engage with it at the dissemination of results end.

To demonstrate the work of the SPHERE project in a tangible and intuitive way, as well as creating engagement that allows for active public participation, the project will involve creating of a mock up SPHERE house, with a SPHERE system installed, in We the Curious. This house will be installed in the science centre from the 26<sup>th</sup> July to the 31<sup>st</sup> August.

### **Public Engagement activities**

For the purpose of public engagement there will be a number of activities that visitors can interact with, these activities will incorporate the SPHERE sensors (specifically the wearable and the environmental sensors) and will be a way of introducing the concept of the SPHERE project and contextualising to visitors how the sensors work and how the data gathered from these sensors will be of used in a health-research context.

See below more information about the sensors and the type of data they will be capturing displaying:

1. Environmental sensors: these small boxes (about the size of a fire alarm) include room presence sensors (as used by security alarms), sound level, humidity, temperature, water flow meters. Small white sensors will be plugged to some appliances (kettle, microwave, fridge) to measure electricity use.
2. Wristband: These sensors help the SPHERE system measure movement, including which room you are in. In the We the Curious exhibit, the wearable will be connected to an application that allows participants to 'train a computer' i.e. they wear the wearable, perform a number of actions like waving, clapping and standing still and then they 'train the machine' to recognise these actions. The wristband does not measure heart rate.

### **Date Capture Experience**

Another element of this exhibit will be a facilitated data capture experience. This experience will focus primarily on the SPHERE video sensors (more information below) that are installed into the SPHERE houses recording silhouette data. Small groups of visitors will be guided through this 10-15 minute experience by a Live Science facilitator (employed by We the Curious), who are expert science communicators that will be trained up to deliver this data capture experience. The visitor 'participant' will then be asked to wear a SPHERE wearable (see above) and then perform a number of everyday actions (like sweeping or reading a book) whilst their silhouettes are being recorded by the video sensors. The visitor

'researchers' will then look at the real time silhouette data and try to guess what action the visitor 'participant' is performing.

**Video Sensors:** The SPHERE house at We the Curious will be equipped with video sensors, comprising a small camera and associated small computer (the size of a book). The video sensors do not record video; they capture features such as the position, orientation and silhouette of any person in view of the camera (as shown below). Silhouette below show a person walking. The face is not captured. This is what visitors will be able to see when they are trying to detect the action of the visitor 'participant'. Please note that neither the cameras nor any other SPHERE sensor records sound.



This nicely models the work down within SPHERE on data analysis and activity recognition, again with numerous applications in healthcare. At the end of this data capture experience the visitors will also be asked if they are happy to answer a couple of questions around their opinions on the consenting process, ethics and the governance of research (Appendix 1).

The project aims to collect data on people performing daily activities i.e. sitting and standing, this information gathered from visitors will be used in research that is working towards improving activity recognition of daily activities in the SPHERE sensor data. This recorded video data, recorded in conjunction with the wearable sensor data, will be used for analysis by SPHERE researchers at the university. The information collected around public opinion on the consenting process, ethics and governance of research will be used to inform the future SPHERE ethics process.

By applying technology and techniques used in the SPHERE project the project aims to develop methods to demonstrate SPHERE's capability in a dynamic, appealing and intuitive way to the public without compromising the privacy of the vulnerable or those with health conditions. This experience will also allow visitors to contribute to an active research project whilst also understanding a bit more about the inner workings of a digital-health research project.

**8. Who will be recruited to participate in the research?**

Visitors of We the Curious will be invited to participate.

**9. How many participants be recruited?**

This will be dependent on how many visitors attend We the Curious over the summer, but we estimate around 500 people.

**10. How will the participants be recruited?**

Participants will be recruited by Live Science facilitators who will be manning the SPHERE house at We the Curious. If a group seem interested in taking part in the activity the Live Science facilitators will verbally communicate to them the participant information script (Appendix 2) that details the rationale behind the research; the description of the task; and how long their participation is likely to take. Participation is completely voluntary and it will be made clear to participants that they can stop the activity or withdraw their data from the research at any time within a month of their data capture, past which the data may have already been used in research.

**11. Are there any potential participants who will be excluded? If so what are the exclusion criteria?**

Any persons under the age of 16 who does not have a parent or legal guardian present to provide consent for the child will still be allowed to take part in the activity, but their data will be automatically marked as non-consenting and will be deleted accordingly after the data collection is complete at the end of the installation.

**12. Where will the research take place?**

In the kitchen space of We the Curious, One Millennium Square, Anchor Rd, Harbourside BS1 5DB

**13. How will informed consent be obtained from all participants or their parents/guardians prior to the individuals entering the research study?**

Consent will be sought at the start of the data capture experience. For children under the age of 16 the facilitator will have to ask if there is a parent or legal guardian present who can give consent for the child. If there is no parent or legal guardian present, the child will be allowed to take part in the activity, but their data will automatically be marked as non-consenting and will be deleted accordingly after the data collection is complete at the end of the installation.

During the consenting process:

- The Live Science facilitators (who will be thoroughly trained in delivering the data capture protocol) will talk through the participant information script (Appendix 2) and ask if they

have any questions or if the group need anything further explained.

- Consent for taking part in the research activity will be gained at the start of the activity by the Live Science facilitator asking if the group is happy to take part in the research project. The Live Science facilitator will then ask the visitor, acting as the participant, to select the yes or no button on the ipad survey (Appendix 1) to whether they would like to take part in the research activity or not, thus consent will be recorded. The Live Science facilitator will also make a note of the time the group started the activity.
- If a group still wants to do the activity but they do not want any silhouettes to be recorded at all, the video sensor will physically obstructed (by a tea towel etc).
- After the data capture activity is complete the facilitator will seek further consent from the group and ask if they would be happy for their recorded data to be used by the University in research, the group will be able to physically select the yes or no option on the survey in response to this question, thus again there will be a record of consent. The Live Science facilitator will also record the end time of the activity.
- The facilitator will then have a record of whether consent was obtained and a time period of when the group's data was recorded, this can be used to identify and delete non-consenting groups after data collection is complete at the end of the installation.

For people who are visually impaired, they will be verbally informed of the participant information script, and verbal consent will be recorded by the Live Science facilitator. For visitors who are hearing impaired, a physically copy of the participant information script will be given to the visitor and consent will be gained from them by physically selecting the yes or no option in response to the consent question on the survey. If the Live Science facilitator is in any doubt that the visitors don't fully understand what the data capture experience entails and that their data is going to be recorded, they will record the group as non-consenting.

**14. Will the study involve actively deceiving the participants?**

No

**15. Will participants be made aware they can drop out of the research study at any time without having to give a reason for doing so?**

Yes, during the data capture activity participants will be told that they can stop the activity at any time. After the activity is complete, participants will also be given a debrief letter (Appendix 3) which contains their unique code, further details of the project, what will happen to their data and contact details which they can contact if they decide they want to withdraw their data from the project. The unique code will be linked to the time period they performed their activity and used to identify their data in the data set and can be deleted accordingly if they decide to withdraw, but they will be told they have a month from the date of data capture to withdraw, as past this date their data may have already been used in research.

**16. Outline the design of the research study and list the procedure to which participant will be subjected, the anticipated testing and any treatment administered?**

After giving verbal consent to participate in this study, the small group of visitors will be guided through a 10-15 minute activity by a Live Science facilitator. Visitors will be given either the role of the researcher or a participant. The facilitator will then talk the group through the activity and when they are comfortable with the activity it may begin. The visitor 'participant' will then be asked to perform a number of daily actions (like sweeping or reading a book) whilst their silhouettes are being recorded by the video sensors, the visitor 'researchers' will then look at the silhouette data and try to guess what action the visitor participant is performing. This nicely models the work done within SPHERE on data analysis and activity recognition, again with numerous applications in healthcare. This activity maybe performed several times with different members of the group taking on the role of researcher or participant.

At the end of this data capture experience the visitors will also be asked if they are happy to answer a couple of questions around their opinions on the consenting process, ethics and the governance of research (Appendix 1).

The project aims to collect data on people performing daily activities i.e. sitting and standing, this information gathered from visitors will be used in research that is working towards improving activity recognition of daily activities in the SPHERE sensor data. This recorded video data, recorded in conjunction with the wearable sensor data, will be used for analysis by SPHERE researchers at the University. The information collected around public opinion on the consenting process, ethics and governance of research will be used to inform the future SPHERE ethics process by addressing some of the main concerns the public may have around ethics/research and what information they would like to know to feel fully informed.

**17. Describe potential risks to participants (physical, psychological, legal, social) arising from these procedures.**

Before agreeing to take part in the study, potential participants will be told that they can change their mind and end their involvement at any time during the activity and up until a month after their data has been captured, after this point their data may have been used in research already.

This activity will take place in a science centre which welcomes thousands of people through its doors over the summer. The SPHERE house will be located in an area of the science centre that receives a high flow of visitors. Therefore, when the small groups are taking part in their data capture experience, other visitors in the vicinity will be able to see them performing the activity. This is a planned part of activity as we want the research activity taking place to be a very open process. However, for some people, especially children, they may feel uncomfortable performing in front of other members of the public, or having other people see their silhouette data. To overcome this, we will enclose the area so that the field of view for other visitors is small and it creates a more personal experience for the small group performing their data capture activity. The monitors that will be displaying the silhouette data will be semi-blocked off from the view of other members of the public not taking part in the activity. The group will also be fully informed of what the activity entails and what data will be displayed, but they will also be reassured that if they do not feel comfortable they can stop at any time. The Live Science facilitators are fully trained in working with members of the public and putting them at ease when taking part in non-conventional engagement activities.

The actions that we will be getting visitors to perform for the data capture activity will be actions they would normally encounter in their normal life and also may well be actions they would do in the science centre that day i.e. reading, walking, sitting down. The area will be fully risk assessed and the Live Science facilitators will be fully trained to deal with any problems that could arise. In the unlikely event of an injury, there are always trained first aiders in venue who will be able to assist. All Live Science facilitators members are DBS checked and are fully trained in working with members of the public, they will receive training in delivering the data capture experience, with emphasis on the ethical precautions and the process of consent to minimise risk to the visitors. These Live Science facilitators are also trained science communicators so are highly experienced at adapting and delivering content so that it is accessible and understandable to the person/s they

are interacting with, thus we can confidently ensure that group will be able to understand all aspects of the activity before entering into it.

**18. How will participants be debriefed?**

Each participant will be orally debriefed as well as given a debrief letter (Appendix 3) detailing further information around their involvement in the project and contact details for them to contact if they wish to withdraw at any point.

**19. Is any reimbursement of expenses or other payment to be made to participants?**

No.

**20. Will personal data, beyond those recorded on the consent form, be used in the research?**

We intend to collect demographic information, such as age and gender, height and city of residence, in order to describe the population of participants. We will also gather information on group type (i.e. family, friends, unrelated) in order to find out if there is a parent or legal guardian present who can give consent for all children, and if not their data will be marked as non-consenting (as detailed above). Each group recording will be assigned a unique participant code and only labelled with the date and time of recording. No names or contact information will be recorded so any data will not be linked to information that may identify the participants. No information on medical conditions will be recorded, this activity will also not have any diagnostic potential and not reveal any conditions that the visitors themselves are not already aware of.

Anonymised data will be stored on University of Bristol (UoB) servers and will be accessible to staff on the SPHERE project. The project includes the Universities of Southampton and Reading, as well as industrial collaborators (Toshiba and IBM) who have signed collaboration agreements with UoB and are permitted to use such data for the purposes of their participation in the project but not to disclose it to third parties. All anonymised data linked to publications will be available for research in compliance with RCUK policy on Open Access: <http://www.rcuk.ac.uk/RCUKprod/assets/documents/documents/RCUKOpenAccessPolicy.pdf>

All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection. Anonymised data will be stored in accordance with the University of Bristol and EPSRC guidance and RCUK policy on open access (details are available at



<http://data.bris.ac.uk/files/2014/02/data.bris-EPSRC-DMP-guide.pdf>). All datasets are made available under the National Archives' Non-Commercial Government License for public sector information (see <http://www.nationalarchives.gov.uk/doc/non-commercial-government-licence/non-commercial-government-licence.htm>). Data linked to published papers will be available for research; a small subset of data will be used to support school outreach events for students studying coding and mathematics; all other data will be kept for a period of 10 years, accessible by the SPHERE project manager and SPHERE data manager only.

**21. Will the participant be audio-recorded or video-recorded?**

No

**22. When will this research be completed?**

The research will be complete by the end of August 2018

**23. Any other relevant information?**

No